

*A Guide to Help Consumer Advocates Participate in  
Strengthening HIV/AIDS Provisions in Managed Care Contracts*

MEDICAID MANAGED CARE  
PROGRAMS



# BUILDING STRONG MEDICAID MANAGED CARE PROGRAMS

**A Guide to Help Consumer Advocates Participate in Strengthening HIV/AIDS  
Provisions in Managed Care Contracts**

**Produced by**



**Written by**

Jeffrey S. Crowley, M.P.H.  
Deputy Executive Director for Programs

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## i. Forward

The National Association of People with AIDS (NAPWA) first became directly engaged in advocating for the Medicaid program in 1995 when we fought to protect its funding from being block granted to the states. Before then, like others in the HIV community, we were probably inclined to take Medicaid for granted.

Along with others in the HIV community, we have received quite an education about how truly important Medicaid is to people living with HIV. In fighting against block grants, per capita caps and enormous cuts in funding, we have learned to appreciate that Medicaid is a dynamic collection of fifty-plus state programs that provides the cornerstone of HIV care in this country. NAPWA's perspective on the importance of Medicaid has evolved at a time when the way in which state Medicaid programs deliver health care services has been undergoing a fundamental reorganization. In 1995, many Medicaid programs had begun mandatory enrollment in managed care, but this was largely restricted to the healthiest Medicaid beneficiaries—children, mothers of children, and pregnant women. Most people with HIV/AIDS were exempt from managed care. Today, most people with HIV/AIDS in Medicaid are either in managed care already—or it is on the horizon, with their states making plans to mandate their enrollment in managed care.

In March 1997, NAPWA released *Making Medicaid Managed Care Work: An Action Plan for People Living with HIV* a report that was produced with support from the Henry J. Kaiser Family Foundation. This consumer action plan was developed in consultation with people living with HIV who were receiving health care through Medicaid in more than 15 states, as well as with key policy makers from inside and outside of the HIV community. Intended to educate people living with HIV and their advocates about how Medicaid works and how managed care will change Medicaid, the action plan also laid out key areas where people living with HIV should focus their attention in order to realize the promise of improved care that

can come with managed care. Consumers and advocates gave us feedback that they found *Making Medicaid Managed Care Work* very useful. One of the key recommendations of *Making Medicaid Managed Care Work* was that people living with HIV and their advocates focus their efforts at the state level. While consumer advocates should do more than advocate for well-written contracts, we believe that contract advocacy plays an important part in an overall strategy for working at the state-level to improve the quality and accessibility of health care services received by people in Medicaid.

This Consumer Advocate's Guide was also developed with the generous support of the Henry J. Kaiser Family Foundation. The guide was written for Medicaid beneficiaries living with HIV who do not have a professional background in health care or advocacy who want to use their experiences with Medicaid managed care to help make sure that contracts are well written. It was also written for advocates within HIV/AIDS service organizations and other health policy professionals whose jobs involve monitoring Medicaid programs and advocating for people living with HIV and other beneficiaries. Throughout the guide, we refer to "consumer advocates" which we believe includes both people living with HIV and people who advocate on their behalf.

Based on our history as a consumer-based organization, NAPWA believes that any process for delivering services to a community of people will be improved by obtaining the active participation of the persons who seek to benefit from the service. Nearly all of our advocacy efforts center around the proposition that people living with HIV must be involved in making decisions about how Medicaid and other health care and social services are organized.

The purpose of this guide is to help state-level consumer advocates become engaged in working as partners with state Medicaid officials to ensure that contracts are written that take into account the needs of people living with HIV. Throughout the Guide, we use the term states. We intend for this to include all fifty states, as well as the District of Columbia, Puerto Rico and the other territories. It is designed to explain how state Medicaid programs develop contracts with health plans in order to highlight opportunities for consumer input. The guide is also intended to provide “model contract language” and explain this legal language in a way that helps consumer advocates to understand the importance of various provisions within a contract. NAPWA hopes that this guide will encourage state-level advocates to establish or strengthen their interactions with persons working in their State Medicaid programs.

Unless specifically noted otherwise, all of the model contract language was drawn from sample purchasing specifications developed by the Center for Health Services Research and Policy (formerly the Center for Health Policy Research) at the George Washington University Medical Center. The sample purchasing specifications were developed in conjunction with the Centers for Disease Control and Prevention and the Health Resources and Services Administration.

It is important to note that health plans also sign contracts with individual physicians and other health care providers or with medical groups which are providers who are part of a single medical practice. While these contracts are also important, contracts with individual providers are beyond the scope of this guide. To the extent possible, however, consumer advocates are encouraged to strive to ensure that provider contracts are consistent with the contracts between the state Medicaid agency and health plans.

Along with the release of this guide, NAPWA is releasing the second edition of Making Medicaid Managed Care Work. NAPWA is hopeful that this action plan, updated to reflect changes in Medicaid managed care, will continue to be useful in giving focus to the work of people living with HIV and their advocates who are working to make Medicaid managed care work for them.

Finally, NAPWA is committed to the belief that there is much in common between the needs of people living with HIV and other people with disabilities. While this consumer guide presents recommendations that are specific to the needs of people living with HIV, we believe that it can also serve as a template for articulating the contract terms needed to protect other beneficiary groups within Medicaid. If you are working to make Medicaid a better program, we hope that this consumer advocate’s guide is useful to you.

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## ii. Acknowledgments

I am extremely grateful for the assistance of a large number of people who helped conceive, shape and produce this consumer advocate's guide. First and foremost, I thank the Henry J. Kaiser Family Foundation for enabling NAPWA to produce this guide. In addition to their generous financial support, I am especially appreciative to Dr. Sophia Chang, Jennifer Kates, Dr. Marsha Lillie-Blanton, Dr. Barbara Lyons, and Tim Westmoreland for their consistent support, feedback, and guidance in developing this project.

When we conceived this project, we knew that we needed to work with the Center for Health Services Research and Policy at George Washington University given their wealth of knowledge gained from conducting their landmark study, *Negotiating the New Health System: A Nationwide Study of Medicaid Managed Care Contracts*. In the beginning, however, we were unaware that this guide would be written to build so closely on the Center's Sample Purchasing Specifications for Services for HIV Infection, AIDS, and HIV- Related Conditions. From beginning to end, the staff of the Center have been enormously helpful by participating in NAPWA's Advisory Group, sharing drafts of their documents, and reviewing and assisting with the development of this guide. We thank Jeff Levi for serving as our liaison with the Center and for being so accommodating and helpful over the last year and a half. We also thank Liz Wehr, Julia Hidalgo and Sara Rosenbaum for their insights and willingness to help us make this guide useful to consumer advocates and technically accurate.

Given the number of issues on which NAPWA works, the only way to get anything done is to work in coalition with others—and where possible, to rely on the good work of others. The National Health Law Program is one organization upon which we depend for consistently high quality work. Kristi Olson was enormously helpful in participating in our Advisory Group, reviewing a draft of this guide, and in providing advice and counsel. We also acknowledge the contribution of her colleague, Jane Perkins. NAPWA relied heavily on published work of Jane Perkins and Kristi Olson with regard to contract advocacy and consumer involvement in managed care. NAPWA also works closely with the Judge David L. Bazelon Center for Mental Health Law. Their document on involving mental health consumers in contract advocacy was very helpful as we shaped our own consumer guide.

Collaboration is often key to any successful endeavor and we thank all of the members of our Advisory Group who helped provide guidance as we began this project and who reviewed drafts of this consumer advocate's guide:

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**Kristi Olson**, National Health Law Program

**John Palenicek**, formerly with the Office of the  
Assistant Secretary for Health, DHHS

**Kathy Rama**, Health Care Financing Administration

**Andy Schneider**, formerly with the Center on  
Budget and Policy Priorities

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**Liza Solomon**, Maryland AIDS Administration

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Finally, it is a pleasure to work with the **staff of NAPWA**. A few individuals, however, contributed in significant ways to the development of this guide. I especially thank **Cornelius Baker**, **Robin Massengale**, **Joe Nickens**, and **Mike Shriver** who each contributed to this project their views and comments, and administrative or other production support.





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### **iii How to Use this Guide**

This guide was written to help explain how state Medicaid programs develop contracts with health plans in order to highlight opportunities for consumer input. The guide also provides “model contract language” and explains it in simple terms that help consumer advocates understand the importance of various provisions within a contract. We hope that this guide will enable state-level advocates to work with State Medicaid programs to include this model contract language in their contracts with health plans.

The guide has four sections.

#### **I. Understanding the Role of Medicaid and Medicaid Managed Care in Serving People Living with HIV**

Read this section to get you started. It provides an overview of the Medicaid program and discusses issues related to enrolling people living with HIV in managed care programs. It also outlines key elements of a Medicaid managed care system—elements that consumer advocates will want to make sure are part of the Medicaid managed care programs in their states.

Use this section as a reference. As you work to make Medicaid managed care programs work for people living with HIV, turn back to this section if you want to find details about Medicaid and people living with HIV—or if you want to review some of the problems and potential solutions for serving people living with HIV in managed care programs.

#### **II. Focusing on Contracts as a Strategy for Protecting Consumers**

This section will help you understand why it is important to advocate for well-written Medicaid managed care contracts. It will explain how states develop contracts, and it will define a role for consumer advocates.

Use this section to give you action steps for developing partnerships with state Medicaid officials and others in order to impact the development of contracts. Through sustained advocacy, you can help contract developers understand the needs of people living with HIV and prevent access problems by ensuring that health plans factor into their planning the needs of people living with HIV.

#### **III. An Explanation and Description of Model Contract Language**

This section gives you the tools you need to strengthen your state’s contracts. It provides model contract language along with an explanation of this language and why each contract section is important.

Use this section to advocate for actual contract provisions and to help you identify key principles regarding the various sections of the contract.

#### **IV. Additional Resources**

This section provides information about federal and state contacts along with information about organizations doing work related to Medicaid. This section also includes a glossary and an index.

Use this section to identify additional resources to help you in your consumer advocacy.



# **SECTION I**

**Understanding the Role of Medicaid and Medicaid Managed Care  
in Serving People Living with HIV**



## **1. An Overview of Medicaid**

Medicaid was enacted by Congress in 1965 as Title XIX of the Social Security Act to provide a health care safety-net for low-income persons considered to be especially vulnerable and who have an acute need for health care—children and mothers of children, pregnant women, people with disabilities, and the elderly who require long-term care. Over the years, Medicaid has grown into a major health care provider, ensuring health care benefits for 41.3 million people (in 1996).

Medicaid is a federal-state program, administered by the Health Care Financing Administration (HCFA), an agency within the U.S. Department of Health and Human Services (DHHS) that is also responsible for the Medicare program. The federal government pays a matching percentage of state costs ranging from 50% to 83% of total costs, depending on the state. While the federal government defines the parameters of the program, states have considerable flexibility in the design and implementation of their programs. Since Medicaid's establishment, the need for the federal government to become involved in regulating state programs in response to abuses within some states has become apparent. Federal oversight can also achieve a level of uniformity in the benefits and services received by beneficiaries from state to state.

Recently, Congress and the Administration have become interested in giving more power to the states. This has meant that programs such as Medicaid, which are operated at the state-level, have been given even more freedom by the federal government to operate at the state's discretion. The State Children's Health Insurance Program (CHIP), established in 1997, gave states the option of using Medicaid or creating a new state program for expanding health insurance coverage among low-income children of working families. This is an example of increased state autonomy. In the past, when Congress has addressed health care access for other vulnerable

From an historical perspective, it is important to recognize the profound impact that Medicaid has had on extending health care to some of the most vulnerable low income people in our country.

We must recognize, however, that Medicaid has not been a panacea for resolving all health care access issues faced by eligible beneficiaries. Medicaid has also not always lived up to the expectations that have been placed on it.

Since the establishment of Medicaid, health care in the United States has changed dramatically. Without this essential safety net program, the disparities in access to health care and the health status of the nation would be much worse.

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populations, it has added new mandatory eligibility categories within Medicaid. While many states have elected to cover children in low-income working families through expanding Medicaid, some states have elected to create new CHIP programs in order to be free of the numerous federal Medicaid requirements. In addition, under the Balanced Budget Act of 1997 (BBA), Congress gave states new powers to mandatorily enroll Medicaid beneficiaries in managed care. This is not to say, however, that Congress is not mindful of the potential problems of too much state autonomy. While the Congress will now allow states to deny Medicaid beneficiaries a right to freely choose any provider, they have protected a right (except in rare circumstances, such as in rural areas) for Medicaid managed care beneficiaries to choose from at least two health plans. Indeed, although Congress gave states new powers under the BBA, it also sought to balance state flexibility by enacting several new consumer protections (See inset on page 3).

It is useful to remember that notwithstanding current ideological beliefs about the proper roles of the federal and state governments, Medicaid is still operated subject to a federal law that imposes substantial regulatory requirements on the states and more than thirty years of court decisions have defined the scope of federal authority. While states do have considerable freedom with regard to the structuring of Medicaid and they have the option of serving additional optional populations, they are required to serve specific mandatory populations. They are also required to cover specific mandatory services which include: inpatient and outpatient hospital, physician, laboratory, x-ray, nursing home, and home health services. Prescription drug coverage, which is especially important to people living with HIV, is an optional service that all states currently elect to provide.

Children are entitled to a broader range of Medicaid benefits under provisions of the Medicaid law related to early and periodic screening, diagnosis, and treatment (EPSDT). In particular, prescription drugs are a mandatory service for children (see inset on page 4).

States seeking changes in Medicaid, such as mandating enrollment of Medicaid beneficiaries in managed care, have been previously required to obtain a waiver from the federal government. A waiver is federal permission that can be granted, at a state's request, to exempt the state from certain provisions of the federal Medicaid law. Waivers have been used to expand coverage, experiment with new ways of delivering health care services, and to mandate enrollment in managed care programs. Even though the BBA allows states to require Medicaid beneficiaries to enroll in managed care programs without seeking a waiver, the BBA did not eliminate the need for federal waivers in all circumstances. States will continue to seek federal waivers in cases where they are seeking a broader federal exemption from the Medicaid law than provided by the BBA, such as expanding Medicaid eligibility.

For the majority of the last century, health care costs have been increasing more rapidly than the costs for other goods and services. The way that health care was financed in the past was through a system called fee-for-service. Many people with Medicaid and other types of insurance still receive care in fee-for-service systems. Under a fee-for-service system, an individual generally can go to any doctor or provider they wish. The insurance company will pay a set fee to the provider for every service that an individual receives. As health care costs have increased, insurance companies have attempted to limit their responsibility for these costs by reducing the portion of a bill that they pay. In the past, an individual may not have paid any of their own money when accessing health care services. Over time, many insurance plans have reduced their



## **Balanced Budget Act of 1997**

*Adapted from: Negotiating the New Health System: A Nationwide Study of Medicaid Managed Care Contracts (Volume 1, Second Edition), Center for Health Policy Research, George Washington University Medical Center*

In enacting the Balanced Budget Act of 1997, Congress simultaneously gave states new flexibility in operating their Medicaid programs and imposed new consumer protections which states must ensure are met. States that mandate that Medicaid beneficiaries participate in managed care must:

- ensure that beneficiaries in non-rural areas be given a choice of at least two managed care organizations and beneficiaries in rural areas must be given a choice of at least two primary care case managers.
- allow beneficiaries to change health plans or case managers without cause for the first 90 days after enrollment and at least once during any twelve month period.
- allow beneficiaries to change health plans or primary care case managers at any time for good cause.
- conduct an enrollment system that gives priority enrollment to individuals already in a health plan in cases where the plan is full.
- conduct an enrollment priority system that is equitable among health plans and that takes into account the presence of existing relationships and traditional providers of care.
- provide detailed enrollment information to prospective enrollees, including contract and non-contract Medicaid coverage and information about which providers participate in a health plan's network.
- prohibit "cold call" (unsolicited calling from purchased mailing lists) and door-to-door marketing by managed care organizations.
- provide coverage for emergency care and post-stabilization care in accordance with the "prudent layperson" standard.
- prohibit contracting with managed care organizations that limit provider/patient communications and discriminate against classes of providers.
- maintain grievance processes that allow beneficiaries and providers to appeal coverage decisions.
- sign contracts only with managed care organizations that can demonstrate that their networks have adequate capacity to serve the needs of their enrollees.
- operate a comprehensive quality assurance system that examines access, clinical quality, consumer grievances, and other indicators of health care quality.
- operate a quality assurance system that provides for external review of health plan performance.
- impose intermediate sanctions against managed care organizations that engage in fraudulent practices, substantially fail to provide medically necessary care, or discourage enrollment by persons with complex health care needs.

Once a law is enacted, the federal agency with jurisdiction then must develop regulations to give further guidance regarding what the Congress intended in enacting a law. In October 1998, HCFA released proposed regulations for most aspects of the Medicaid provisions in the BBA for public comment (Proposed regulations on external review requirements have been published separately). HCFA is reviewing the comments it received and final regulations are expected to be issued late in the summer of 2000, with the final external review regulations being issued some time later. Once regulations are issued, they have the force of law.

### **EPSDT Services**

EPSDT services are mandatory services for children that are necessary, “to correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services, whether or not such services are covered under the state plan”.

These services include:

- Inpatient services (other than services in an institution for mental disease)
- Outpatient hospital services
- Rural health clinic services (including home visits for homebound individuals)
- Federally-qualified health center services
- Other laboratory and X-ray services (in an office or similar facility)
- EPSDT services
- Family planning services and supplies
- Physician services (in office, patient’s home, nursing facility, or elsewhere)
- Medical and surgical services furnished by a dentist
- Medical care or any other type of remedial care
- Home health care services (in place of residence)
- Private duty nursing services (in the home, hospital, nursing facility, and/or skilled nursing facility)
- Clinic services (including services outside of clinic for eligible homeless individuals)
- Dental services
- Physical therapy and related services (includes occupational therapy and services for individuals with speech, hearing, and language disorders)
- Prescribed drugs
- Dentures
- Prosthetic devices
- Eyeglasses
- Other diagnostic, screening, preventive, and rehabilitative services, including medical or remedial services recommended for the maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level (in a facility, home, or other setting)
- Services in an intermediate care facility for the mentally retarded
- Inpatient psychiatric hospital services for individuals under age 21
- Services furnished by a mid-wife, which the nurse-midwife is legally authorized to perform under state law
- Hospice care
- Case-management services
- TB-related services
- Respiratory care services
- Services furnished by a certified pediatric nurse practitioner or certified family nurse practitioner, which the practitioner is legally authorized to perform under state law
- Community supported living arrangement services to the extent allowed and defined by law (42 U.S.C. §1396u)
- Personal care services (in a home or other location) furnished to an individual who is not an inpatient or resident of a hospital, nursing facility, intermediate care facility for the mentally retarded, or institution for mental disease
- Primary care case management services
- Any other medical care, and any other type of remedial care recognized under state law, specified by the secretary (includes transportation and personal care services in a recipient’s home)

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payments to cover only 80% of the total bill. Recently, some fee-for-service programs have reduced their responsibility to 70% or less of the total cost. In these cases, the individual is responsible for paying the remainder of the bill. Fee-for-service programs have also added other mechanisms for increasing the portion of the cost paid by the consumer. This includes increasing deductibles, which are a set amount of money that an individual must pay each year before the insurance company begins to pay for their health care costs. These types of cost-saving mechanisms are more difficult to use with Medicaid because individuals must have low incomes to qualify for Medicaid. In particular, Medicaid requires all participating providers to accept its payments as payment in full for services rendered to its beneficiaries. In addition, for many groups of beneficiaries, states are prohibited from imposing deductibles, co-insurance, co-payments, or other types of cost-sharing. Medicaid beneficiaries have very little capacity to pay a substantial percentage of their health care costs.

Fee-for-service, in the context of Medicaid, has always had serious structural problems. For example, states have always struggled to finance the state share of Medicaid costs. This pressure on states to keep their Medicaid costs low has led to Medicaid payment levels that are significantly lower than limits set by Medicare or private payers. This has created an environment where many providers will not accept Medicaid patients. In places Medicaid is accepted, beneficiaries are sometimes treated as second class patients, not receiving the same respect or level of care as persons with Medicare or private insurance. Further, the detachment between the payment for health care services and the delivery of services has meant that Medicaid exercises very little oversight over the quality of care received by beneficiaries.

Largely motivated by concerns over the cost of health care, there has been a strong trend for public and private health

insurance programs to move away from paying for health care on a fee-for-service basis, and to finance health care delivery differently, such as through various types of managed care arrangements. Managed care as it exists today has developed from health maintenance organizations (HMOs) that were first established earlier this century and which have gained prominence since the early 1970s. The purpose of managed care is to improve the health status of individuals and reduce the cost of care. Managed care seeks to achieve this purpose by integrating the health care delivery system (which includes doctors, nurses, hospitals, laboratories, and other health care providers) with the insurance system that finances health care. There are many types of managed care organizations including health maintenance organizations (HMOs), preferred provider organizations (PPOs), independent practice associations (IPAs), and primary care case management programs (PCCMs).

While managed care exists in many forms, there are certain features that are shared by most types of managed care. These include limits on an enrollee's choice of providers, requirements that patients obtain approval from a primary care provider before seeking care from specialists, and requirements that patients obtain prior approval from their health plan before being hospitalized for non-emergency care and before having non-emergency procedures performed.

Managed care has developed, in large part, as a strategy to control health care spending. Nonetheless, there are features of managed care that can improve the quality of care received by enrollees of a health plan. Under the fee-for-service system, insurance companies develop lists of covered benefits and if you desire or your provider prescribes a benefit or service that is not covered, it is often difficult to obtain authorization for the benefit. Under managed care, providers may have more flexibility to authorize services that they believe are medically necessary. Under the fee-for-service system, prevention services often have not been adequately covered and providers

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are not given strong incentives to focus on health promotion activities. Under managed care, however, providers theoretically have new incentives to keep their patients healthy—which, in some cases, has led to an expanded focus on prevention. Another potential advantage of managed care is the improvement in care coordination. Under fee-for-service, if an individual has complete freedom to select any provider, it is possible that individuals would see numerous providers who never consult with one another. In managed care programs where a single health plan takes responsibility for managing all aspects of a person's health care, it is possible to ensure a stronger level of communication and coordination among multiple providers.

In Medicaid, a major advantage of managed care is that health plans that sign contracts with state Medicaid programs are accepting legal obligations to provide a specific range of health care services. This means that beneficiaries should not experience the same barriers to access because they cannot find a provider who is willing to treat them. While inadequate payment rates can still create barriers to care for Medicaid beneficiaries in managed care, managed care has at least improved access to primary care providers—an essential entry way into care.

### **2. Medicaid's Role in HIV/AIDS Care**

Medicaid is the single most important health care program for people living with HIV disease. HCFA 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 with AIDS were living in the United States in 1998, more than 163,000 people with AIDS received health care through Medicaid in that year. Most people with HIV who qualify for Medicaid have an AIDS diagnosis and are considered disabled which makes them eligible for Supple-

mental Security Income (SSI, an income assistance program for people with disabilities operated by the Social Security Administration). Persons who receive SSI are automatically eligible for Medicaid. When Congress enacted SSI in 1972, through the Social Security Amendments Act of 1972, section 209(b) created an exception that allowed states that had already established a more restrictive SSI eligibility standard for people with disabilities to continue using their own standard. These states (Hawaii, Illinois, Indiana, Minnesota, Missouri, New Hampshire, North Dakota and Ohio) are referred to as 209(b) states. While everyone who receives SSI is eligible for Medicaid, persons living in 209(b) states may be subject to a more restrictive income eligibility standard for SSI.

Another major category through which people with HIV/AIDS become eligible for Medicaid is through the Medically Needy Program. This is an optional category for beneficiaries who meet the definition of disability for SSI, but who fail to meet the financial criteria for SSI. These persons do not have incomes low enough to qualify for Medicaid, but when medical expenses are subtracted from their income, they fall below the Medicaid income limit. State Medicaid programs are not required to give Medicaid to medically needy individuals, but 34 states currently have such programs.

Finally, although most persons with HIV enter Medicaid through SSI or the medically needy program, some people with HIV/AIDS also enter Medicaid through other categories. In particular, many women and children with HIV become Medicaid-eligible through the AFDC/TANF category (AFDC stands for Aid to Families with Dependent Children, the federal income assistance program that was reformed into TANF or Temporary Assistance for Needy Families in 1996. Despite major changes to who may receive cash assistance benefits, most persons who previously qualified for Medicaid under the AFDC program remain eligible for Medicaid today).

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Women and children who become eligible for Medicaid in this way are the only significant category of people living with HIV who qualify for Medicaid before they have an AIDS diagnosis. As the demographic profile of the HIV epidemic in the United States changes, with women representing an increasing portion of the total number of people living with HIV, this eligibility category will become even more important for consumer advocates to monitor. Recent advances in the treatment of HIV have created a greater urgency for broadening access to Medicaid to people in the early stages of HIV disease who do not yet qualify for SSI. When successful treatments were not available, and a person would progress from HIV infection to AIDS in roughly the same amount of time whether or not they received comprehensive health care, it was easier to save the battle for earlier access to Medicaid for another day. In the era of highly active antiretroviral therapy (HAART), however, the potential exists to forestall progression to AIDS—and this makes ensuring that all people living with HIV have access to high quality health care one of the highest priorities for advocates nationwide. Changing Medicaid policy to allow asymptomatic people with HIV to become Medicaid eligible before they are disabled is one of many essential strategies for expanding access to health care.

In the fall of 1999, the Congress passed, and the President signed into law, the Ticket to Work and Work Incentives Improvement Act (Public Law 106-170) that establishes a new Medicaid demonstration program that states can use to expand Medicaid eligibility to people living with HIV who are not considered disabled (under the Social Security Administration's definition of disability which is used to determine eligibility for supplemental security income (SSI) and Medicaid).

For more information about Medicaid managed care, readers are encouraged to contact NAPWA or the Kaiser Publication Line to request the companion document, ***Making Medicaid Managed Care Work: An Action Plan for People Living with HIV.***

For a more comprehensive understanding of how the Medicaid program works and how it serves people living with HIV and AIDS, check out another publication of the Kaiser Family Foundation: ***Medicaid and HIV/AIDS Policy: A Basic Primer*** by Tim Westmoreland (July 1999). This publication is available at the Foundation's website: **[www.kff.org](http://www.kff.org)** or by contacting their publication request line at 1-800-656-4KFF.

### **Expanding Medicaid is a Community Priority**

Over the last few years, expanding Medicaid has become an urgent priority for many advocates. NAPWA believes that this is one important element of an overall strategy to broaden the base of public programs that provide health care services to people living with HIV. Expanding Medicaid is not a new idea, but recent treatment advances have created a new rationale and brought a new urgency to this task.

Medicaid is a categorical health care program for low income individuals. This means that to receive services, you must have a low income and you must fit into a specific category of eligible people. For most adults living with HIV, they do not become Medicaid eligible until their illness has progressed to AIDS--at which point they would meet the criteria for the supplemental security income (SSI) category (i.e. they meet the Social Security Administration's (SSA's) definition of disability). Persons living with HIV have always advocated for earlier access to Medicaid, but if everyone was expected to progress to AIDS, at least all low income people with AIDS could get Medicaid when they were sickest and had the most extensive health care needs.

The FDA approval of effective antiretroviral therapies (starting in late 1995) was a watershed event that changed much regarding common perceptions about HIV and how to most effectively deliver health care services to people living with HIV. Combination drug therapies have been able to produce drops in the amount of HIV virus circulating in a person's blood stream (i.e. viral load) to undetectable levels that have been accompanied by remarkable stories of many people who have gone from being very ill to feeling and appearing very healthy. This has led many people to believe that HIV disease is becoming a manageable chronic disorder. Further, treatment guidelines issued by the Department of Health and Human Services and the Kaiser Family Foundation (referenced in the model contract language in section III.) recommend the initiation of antiretroviral therapy early in the course of HIV infection.

Because most people living with HIV depend on becoming Medicaid eligible through the SSI category, they are presented with a catch-22. Their eligibility is postponed until SSA considers them disabled, but if they could gain access to health care including effective combination therapies, they may be able to prevent becoming disabled. As a recognition of this new reality, there has been a broad call to expand Medicaid eligibility to include people living with HIV. At the federal level, the AIDS Action Council has spearheaded advocacy on this issue. In 1997, the Vice President proposed expanding Medicaid to cover people living with HIV in earlier stages of disease. Citing concerns about cost, however, the Clinton Administration decided not to pursue a Medicaid expansion at the federal level. States were encouraged, however, to submit waiver applications to develop demonstration projects to determine if a Medicaid expansion could be done in a cost-effective manner. Essentially, the argument has been made that by paying for combination therapies and other services up-front, Medicaid can avoid paying later for big-ticket health care expenses such as extended hospitalizations. Legislation has also been introduced in Congress that, if enacted, would expand Medicaid to people with HIV who are not disabled.

The Kaiser Family Foundation has attempted to support this effort by establishing a technical assistance effort aimed at state Medicaid programs who are considering submitting waiver applications for this purpose. In February 2000, HCFA approved Maine's waiver application. Further, it is believed that at least five other states (California, Colorado, Florida, Massachusetts and North Carolina) are involved in this effort. As this issue is critical to people living with HIV, consumer advocates should closely monitor the progress of these waiver applications and should consider if such a demonstration project could be achieved in their own states.



### **3. The Challenges of Enrolling People Living with HIV in Managed Care**

States have embraced Medicaid managed care out of a desire to restrain increases in Medicaid costs and to improve quality and accountability after looking at much touted private sector “successes” with this system of cost containment. In the private market, managed care has shown an ability to lower initial health care expenses. Consumer advocates have argued, however, that it is unreasonable to expect private market managed care savings to be transferrable to long-term Medicaid savings. First, it has not been proven that managed care will be able to sustain cost-savings in the private market over the long-term. Indeed, recent projections are that private market health spending will accelerate in the coming years. Second, Medicaid is not the private market. Because the majority of Medicaid’s expenses are from seniors in nursing homes and persons with disabilities (including persons with HIV/AIDS), Medicaid is called upon to provide a higher level of care than most private health insurers who serve relatively healthy workers and their families.

A bottom-line reality for consumer advocates is to recognize that no matter what your own perspective is about managed care, an increasing proportion of people living with HIV in Medicaid will get their care through managed care. If the fee-for-service health system is disappearing around us, and the providers and institutions upon which people living with HIV depend are being integrated into managed care programs, moving people living with HIV into managed care may ultimately prove to be important in order to protect high quality care. To move Medicaid to a place where people living with HIV are well-served, however, requires an honest analysis of the fears of beneficiaries and an acknowledgment of the challenges posed by HIV care for managed care providers. It is also important to recognize that Medicaid has never been a perfect system for people living with HIV.

Many of the concerns that consumer advocates raise with Medicaid managed care are also problems in fee-for-service Medicaid. As state Medicaid programs are building new managed care programs where none previously existed, the development of new systems of care may provide new opportunities to address systemic problems that have prevented many Medicaid beneficiaries from receiving the high quality care they need. An important distinction between managed care and fee-for-service health care, however, is that in the fee-for-service system, an individual can resolve some problems by looking for a different provider. Managed care limits the ability of individuals to “vote with their feet” and move from provider to provider. Further, some concerns that consumer advocates express are exacerbated in managed care because the focus on controlling spending has made the gaps in care worse for people living with HIV who require extensive and often costly health care services.

Although many Medicaid beneficiaries living with HIV are highly satisfied with their care in managed care, this is not universally the case. When consumer advocates express concerns with managed care, they will often speak of many of the same issues that must be addressed when state Medicaid programs negotiate contracts with health plans. The following are commonly expressed concerns by consumer advocates:

#### **Some states have not adequately prepared for mandatory enrollment of people with HIV in Medicaid managed care.**

Based on observing states that have rushed into mandatory enrollment of all Medicaid beneficiaries into managed care, there is a concern that states will mandate enrollment in managed care even if they are not ready and the proper infrastructure does not exist to ensure high quality care.

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### **Some managed care organizations entering the Medicaid market focus on profits at the expense of patient care.**

In some cases, the concerns of consumer advocates are not based on systemic problems with managed care, but result from negative experiences with one health plan. Some managed care plans are inexperienced and ill-equipped to serve people living with HIV.

With the growth of Medicaid managed care, commercial for-profit health care plans have begun to actively compete for business from the traditional, not-for-profit health care providers, public hospitals and health centers that have more experience serving Medicaid beneficiaries. Many commercial managed care organizations do an excellent job of serving their enrollees living with HIV, and not-for-profit institutions can also be poorly administered and can provide poor quality care. Some advocates believe, however, that the profit motive and the absence of an identified commitment to the communities in which they operate can mean that commercial managed care organizations are less inclined to serve people living with HIV well. A related concern is that the competition within some health care markets is so intense that even well-intentioned health plans face economic obstacles that impede their ability to provide adequate service to beneficiaries.

### **Some states lack an appropriate regulatory environment to monitor health plans and hold them accountable for providing high quality care.**

Advocates are also concerned that appropriate enforcement of existing laws is not taking place. One of the fundamental rights for people in Medicaid is the right to demand an administrative fair hearing, and if necessary to pursue a private right of action (i.e. to sue the state Medicaid program). Suing a state Medicaid program, while a timely and costly endeavor, could be necessary to

force a state to live up to its responsibilities under the federal Medicaid statute.

In addition to maintaining a private right of action, advocates believe that state Medicaid programs must devote far greater resources to monitoring the performance of plans with whom they contract. And much more work needs to be done to develop markers of performance to enable outsiders to evaluate how well a plan is meeting the needs of its enrollees.

### **Payment levels to health plans are inadequate and the absence of risk adjustment creates powerful incentives to underserve people living with HIV.**

The fiscal pressure on states to pay for Medicaid has been discussed previously. This is often a major issue, in part because legislators find other state expenditures (such as education or transportation spending) more attractive. For a variety of reasons, many states underpay for Medicaid health care services (through such means as paying providers at rates so low that most will not accept Medicaid and through placing tight limits on specific services). While consumer advocates encourage states to demand efficiency, low payment levels have real consequences.

This problem is exacerbated in states where Medicaid programs do not risk adjust payments to health plans on the basis of HIV or AIDS. The huge differences in cost between treating people living with HIV and other Medicaid beneficiaries create enormous disincentives for health plans to serve people living with HIV. In such an environment, health plans are almost punished by developing a good reputation for serving people living with HIV.

Further, legal experts have articulated a strong rationale for Medicaid beneficiaries to exercise their rights as third-party beneficiaries. In cases where this argument is accepted by



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the courts, it gives an individual a right to sue their health plan directly (instead of having to sue the state Medicaid program) to enforce the terms of the managed care contract.

Under contract law, a health plan (the promisor) agrees with the state Medicaid agency (the promisee) to render a performance/service to a Medicaid beneficiary (the third-party). To enforce the terms of the contract, the third party generally must demonstrate that they are the intended recipient (and not simply the incidental recipient) of the contract. Constraints have been placed on third-party rights so as to not create unreasonable financial burdens on entities that contract with the government.

In the case of a Medicaid beneficiary, a clear argument can be made that they should be able to exercise third-party rights. They are part of a well-defined class, the purpose of the contract is to benefit the health of the beneficiary, and third-party enforcement furthers the purpose of the federal Medicaid statute.

### **Consumers who experience problems with managed care do not know where to turn or how to resolve their problems on their own.**

Another concern with the rapid transition to mandatory Medicaid managed care programs for people living with HIV is that consumers are lost. So much change is happening around them, and many of their relationships with their providers, case managers and others are being interrupted, that they do not even know where to turn for help.

This may be made worse by a culture clash when for-profit health plans replace existing non-profit health care providers. Non-profit community-based providers often operate under an ethos where they strive to meet all of the needs of their clients—and they also may have had multiple funding streams that they could pool together to provide

medical and non-medical services in an integrated manner. Commercial health plans, on the other hand, have expressed the view that providing non-medical services such as housing is not what they have been contracted to provide. It may not be a health plan's responsibility to provide such services, but an enrollee's source of such services may have been disrupted by the arrival of new health plans as Medicaid providers. When this happens, many consumers do not know where to turn.

### **In some cases, carve-outs and other financing arrangements have increased the fragmentation of care.**

One of the potential benefits of managed care is that the manner in which health care services are purchased creates incentives for health plans to provide whatever services are necessary to keep a person from becoming sick—or from progressing in an illness. In some cases, managed care has led to the development of health care delivery systems where all services are provided in a coordinated manner—and enrollees benefit from this approach. In other cases, however, attempts to save money on expensive services or efforts to ensure that all Medicaid beneficiaries have uniform access to a specific benefit may lead some state Medicaid programs to carve-out populations or services.

A carve-out means that the state Medicaid program has decided to handle the delivery of a particular benefit differently than other benefits. Or it means that a state Medicaid program has established a different program for providing all health care services to a specific group of beneficiaries, such as people living with HIV. In some cases, a state may carve-out a service in a way that is transparent to the beneficiary. For example, a state may pay a capitated payment for most services, but it will pay the health plan on a fee-for-service basis for prescription drugs. Because one health plan is providing all of the services, the enrollee may

not be aware that prescription drug benefits are treated differently than other services.

Sometimes, when state Medicaid programs have set-up multiple sources for delivering services, beneficiaries may be given the run around concerning which entity or health plan is responsible for paying for specific services. For example, a beneficiary could go to their primary care provider in need of substance abuse treatment services only to be told that this benefit is covered by a carve-out arrangement that a state Medicaid program has made for covering mental health services. When the individual goes to the mental health provider, however, the same beneficiary could be told that substance abuse treatment is not covered by them, and they should go see their primary care provider (PCP).

**High quality HIV care is related to provider experience. Too often, closed networks are inadequate.**

An important feature of many managed care programs is that they save money by limiting choice of providers to a group of providers with whom they have contracted. The groups of providers are called closed networks because the health plan does not have to accept any provider—and they frequently limit the size of their networks. This saves the health plan money because the participating providers (called in-network providers) have agreed to follow certain rules established by the health plan and they have agreed to terms for payment. Consumers and consumer advocates have concerns about the qualifications and HIV experience of providers in some health plan networks.

Closed networks are not inherently problematic. People living with HIV experience problems, however, when a specific type of provider is not readily available within the health plan's network, when a health plan lacks qualified providers who are also experienced HIV providers, or when

**A Little More About Carve-Outs...**

Carve-outs are neither inherently good or bad. In some cases, they improve access to a service. In other cases, they may impede such access.

A state may decide, for example, to contract with its health plans on a capitated basis. This means that the state Medicaid agency will pay the health plans with which it contracts a per-member per-month payment for all of its enrollees. The health plan will then take responsibility for providing all medically necessary services. The state may be concerned, however, that its health plans do not have the expertise to appropriately deliver substance abuse treatment services. Or the state may believe that substance abuse treatment is a benefit that would cost too much money if the state were to factor it into the per-member per-month payment that it makes to its health plans. For these and a variety of other reasons, a state may decide to exempt substance abuse treatment from the services to be provided by the health plan. It can then provide this service on a fee-for-service basis (meaning that Medicaid will pay for services each time they are used and in some situations allow beneficiaries to select their own provider). Alternatively, the state can contract with a health plan that specializes in providing substance abuse treatment to take responsibility for providing this benefit to all Medicaid beneficiaries in a state or geographic region.

The bottom line, however, is that the beneficiary may be asked to follow different rules for how to go about getting services—and coordination among providers may be challenging. Careful consideration needs to be given to explain to beneficiaries how to get the services they need and how to ensure coordination among multiple providers.

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they want to maintain an existing relationship with a provider whom they trust and that provider is not in the health plan's network.

In the context of HIV care, it has been documented that provider experience plays a role in determining patient survival. With the rapid change in understanding of HIV therapy and the nuanced decision-making that is involved with determining the most appropriate therapeutic regimen, people living with HIV need to be treated by providers with the appropriate training and with the experience that comes with treating others with HIV. In too many cases, health plans construct networks and experienced HIV providers are either intentionally or unintentionally excluded.

### **4. Addressing Consumer Concerns through the Development of a Sound Managed Care System**

While NAPWA believes it is important to acknowledge the challenges of Medicaid managed care, we also believe it is equally important to remind beneficiaries and consumer advocates that they have many opportunities to improve health care delivery within Medicaid. The concerns discussed in Chapter 3 point to problems to be overcome and can provide a useful focus to consumer advocacy. Beneficiaries and advocates in each state or community will have different experiences and face different challenges that will drive what they need to do to ensure that Medicaid provides access to care and delivers high quality and appropriate care. Beyond simply responding to problems, however, we believe that there are essential components that are necessary for any Medicaid managed care system to serve its beneficiaries well. While this list is not exhaustive of all of the things necessary in a managed care system, the following five elements are critical elements of a Medicaid managed care system:

#### **Organized advocates and empowered consumers**

Medicaid programs are subject to enormous political and financial pressures. If Medicaid managed care programs are going to serve their beneficiaries adequately and be responsive to the citizens of their state, strong advocates are necessary to ensure accountability and to secure a place at the table for consumers. Accountability, however, only makes sure that managed care organizations provide the level of care purchased by the state Medicaid program. This is essential, but if a state has not purchased an adequate package of benefits or negotiated a contract that is specific with regard to the responsibilities and expectations of the health plan, beneficiaries may not be protected.

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For managed care to effectively meet anybody's needs, the beneficiary must be actively engaged in their own care, to the extent of their abilities. Federal Medicaid law gives beneficiaries limited rights to choose from among health plans. Beneficiaries need to be active in deciding which health plan best meets their needs. They should learn how their health plan operates; they need to choose a primary care provider; they need to ask questions and share any concerns that they have with their providers; and they must not be afraid to ask for and advocate for services that they believe they need.

### **Well-funded consumer assistance programs**

If consumers are lost in managed care, it can often be because they do not know where to turn, or they are not aware of how they must change their behavior to follow new rules put in place by managed care programs. An important way to help beneficiaries is for states to establish independent sources of assistance. Recently, many states have begun to establish consumer assistance programs for both their Medicaid and non-Medicaid residents. In some cases, these programs are called ombudsprograms (or the state will announce that it has an ombudsman). These programs function to help beneficiaries understand choices that they have in their health care. Consumer assistance programs serve as a resource for independent information about health plans. These programs can also help beneficiaries to assess their own health care needs. For example, a critical element in the choice of health plans for a person living with HIV is the level of experience the provider has in treating other patients with HIV. Without the guidance of a consumer assistance program, the beneficiary may not have considered this criteria.

Consumer assistance programs can also be a valuable resource for helping beneficiaries when they experience a problem with their managed care organization. This can include counseling a beneficiary to call the managed care organization's Member Services Department, making inquiries on behalf of beneficiaries, and helping a beneficiary to file a grievance or request an administrative fair hearing. As currently structured, most consumer assistance programs do not provide legal advice and they do not become engaged in legal proceedings against a managed care organization or against a state Medicaid program.

### **Enforceable quality standards**

One of the major changes from fee-for-service Medicaid to Medicaid managed care is that managed care organizations are accepting legal responsibility for providing a specified level of care. Too often, beneficiaries are disappointed because they are not able to receive services they believe they need and the managed care organization feels that it is living up to the terms of their agreement with the state Medicaid program. Further, beneficiaries and advocates complain about poor-performing managed care organizations, yet objective evaluation tools are insufficiently developed. This calls for the creation of uniform quality standards that specify minimal levels of performance by all managed care organizations with whom a state agency may contract. These standards cover a range of issues from: maximum waiting times for an appointment with in-network providers, or maximum travel distances from a beneficiary's residence to their provider's office, to access standards such as minimum requirements regarding the number and types of specialists a managed care organization must maintain in its network.

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Further, many people may readily agree that there are some things that all beneficiaries need, yet which are far more important to people living with HIV than other beneficiaries. Similarly, in addition to advocating for quality standards that cover all Medicaid beneficiaries or all enrollees within a health plan, there are also HIV-specific quality standards for which consumer advocates should advocate.

### **Health-Based Payment Systems**

It has been said that one of the best ways to make sure that managed care organizations meet the needs of people living with HIV is to make sure that these organizations are adequately paid to do so. One of the biggest barriers to appropriate care for people living with HIV in managed care programs has been the severe financial disincentives to serving people living with HIV. Under most managed care arrangements, managed care organizations are paid on a per person per month (capitated) basis for all of their beneficiaries. Typically, this payment rate may be the same for all beneficiaries. Because the cost of treating individuals varies dramatically and health plans are able to predict which beneficiaries are likely to cost more than others, there are enormous disincentives to avoid high cost beneficiaries and to skimp on care needed by the costliest beneficiaries. For example, if a health plan receives the same payment for serving a relatively healthy person and a person living with HIV whose care may cost eight to thirty times more, then it is understandable why a health plan may seek to avoid serving the person with HIV.

Because of the high cost of HIV care, some state Medicaid programs have pioneered the establishment of comprehensive health based payment systems which pay a capitated payment that is adjusted for the predicted health care costs for each beneficiary. This is called risk adjustment. Presently, adjustments are made by assessing the history of health care claims in fee-for-service Medicaid.

Medicaid programs and other purchasers of health care have experience with risk adjustment on the basis of factors such as geography, and the capitated payment may depend on where a person resides in the United States, or other factors such as gender or age.

States have sometimes been reluctant to risk adjust payments on the basis of HIV status because it is a complex undertaking and such a risk adjustment program would be difficult to administer. One reason for this may be that states are unable to identify persons living with HIV. States also may be concerned about creating opportunities for fraud by overpaying for certain categories of care. Some state officials have also expressed a concern that risk adjustment undermines part of the rationale of managed care—namely, for managed care organizations to accept a certain level of risk for “managing” the care of beneficiaries along a spectrum of health care needs.

Risk adjusting for HIV care is also made more difficult due to the rapid changes in HIV. It is hard to establish appropriate baseline payment levels (which have been based on claims history), as well as to account for covering the costs of rapidly evolving medical technology. If a risk adjusted payment were introduced in 1995 based on historical costs, for example, it would not account for the costs of protease inhibitors and highly active antiretroviral therapy. In setting a payment level in 1999, it is difficult to predict what new therapies or treatments are on the horizon.

Recently, however, there has been a pronounced increase in interest in risk adjustment for people with AIDS (and in some cases people with HIV also) among state Medicaid officials. NAPWA believes this is a highly positive development and we urge advocates to encourage their state Medicaid officials to consider this approach to payment. We also encourage states to take the next step and work toward

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the adoption of a comprehensive health based payment system for all beneficiaries. This is important because people with HIV/AIDS are not the only beneficiaries with above average health care costs—and who experience similar access barriers due to the incentives to underserve them. While the extreme cost differences between care for people living with HIV and many other groups of beneficiaries may provide a rationale for states to begin to risk adjust with their HIV/AIDS beneficiaries, equity and efficiency argue for the eventual development of a program that seeks to appropriately capitate all care based on predictable health care costs.

### **Well-written contracts**

Well written contracts are essential to receiving high quality care because they are the legal agreement between the state and the managed care organizations who will deliver the health care. Under a fee-for-service system, state Medicaid programs establish what they will pay for a service and a health plan or provider can decide whether or not to accept this payment and in so doing, whether to provide the service. In fee-for-service, there generally is not a pre-established legal arrangement between the health plan and the provider.

One of the merits of managed care is that it creates legal obligations on the health plans. By contracting with a state Medicaid agency, the health plan agrees to accept all eligible beneficiaries, they agree not to discriminate in the delivery of health care, and they agree to provide all medically necessary services, as defined by the contract.

In order to ensure that health plan enrollees benefit from a managed care arrangement, however, it is critical that the state Medicaid agency clearly articulate what services it wants to purchase from the health plan, and it must describe how it wants specific circumstances to be handled. In managed care, if a beneficiary wants a service, the bottom line frequently comes down to whether or not the service in question is described in the contract. If the contract is unclear about whether or not the health plan must provide the service, it will be difficult to hold the health plan accountable for providing the service—and the beneficiary probably will not get it.

Medicaid beneficiaries are entitled to have payment made for all medically necessary benefits specified in the state's Medicaid plan, and in the case of children under 21, to all necessary followup treatment covered under federal law. If a state has signed a contract with a health plan and a Medicaid service is not covered by the contract, the state Medicaid agency is still responsible for providing it. To protect beneficiaries from legal wrangling and major delays while a determination is made regarding whether a service will be provided and who must pay for it, consumer advocates should focus careful attention on trying to anticipate as many situations and contingencies as possible, to ensure that contracts are written to protect access to care in a variety of circumstances.

# **SECTION II**

**Focusing on Contracts as a Strategy for Protecting Consumers**





## **5. The Growing Importance of State-Level Advocacy**

In the past, federal control of Medicaid was much stronger. When consumers experienced problems, advocating for intervention by the Health Care Financing Administration (HCFA) was often an effective way to improve the quality of care received by beneficiaries. Advocating at the federal level remains important. Consumer advocates must also be vigilant to insist that HCFA fulfill its public responsibility to protect beneficiaries by providing oversight of state Medicaid programs. In the context of managed care where states are no longer passive bill payers, however, working at the state level has become just as important as federal advocacy. This is especially true in the current environment where the political climate is relatively hostile to a strong federal involvement in many programs.

In the Medicaid managed care environment, states are contracting with many health plans who commit themselves to providing a defined set of benefits. Therefore, monitoring the relationship between a state Medicaid agency and its contractors (commercial and not-for-profit managed care organizations) can be the most direct way to impact the quality of care received by beneficiaries.

It is strategically important for consumers and consumer advocates to focus increased attention on working at the state-level. Working to ensure that strong contracts are written that take into account the complex needs of people living with HIV is a sound way to prevent or minimize many of the access problems faced by people living with HIV. In working at the state level to ensure that contracts are well-written, it is important to identify goals for consumer advocacy.

### **Potential Goals for Your Advocacy May Include:**

- Increasing the understanding of the specific needs of people living with HIV among state Medicaid officials who negotiate contracts.
- Raising awareness of the common problems experienced by people living with HIV in Medicaid managed care.
- Identifying specific access issues that need to be addressed through contract language.
- Developing sustained and on-going relationships with state Medicaid officials.
- Identifying specific actions that can be taken to ensure compliance with contract specifications.

**6. What Gives You the Right?...**  
**The Legal Basis for Consumer Involvement  
in Contract Development**

Consumer advocates may face challenges when advocating on an issue in which the people who make decisions are unaccustomed to working with consumers. Decision makers may feel that consumer advocacy is inappropriate or unwarranted. Public officials, however, may also be unaware of the value that can be derived from working closely with beneficiaries and their advocates. People with AIDS have been on the cutting edge of changing common perceptions of the value and need to work with consumer advocates. Beyond our community's history of activism, however, lies a legal rationale that gives consumers a right to have their voices heard.

At the federal level, the Medicaid law requires state Medicaid agencies to form medical care advisory committees—which are required to include consumers as members. Your state Medicaid agency must consult with these advisory committees before they implement major policy or program changes. Getting HIV consumer advocates on state medical care advisory committees can be an effective way of getting the issues and concerns of people living with HIV addressed by state-level policy makers. Because medical care advisory committees are required by federal law, consumer advocates can insist that states are using such committees and if they are not, then advocates can complain to the Health Care Financing Administration (HCFA). Contact your state Medicaid office and ask about how to join their medical care advisory committee.

At the state level, there are also laws that can be used by consumer advocates to ensure that the state Medicaid program considers their views before making policy decisions. Further, in carrying out state functions, such as in developing and implementing a Medicaid managed care contracting system, states will go through various procedures for developing their

NAPWA works closely with our allies in the disability community and other consumer and legal services advocates.

This section was based (with permission) significantly on *Partners in Planning:*

*Consumer's Role in Contracting for Public-Sector Managed Mental Health and Add-*

*iction Services*, published by the Judge

David L. Bazelon Center for Mental Health

Law and the Legal Action Center and

*Making the Consumers' Voice Heard in*

*Medicaid Managed Care: Increasing*

*Participation, Protection and Satisfaction*

published by the National Health Law

Program and the Cecil G. Sheps Center for

Health Services Research.

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contract specifications and soliciting health plans to submit bids. By monitoring these procedures, consumer advocates can also take advantage of opportunities for providing input. While specific laws vary from state to state, and the processes by which state Medicaid programs develop their contracts will be unique to each state, the following laws or procedures can provide consumer advocates with the opening they need to become engaged in helping states to shape specific and well-written contracts:

- **Administrative Procedures Acts may require public comments or public hearings**

Administrative Procedures Acts (APAs) are state laws which require public notice and an opportunity to comment prior to implementing a rule of general applicability. These laws set deadlines for public comment and/or public hearings on proposed rules, such as those involved in the shift to managed care. All fifty states and the District of Columbia have APAs. Nevada and Missouri, however, exempt Medicaid from complying with the requirements of their APAs.

- **State laws and regulations may give opportunities for public input**

In addition to federal regulations, states enact their own statutes and issue their own regulations to implement their Medicaid programs and ensure that they comply with the federal law. As with federal laws and regulations, consumer advocates can play an important role in shaping proposed state laws and in providing public comments on proposed regulations.

- **Review waiver applications or terms and conditions of approved waivers**

Each state may elect to undertake a different process in developing its Medicaid managed care contracts. First, it will be necessary to determine if a state is developing or has received a waiver from the federal government to mandate

enrollment of Medicaid beneficiaries into managed care or to be exempt from other provisions of the Medicaid law. If the state is developing a waiver proposal or it has submitted a waiver application that has not been formally approved, it is important for consumer advocates to become involved in this process. If a waiver has been approved, it will be necessary to review the terms and conditions to ensure that the contracts comply with all waiver requirements.

- **Review and comment on requests for proposals (RFPs)**

A state will conduct a process for fairly evaluating competing bids and defining desired contract specifications. This can take place after a state obtains a federal waiver, or it can take place whenever the state decides to develop a managed care program. As an initial step, a state will issue a Request for Proposals (RFP), a Request for Information (RFI), or a Request for Applications (RFA). All of these are slightly different mechanisms for the state to seek input on how to develop its managed care program, and to learn from managed care organizations in the state how they would propose to structure their own Medicaid managed care delivery system. By reviewing these requests, advocates can gain an understanding of their state's intent with regard to contracting. Consumer advocates can also serve as a vital resource for states still transitioning people living with HIV into Medicaid managed care (or re-opening the contracting process) by providing information about the special health care needs of people living with HIV or by highlighting infrastructure requirements needed to effectively serve beneficiaries.

### **Asserting Your Role In the Process**

You may be faced with a state agency, managed care organization or other entity who is not accustomed to a high level of consumer involvement or who does not appear to recognize the benefit of listening to your input. In such a case, your success in obtaining a place at the table may be dependent on your ability to demonstrate that you provide a valuable resource. You should be confident that your experience living with HIV and your experiences with the health care system enable you to make an important contribution to the development of well written contracts. You should also recognize that you have the power to convince state agencies, managed care organizations, and others to work with you by demonstrating that you know how to be a partner with them. You can do this by:

- Maintaining strong, sustained relationships with key Medicaid officials.
- Demonstrating that you can help Medicaid officials to do a better job or make their job easier. For example, if a state official wants to ensure access to experienced HIV providers, consumer advocates can help support this effort by providing published studies that support the need for experienced providers or by providing stories of “real people” that illustrate the need for experienced providers.
- Backing up your claims about the needs of people living with HIV with data. Often it is most useful if you can quantify a problem by giving numbers of people affected by a certain issue.
- Identifying constructive solutions that are both practical and politically supportable.

### **7. How You Can Impact the Contract Development Process**

Based, in part, on An Advocate’s Primer on Medicaid Managed Care Contracting by Jane Perkins and Kristi Olsen of the National Health Law Program and published in 31 Clearinghouse Review 19 (May/June 1997).

Successful advocacy of any kind involves creating relationships with people who have the power to influence the issues you care about and then convincing these persons that your views are ethically correct, politically feasible, or affordable—and hopefully all of these. In order to have an impact on Medicaid managed care contracts, we recommend that consumer advocates focus on five key actions:

#### **1. Form Relationships with Key Players**

In a state Medicaid agency, there will be many people with the power to help or hurt your advocacy efforts. It is important to develop as many relationships with key personnel as you can. There may be a designated HIV coordinator, and this individual should be a natural ally for you. Even with the most supportive person, however, nobody will be empowered to influence all of the decisions you care about. Therefore, you should also try to identify and get to know the persons responsible for writing and negotiating the managed care contracts, the persons responsible for communicating with the public about changes in Medicaid, and the persons responsible for monitoring and evaluating the performance of health plans.

#### **2. Learn About the Process Your State Uses in Developing its Contracts**

As discussed previously, each state will follow its own process for developing contracts. By working with Medicaid officials and other consumer advocacy organizations, you

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should try to learn as much as you can about the process that your state follows. This will help you to identify key pressure points where you can focus your attention. Learning about your state's process will also give you a sense of the time frame from which your state is working. Unfortunately, many states have elected to mandate mandatory enrollment in Medicaid managed care without sufficient planning. This means that your state may have moved quickly or intends to move very quickly to develop model contracts and negotiate with managed care organizations in your state. Nonetheless, for your own planning, it will be important to know about key milestones and time frames.

Some states contract with all managed care organizations that meet a set of defined requirements. Most states, however, use an RFP to require managed care organizations to submit a formal proposal on how they would provide a defined set of services to beneficiaries within a defined geographic area. In some cases, the state may set the payment level up front, and the receipt of a proposal implies acceptance of this rate. Other states may require the managed care organization to include a proposed payment rate in their proposal. In such a case, competing bids among managed care organizations will be evaluated on the basis of cost, as well as quality. The state may set criteria, up front, that acknowledge a particular weighting of price versus quality. For example, a state could review bids on a scoring system where they say that 70 points will be based on quality criteria and 30 points will be based on price considerations. The state could also decide to accept all bids that score above a minimum level, or they could establish a fixed number of bids and accept the highest scores.

### **3. Learn About Your State's Procurement Laws**

Most states have enacted procurement laws that stipulate how state agencies must conduct their purchasing activities

that would cover contracting with health plans. Unless a Medicaid agency is specifically exempted, procurement laws can be an important tool in ensuring that the Medicaid agency conducts a fair bidding process and makes reasonable decisions about the organizations with which it will contract. Generally, there will be a requirement that notice of a proposed contract be made public. This notice would indicate where and when bids will be received and reviewed. The notice of a proposed contract may also identify the objective criteria by which bids will be reviewed, including the particular weighting that will be given to various evaluation criteria.

### **4. Obtain , Review and Comment on Contracts Materials**

You should attempt to obtain any contract materials that you can from your state Medicaid agency. This would include, but not be limited to, any RFPs, RFAs, RFIs, model contracts, or actual signed contracts. In many cases, you can obtain these materials by simply requesting them from the Medicaid agency. In some cases, however, you may need to file a Public Records Act Request. Public Records Acts are state laws patterned after the federal Freedom of Information Act. These laws, in general, create a requirement that government business be conducted openly and give citizens the right to inspect and review government materials. In cases where personal or proprietary information is involved, the laws provide for the deletion of such information, while allowing for the public disclosure of the remainder of the document. These requests can sometimes be time-consuming, but they do give you an important legal right to review most government information.

When reviewing the contract materials, you should ask several critical questions. The first of these is that if a managed care organization did the very minimum that it could do as mandated by the contract, would people living

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with HIV be ensured that they would get the care they need—and the care that the Medicaid program is paying for?

Your expertise as a consumer advocate probably does not relate to your understanding of the law, but your knowledge of what people living with HIV need to get high quality care. Your insights are very important. If you are looking at a contract as a way of preventing problems, you should ask yourself if the contract is sufficiently specific and stringent to protect people living with HIV. Given recent treatment advances, you should assess whether the contract would ensure that people living with HIV are provided treatment options consistent with the Guidelines on the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents, Guidelines for the Use of Antiretroviral Agents in the Treatment of Pediatric HIV Infection, and the Guidelines for the Prevention of Opportunistic Infections in Persons Infected with the Human Immunodeficiency Virus (For information on obtaining these guidelines through the Internet, refer to footnote 34 on page 50). You should also reflect upon problems with health care that you have experienced or others you know have experienced. Would the contract prevent these types of problems from occurring by placing requirements on the managed care organizations?

### 5. Monitor Contract Renewals

Once a contract has been signed, consumer advocates can still have an impact. Any contract will set out requirements on the part of the managed care organization and the state Medicaid agency. Consumer advocates should monitor whether the terms of the contract are being fulfilled. For example, if a contract calls for a managed care organization to maintain a twenty-four hour help line, and you have tried to call this line late at night without getting an answer, you should document such instances and report them to the state Medicaid agency.

### Critical Questions When Reviewing Contract materials

- If a health plan did the very minimum that it could do as mandated by the contract, would people living with HIV be ensured that they would get the care they need?
- Would this contract allow people living with HIV to seek care from experienced and qualified providers?
- Would this contract ensure that people living with HIV receive the current standard for HIV care?
- Would this contract allow people living with HIV to obtain specialty care when they need it?
- Does this contract contain any restrictions that may limit care needed by people living with HIV?
- How would this contract make sure that the health plan continues to improve the quality of care it provides?
- Would this contract require the health plan to work with and listen to enrollees to improve the delivery of care?

Further, contracts do not last indefinitely and usually expire after a specified period of time, generally from one to five years. Consumer advocates have an important role to play in evaluating the performance of managed care organizations as their contracts come up for renewal. Did your experience with a particular managed care organization demonstrate that there are deficiencies in the contract? Or did your experience demonstrate that the managed care organization is not fully complying with the terms of the contract? In such instances, the extent to which consumer advocates can gather logs of incidents experienced by a variety of individuals will help to substantiate claims they wish to make.

It is also important to remember that an advocate's job is not simply to identify problems. If you believe that consumers living with HIV have positive experiences with a specific health plan, or if policy decisions taken by a state Medicaid program are helping to resolve a problem, it is also necessary to document positive improvements.

#### **6. Raise concerns with the Feds**

Federal law requires HCFA to approve any Medicaid managed care contract that exceeds \$1 million prior to states receiving their federal matching payments—and nearly all contracts are greater in value than this. If you do not believe that your state Medicaid agency is taking your concerns seriously, you should write to the HCFA Regional Office (and send a copy to the HHS Inspector General) to express your concerns. At a minimum, this should force the state to justify its actions to HCFA.

Also, contracts expire and states routinely seek extensions or they renew. As most of these extensions or renewals have changes in their terms and conditions, consumer advocates are encouraged to treat them as new contracts. This means that you should review them closely—and urge HCFA to do the same.

#### **The Fate of Health Care for People Living with HIV Does Not Rest on Your Shoulders**

In order to maintain sustained advocacy, it is important not to become burned out. Therefore, it is necessary to establish reasonable goals for what you can do and what you can accomplish. **Nobody is expected to do all of the things recommended in this guide.** Consumer advocates should feel good—and recognize they are making a real contribution to improving health care delivery—if they do even a few of the things recommended here.



**7. The media can help consumer advocates achieve accountability**

Consumer advocates depend on committed public employees to work with them to make improvements. And, depending on the circumstances, media reporting of an issue could either bolster your allies in the Medicaid program in order to make positive changes, or it could foster a bunker mentality where communication with consumer advocates is avoided, and it becomes harder to get what you want.

State officials probably like nothing less than reporters asking questions about how Medicaid is serving its beneficiaries. Some of your key contacts may also perceive public media advocacy as a hostile action. Calling a press conference, for example, to criticize the Medicaid program may not help you strengthen partnerships with public employees, but it may be what is necessary to get the attention of the people who can respond to your issue.

Consumer advocates should recognize that members of the media can be helpful—and working with the media is an appropriate way to raise public awareness of problems faced by real Medicaid beneficiaries. But, consumer advocates are also cautioned—a reporter’s job is to report the news, not to advocate for a cause. You cannot assume that any news story will be reported from your perspective.

The challenge with working with the media may be one of discretion. No matter what are the particular circumstances, consumer advocates are strongly urged to never lie or exaggerate to a reporter. Also, never speak about things that you do not fully understand. Telling a reporter something, and then learning after you are quoted in the press that you misstated the facts can be damaging to your credibility and effectiveness. Also, in talking to the media, it is important to avoid making personal attacks. When we feel passionately

about an issue, it is easy to believe that people who do not share our perspective are evil or have “sold out”. First, mounting a personal attack is not a sound advocacy strategy—it is not likely to help you get what you want. Second, people can disagree or they can follow orders from their superiors—and this does not make them bad people. Whenever possible, advocates should try to win over friends rather than make new enemies. And when dealing with the media, it is important to remember that beliefs and opinions are often magnified.



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**Contract Law is Different from Statutory Law**

Medicaid managed care contracts often are not as well-written as they should be because the people who negotiate and write them are public employees more familiar with statutory law than contract law. This distinction is important. It is also important to understand that many people working in state Medicaid agencies share your values and want people living with HIV and others to get high quality health care.

The difference between statutory law and contract law is important in that it determines what happens when there is a lack of clarity regarding what the contract says. It also affects how disagreements between the state Medicaid agency and the managed care organization get resolved.

Under statutory law, Congress or state legislatures pass laws which authorize either federal or state agencies to serve as regulatory bodies. This means that for Medicaid the federal Health Care Financing Administration (HCFA) and the state Medicaid agency are given the power to write rules that describe in more detail the intent and meaning of the legislation. Agency regulations have the force of law, so regulatory agencies have significant power. In most cases, even if a law is passed that seems very specific and clear, there are numerous unanticipated circumstances where the regulatory agency will be called upon to give guidance. In this way, regulatory agencies are shown deference. This means that courts will generally defer to the interpretation of a regulatory agency regarding the meaning of the law.

This is in sharp contrast to contract law. A contract is a legally enforceable document. The state and the health plan have entered into the agreement freely, and ambiguities are interpreted against the party that wrote the contract, the state Medicaid agency. In a Medicaid managed care contract, this means that if a contract is not well-written and specific, it is often not possible to force a managed care organization to provide a service—even if it was your understanding that this was clearly the intent of the contract. There is no ability of the public agency to interpret the meaning—and if the contract does not specifically state that a managed care organization (MCO) must provide a service, then they don't have to.

This is also important because the federal Medicaid statute (Title XIX of the Social Security Act) creates obligations for states who voluntarily accept federal Medicaid monies. If the states, in turn, do not write contracts to ensure that their contractors will fulfill all of the requirements of the Medicaid law, then the states are still legally bound to fulfill all of the requirements of the law.

The move to Medicaid managed care marks a change in role for state agencies, as they become contract negotiators, enforcers and monitors. This change for state officials can provide advocates with important leverage. Because states are faced with a new and multi-faceted role, they may recognize the benefit that your involvement can provide them.

**Section II:** Focusing on Contracts as a Strategy for Protecting Consumers

# **SECTION III**

**An Explanation and Description of Model Contract Language**

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## **8. Key Provisions for Ensuring High Quality HIV/AIDS Care**

The success of any consumer advocacy related to Medicaid managed care contracts relates to the extent to which the contract reflects a recognition of the complex needs of people living with HIV and includes language that will ensure that people living with HIV receive the health care services and supports they need.

This section of the guide includes an explanation of various HIV provisions in a contract and provides model contract language. The model contract language in this chapter is taken from *Sample Purchasing Specifications for Services for HIV Infection, AIDS, and HIV-Related Conditions* developed by the Center for Health Services Research and Policy (formerly the Center for Health Policy Research) of the George Washington University Medical Center. The sample purchasing specifications were developed in conjunction with the Centers for Disease Control and Prevention (CDC). In developing this language, the Center undertook an extensive review process that involved considering a range of perspectives including those of consumer advocates, HIV/AIDS service providers, state Medicaid officials, federal policy makers, and health law attorneys.

If your state Medicaid program intends to use a different approach, we recommend that you attempt to understand their policy reasoning, and assess if the proposal is likely to achieve the same objective. It is unlikely that you will be able to convince your state to adopt the language presented here exactly as it is written, in every case. If you understand the goals of the various elements of the contract, however, you may be able to partner with state officials in a way that addresses the needs of people living with HIV—while meeting the policy requirements or political circumstances of the Medicaid program in your state.

It is important to underscore that this model language is not a complete contract, but rather sample HIV specifications. Other contract provisions are necessary that pertain to the operation of the health plan and that specify requirements that apply to all enrollees, not just people living with HIV. It is also important to acknowledge that these contract provisions do not address the very critical topic of financing (or issues such as capitated payments, risk adjustment, stop-loss protections, etc.).

This section of the Guide follows the organization of the *Sample Purchasing Specifications* document. It is organized in two parts:

- Part 1 covers HIV Service Benefits; and
- Part 2 covers HIV Service Delivery and Quality Improvement.

In broad strokes, these sections can be thought of as being designed to make sure that people living with HIV get all of the services they need (Part 1) and that the health care systems and relationships with other entities are structured in a way that will lead to the smooth and efficient delivery of the services promised (Part 2).

Each topic identified includes an explanation of the issue to be addressed. Some parts of the contract may seem to duplicate others. The text of this chapter explains why consumer advocates should care about each contract section, as well as gives a rationale for a state to adopt this language. Shaded text is the model contract language for each particular section. Throughout this section, various contract provisions are marked “reserved” with no model language provided. The Center for Health Services Research and Policy is developing sample purchasing specifications that will be completed in the

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future. To look for recently released purchasing specifications, consumer advocates are encouraged to visit the Center's website at [www.gwu.edu/~chsrp/](http://www.gwu.edu/~chsrp/).

The Center for Health Services Research and Policy also has published the third edition of *Negotiating the New Health System: A Nationwide Study of Medicaid Managed Care Contracts* (also available at [www.gwu.edu/~chsrp/](http://www.gwu.edu/~chsrp/)). Table 2.5 of this study summarizes HIV/AIDS provisions in state Medicaid contracts in 1998. This can be a useful starting point in order to understand what your state has done already, and to compare this with other states.

#### Part 1. HIV Service Benefits

Part 1 addresses the range of services and benefits that the state Medicaid program intends to purchase from a health plan.

**Shaded text and footnotes in this section are taken from *Sample Purchasing Specifications for HIV Infection, AIDS and HIV-Related Conditions*.**

#### Introduction and Overview

These sample managed care purchasing specifications address issues in the primary and secondary prevention and medical management of HIV, AIDS and HIV-related conditions (hereinafter termed "HIV/AIDS"). The specifications are intended for use in Purchasing Agreements that are either for a preset fee (i.e., a premium) or under an administrative services only (ASO) agreement for the delivery of comprehensive health care through a network of participating providers. These specifications have been developed for use by both public sector Purchasers (e.g., state Medicaid programs) and private-sector entities (e.g., employers and employer purchasing coalitions).

The specifications were drafted by attorneys at the George Washington University School of Public Health and Health Services, Center for Health Services Research and Policy (CHSRP), (formerly Center for Health Policy Research) with guidance from experts in the field of HIV prevention and management. They were reviewed by consumers, health care providers, policy makers, managed care officials, and state Medicaid agencies. The Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA) provided expertise, direction and financial support for their development.

These sample specifications are illustrative. They are designed to function as one of the many tools that Purchasers employ to develop and oversee managed care systems for their members. The specifications may be used either in their entirety or on an item-by-item basis, depending on the range of issues a Purchaser wishes to address. The individual specifications in this document may be added to appropriate sections in a Purchasing

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Agreement. Alternatively a Purchaser may wish to use the specifications to develop an Appendix or Attachment relating specifically to the prevention and medical management of HIV/AIDS.

Because of variations in Purchasers' financing options, policy preferences and legal duties, there is no single correct method for covering and delivering care, particularly in the case of a condition as complex as HIV/AIDS. However, it is possible to identify the critical decision points that Purchasers may face and to suggest approaches to each. The specifications offer illustrative options for addressing key issues in coverage, access, delivery and quality of care. It is anticipated that Purchasers will tailor them to the laws of the state(s) in which the contract is in operation. (Purchasers should consult with the public health agency in a state to ensure consistency with state laws regarding reporting, confidentiality, and other matters addressed in state public health statutes and regulations.) In the case of Medicaid Purchasers, the specifications have been drafted to be consistent with federal legal requirements pertaining to managed care purchasing. Medicare and other public and commercial Purchasers may wish to consult these specifications for their approach to particular issues in the care and delivery of services and benefits for persons with HIV/AIDS, although it is recognized that most forms of coverage offer a narrower range of benefits than Medicaid, which in great part was designed as a means of financing care for persons with serious and chronic illness.

A Purchaser may elect to remain silent with respect to a particular matter for which illustrative language has been prepared. In such a case, rules of contract construction would

mean that the Purchaser would effectively elect to defer resolution of the particular issue to Contractor discretion.

These specifications do not currently address payment methodologies for HIV/AIDS services. However, Purchasers may wish to consult the HIV Capitation Risk Adjustment Conference Report of the Henry J. Kaiser Family Foundation, which is available through the Foundation's worldwide website address<sup>1</sup>. A second resource is the 1998 National Academy for State Health Policy report on the range of financing strategies (risk-adjusted payment rates, separate payment ("carve out") for HIV pharmacy costs, mandated reinsurance, risk corridors and risk pools) currently being tested in six Medicaid managed care programs<sup>2</sup>. Medicaid Purchasers may also wish to evaluate the experiences of other states (Maryland, Colorado, Oregon, Utah and New York State, all of which have adopted specialized capitation rates either specifically for HIV/AIDS or for enrollees with disabilities.) These public-sector efforts to test appropriate HIV/AIDS payment mechanisms may also be informative to private sector Purchasers.

The specifications are accompanied by Commentaries to aid in reading and interpretation. The commentaries reference clinical practice guidelines cited in the text and provide background explanations. In light of the importance of Medicaid to financing the care and management of persons with HIV/AIDS, the commentaries provide references to federal Medicaid law. In addition, the commentaries reference current relevant treatment guidelines. These specifications will be modified as needed as new guidelines emerge; in addition, the website addresses for the guidelines that are identified in the commentaries will also carry new

- 1 Diane J. Aschman, HIV Capitation Risk Adjustment Conference Report (1997, The Henry J. Kaiser Family Foundation, Menlo Park, CA); Tony Dreyfus, Richard Kronick, Carol Tobias, Using Payment to Promote Better Medicaid Managed Care for People with AIDS (1997, The Henry J. Kaiser Family Foundation, Menlo Park, CA). [www.kff.org](http://www.kff.org); Richard Kronick and Tony Dreyfus, The Challenge of Risk-Adjustment for People with Disabilities: Health-Based Payment for Medicaid Programs (1997, Center for Health Care Strategies, Inc. Princeton, NJ); Changing Environments for AIDS/HIV Service Delivery and Financing, Health Care Financing Review 19:3 (Spring, 1998); Tony Dreyfus, Richard Kronick, Carol Tobias, Using Payment to Promote Medicaid Managed Care for People with AIDS (National Academy for State Health Policy, Portland, ME., July, 1997); DHHS/OIG, Medicaid Managed Care and HIV/AIDS (DHHS, OEI-05-97-00210, April, 1998).
- 2 J. Rawlings-Sekunda and Neva Kaye, Emerging Practices and Policy in Medicaid Managed Care for People with HIV/AIDS: Case Studies of Six Programs (1998, The National Academy for State Health Policy, Portland, ME. E-mail: [info@nashp.org](mailto:info@nashp.org)). This study reports on current Medicaid managed care programs for people with HIV/AIDS in Massachusetts; New Jersey; Orange County, California; Texas; San Francisco; and Tennessee.

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guidelines as they emerge. Of particular significance will be new guidelines from the U.S. Public Health Service on HIV testing of pregnant women.<sup>3</sup>

In several places throughout the document, readers will see blank spaces (\_\_\_\_) accompanied by a footnote. These spaces identify places where purchasers may wish to develop performance standards, particularly with respect to service time-lines and other attributes of managed care service delivery systems. The Commentary accompanying the blank spaces provides recommendations from persons knowledgeable about HIV prevention and care.

These specifications are part of a series of sample purchasing specifications that will be released and posted at the Center for Services Research and Policy's website address.<sup>4</sup> The term "reserved" in this document indicates policy areas that will be addressed in future specifications and that will be linked for use in conjunction with these specifications. Specifications will be hyperlinked to numerous related government and private agency website addresses.

#### Part 1. HIV/AIDS Benefits

Note: As used throughout this document, the term "HIV/AIDS" shall mean "HIV, AIDS, and HIV-related conditions (e.g., opportunistic infections)."

Note on symbols that appear alongside sample purchasing specifications: In order to provide additional guidance to Medicaid purchasers, these sample purchasing specifications contain applicable symbols that are designed to identify the basis (or bases) for the sample specification. The meaning of each symbol is as follows:

- L** The provision is based in whole or in part on federal Medicaid law, as articulated in the Medicaid statute, a federal regulation, or other written HCFA policy such as an Action Transmittal, State Medicaid Directors Letter, Regional Office Memorandum, or other formal HCFA transmittal. Just because an item is marked "L" does not mean that the service or activity is mandatory either for state agencies or for managed care contractors. Where the legal basis in question identifies a required service or activity, a footnote will so indicate. Law-related provisions that relate to optional services and activities also will be identified in a footnote. "L" is also used to indicate provisions that are based on and may incorporate non-Medicaid laws such as those relating to confidentiality of patient information.
- G** The provision is based on whole or in part on formal guidelines issued by, or under the auspices of, a government agency (e.g., Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents), a professional society, or a formally convened, impartial deliberative body (e.g., the Institute of Medicine).
- K** The provision is based in whole or in part on the best judgment and opinions of persons knowledgeable in a particular area of health care practice, health care delivery, or health services organization and management. This symbol is used to signify sample specifications that do not reflect a formal legal policy or that are not part of a formal practice guideline but that are recommended for consideration because they reflect good practice in the opinion of experts.

3 The CDC convened an expert consultant meeting in April 1999 to solicit input on incorporating recommendations made by the Institute of Medicine (IOM) in its book, *Reducing the Odds: Preventing Perinatal HIV Transmission in the United States*. 1998. The IOM recommended universal HIV testing, with patient notification, as a routine component of prenatal care. "Routine notification" is defined by the IOM to mean that HIV tests would be included in the standard battery of prenatal tests and that women would be informed that an HIV test is being conducted and of their right to refuse it. In July, 1999, the American Academy of Pediatrics and the American College of Obstetricians and Gynecologists endorsed the IOM's recommendations. American Academy of Pediatrics, American College of Obstetricians and Gynecologists. Human Immunodeficiency virus screening (RE 9916); Joint statement of the American Academy of Pediatrics and the American College of Obstetricians and Gynecologists. *Pediatrics* 1999;104(1):128. CDC is expected to issue revised guidelines on HIV testing of pregnant women in 1999. The executive summary of the IOM report is available at <http://www.nap.edu/readingroom>.

4 As of July, 1999, CHSRP's web site (<http://www.gwu.edu/~chsrp>) contained sample purchasing specifications for immunization and prevention of vaccine-preventable diseases and childhood lead poisoning. Specifications addressing the following topics were under final review or in the process of development; access to health care; behavioral health (mental health and addiction disorder); cultural competence; comprehensive children's health services (Medicaid; Children's Health Insurance Program (CHIP); specialized children's health services (Medicaid dental and oral health; children with special health care needs; children's behavioral health; children in the child welfare system); data reporting and information; diabetes; health services for the homeless; HIV, AIDS and HIV-related conditions; memoranda of understanding between managed care organizations and state and local health agencies; pharmaceutical services; reproductive health (family planning and perinatal services); sexually transmitted diseases; tuberculosis. Development of sample specifications was supported by the Centers for Disease Control and Prevention (CDC); the Health Resources and Services Administration (HRSA); the National Committee on Vital and Health Statistics the Substance Abuse and Mental Health Administration (SAMHSA); The Commonwealth Fund; Glaxo-Wellcome; and the David and Lucile Packard Foundation, Center for the Future of Children.



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### §101. In General

In developing a contract, state Medicaid officials will be focused on defining expectations for contractors that apply to all beneficiaries. The purpose of this first section is to ensure that the health plan is required to follow practices for enrollees living with HIV/AIDS that are consistent with good medical practices for people living with HIV.

Consumer advocates are encouraged to examine this section to make certain that it covers all aspects of HIV/AIDS care. The goal is to avoid uncertainty about whether a service is covered by stating up front that it is covered. For example, a consumer advocate may believe that counseling is an integral part of the delivery of HIV health care services, but if this assumption is not stated in the contract, it could potentially lead to the denial of this benefit. The golden rule of contract law is that if it is not explicitly mentioned, then it is not a covered service.

Important elements of this model language are that the contractor is expected to cover the range of HIV services from prevention, testing, and counseling, through medical management, health education, and health care coverage. This requires the contractor to make decisions regarding coverage of benefits in accordance with standards set out in other parts of the contract.

### §101. In General

- G** (a) **Contractor duties**—Contractor shall, for each enrollee, cover and furnish, or arrange for the furnishing of, HIV/AIDS services enumerated in this Part in accordance with:
- G** (1) Guidelines covering prevention, testing, counseling, medical management, health education, and health care coverage that are enumerated in **§109** (or any subsequent editions of such Guidelines); and
- K** (2) the coverage determination standards and procedures enumerated in this Part.

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### §102. Scope of Benefit

The purpose of this section is to comprehensively describe all of the types of services that are covered by the contract—those that the health plan will be expected to provide when medically necessary. This section lists general types of services to be provided, and references other sections where the true scope of these services is described in detail. This section is critical for establishing the up-front expectation that a service is a covered benefit.

Consumer advocates are encouraged to review this section of the contract to determine if the full spectrum of health care services needed by people living with HIV is included.

Important elements of a comprehensive package of benefits (which are described in greater detail in subsequent sections) include:

- **Prevention, testing and counseling services.** The purpose for providing these services is to keep persons from becoming HIV positive, and to identify persons who are living with HIV in order to appropriately manage their care.
- **Medical management services.** These benefits encompass most of the types of services that people think of when they think of medical care, including primary care and specialty care, physician and hospital services.
- **Laboratory services.** These services encompass all of the tests or diagnostic procedures that a health care provider may order in the context of a regular screening, in response to a particular ailment, or as part of a scheduled or emergency hospital service.

- **Pharmacy Services.** Prescription drugs are generally recognized as one of the most important benefits to people living with HIV. Due to the potential costs of prescription drugs, however, access to pharmaceuticals has sometimes been difficult. In order to protect access to this benefit, consumer advocates should make sure that the state Medicaid program has clearly determined how it will finance these benefits. If they intend for the health plan to provide them, then they should explicitly state this in the contract.

Some state Medicaid programs have elected to exclude prescription drugs or certain classes of prescriptions (such as protease inhibitors) from the capitated payment (per member per month payment that the state Medicaid agency pays to the health plan to provide all of the services covered by the contract). Financing prescription drugs outside of the capitated payment may actually improve access to this benefit. A discussion of the merits of various approaches for paying for prescriptions is beyond the scope of this guide. Nonetheless, consumer advocates should make certain that the contract language clearly states what the health plan's obligations are for prescribing, providing and paying for prescription medications.

- **Home and community-based services.** These are optional Medicaid services that enable persons to live and receive their care to the maximum extent possible in their own community. Once a state has made a policy decision to provide these services, they become a covered benefit for eligible beneficiaries.

For persons with other conditions, consumer advocates continue to fight policies that force persons who need Medicaid to live in nursing homes, intermediate care

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facilities for the mentally retarded (ICFMRs) and other institutions. This issue has led many people to challenge Medicaid policies that force individuals to live in institutions. In June 1999, the United States Supreme Court issued its decision in the case of *Olmstead v. L.C.* In this decision, the court ruled that unnecessary segregation of individuals with disabilities in institutions may constitute discrimination based on disability. The court held that the Americans with Disabilities Act may require states to provide community-based services rather than institutional placements for individuals with disabilities.

- **Case management and adherence services.** These services are designed to help individuals to receive coordinated benefits, maximize the efficaciousness of multiple services, and help enrollees to maintain a treatment plan that they have chosen with their providers. Given the complex nature of HIV disease, and the multiple medical and social service needs of most people living with HIV in Medicaid, it is necessary that this benefit be explicitly defined and included as a covered benefit.

Consumer advocates are cautioned that great variations exist from state to state in the level of case management services provided through Medicaid. It is important to remember that while case management services are an optional benefit for adults, they are a mandatory service for children when they are medically necessary.

When states transition their programs into managed care, states that had not previously received approval from the federal Health Care Financing Administration (HCFA) to offer case management services (as part of their state plan) may need to seek HCFA approval in order to receive federal matching payments for case management services. In any case, consumer advocates are encouraged to advocate for the state to contract for case management services, but they are cautioned that the state Medicaid agency may be required to make a broad policy decision to expand its Medicaid benefits package—and this may require a more sustained level of advocacy.

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*The following section sets forth illustrative language addressing the overall range of benefits that have been identified as both relevant and necessary by experts in the field and that Purchasers may wish to consider for inclusion in their agreements.*

#### **§102. Scope of Benefit**

(a) **HIV/AIDS services**<sup>1,2</sup> — HIV/AIDS services are:

- L,G** (1) services enumerated in **§103** (relating to prevention, testing, counseling, education, and referral);
- L,G,K** (2) services enumerated in **§104** (relating to medical management);
- L,G,K** (3) laboratory tests enumerated in **§105**;
- L,G,K** (4) prescribed drugs and biologicals enumerated in **§106**;
- L,G,K** (5) home and community-based services enumerated in **§107**; and
- L,G,K** (6) case management and adherence services enumerated in **§108**.

<sup>1</sup> **Commentary:** There is no standard definition of HIV/AIDS services either in the Medicaid or Medicare programs or under private insurance or employee health benefit laws. This definition has been fashioned by experts in the field of HIV/AIDS to guide Purchasers. It draws upon the opinions of expert panels and data evaluation reflected in clinical guidelines referenced throughout the document and the prevention and medical management experience of clinicians and community-based supportive service providers supported by the Centers for Disease Control and Prevention (CDC), and the Health Resources and Services Administration (HRSA) as administrator of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act ( PL 104-146).

<sup>2</sup> **Commentary for Medicaid Purchasers:** Medicaid law makes special provision for HIV/AIDS in two instances: optional eligibility of certain low-income infants and young children exposed perinatally to HIV (42 U.S.C. §1396n(e)) and optional targeted case management for individuals with AIDS (42 U.S.C. §1396n(g)). However, a broad range of health related items and services which either must or may be covered under Medicaid is enumerated and described in the federal Medicaid statute and regulations, Health Care Financing Administration (HCFA) guidance and opinions, and judicial rulings. Consequently, most if not all of the HIV/AIDS-specific items and services enumerated in this document are either in one or more classes of “mandatory” Medicaid services (which states must cover at least for categorically eligible individuals) or “optional” services (which a state may cover). In the case of Medicaid beneficiaries under age 21, the mandatory Early and Periodic Screening, Diagnosis and Treatment (EPSDT) benefit requires coverage of comprehensive well-child assessments and any diagnostic or treatment service found to be necessary in an assessment, including optional services that the state does not otherwise offer. (1396d(r), 42 U.S.C. §§440.40, 441.50). State Medicaid agencies may reasonably limit the amount, scope and duration of covered services through utilization review or “medical necessity” determinations; but even with such limits, coverage must be sufficient for an item or service to achieve the purpose for which it was prescribed. (42 U.S.C. §440.230(b), (d)). In certain instances, a waiver may be needed to offer individuals with HIV/AIDS a package of specialized services such as home health aide, respite care and specialized equipment that might not be generally available under a state Medicaid plan or a range of services such as home health aide, community-supported living arrangements (e.g., home health aide, respite care) that may be otherwise reserved to specific diagnostic or age groups of Medicaid beneficiaries.

The following list identifies the mandatory and optional Medicaid services that the Medicaid statute defines as “medical assistance” (42 U.S.C. §§1396a(a)(10)(A), 42 §1396d(a)). It does not capture all of the coverage options for state Medicaid programs, such as specialized (“targeted”) case management services for individuals with AIDS (42 U.S.C. 1396n(g)(1)), or such state duties such

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as mandatory coverage of home health services for individuals who would qualify for skilled nursing facility services under a state's Medicaid plan. (42 U.S.C. §1396(a)(10)(D)). The statutory list includes both specific benefits such as physician services and several broadly-worded benefits which may be interpreted to include a range of specific services. For example, the comprehensive health assessments and health education that are required elements of EPSDT would require coverage of virtually all the prevention, testing, counseling and patient education services enumerated at §103. For adult enrollees, these services as well as certain medical management services (e.g. adherence services) enumerated at §104 could be covered under the optional benefit, "other diagnostic, screening, preventive, and rehabilitative" services (42 U.S.C. §1396d(a)(13), 42 C.F.R. §440.130), to the extent that such services would not be covered otherwise as physician services, laboratory services or other more specific Medicaid benefits. Finally, states may include in their state Medicaid managed care programs benefits that are not otherwise included in a state's Medicaid plan. (42 U.S.C. §§1396n(a),(b), 1396a(a)(1),(10)). Federal financial participation for such benefits may require a waiver or states may finance them with state dollars.

Mandatory Medicaid items and services are: inpatient hospital services (42 U.S.C. §1396d(a)(1), 42 C.F.R. 440.10); outpatient hospital services (42 U.S.C. §1396d(a)(2)(A), 42 C.F.R. §440.20); Federally Qualified Health Center services as defined in federal law and other ambulatory services offered by Federally Qualified Health Centers and included in a state's Medicaid plan (42 U.S.C. §1396d(a)(2)(C)); rural health clinic services as defined in federal law and other ambulatory services offered by a rural health clinic and included in a state's Medicaid plan (42 U.S.C. §1396d(a)(2)(B), 42 C.F.R. §440.20(b),(c)); laboratory and x-ray services (42 U.S.C. §1396d(a)(3), 42 C.F.R. §440.30); Early and Periodic Screening, Diagnosis and Treatment (EPSDT) services for enrollees under age 21 (42 U.S.C. §1396d(a)(4)(B), 1396d(r), 42 C.F.R. §§440.40, 441.50-62); physician services and medical and surgical services of a dentist (42 U.S.C. §1396d(a)(5), 42 C.F.R. §440.50); family planning services and supplies (42 U.S.C. §1396d(a)(4)(C), 42 C.F.R. §440.40(c)); home health services (which include part time or intermittent nursing, home health aides and medical supplies and equipment) (§1396d(a)(7), 42 C.F.R. §440.70, 441.15); nurse-midwife services (42 U.S.C. (1396d(a)(17), 42 C.F.R. (440.165); and services of certified pediatric nurse practitioners or certified family nurse practitioners (42 U.S.C. (1396d(a)(21), 42 C.F.R. (440.166)).

Optional Medicaid items and services are: prescribed drugs, dentures; prosthetic devices and eyeglasses (42 U.S.C. (1396d(a)(12), 1396r-8(g), 42 C.F.R. (440.120(a)); transportation services that are necessary for a beneficiary to receive diagnostic and treatment services (42 U.S.C. §1396d(a)(13), 42 C.F.R. §170(a)); skilled nursing facility services for enrollees under age 21 (42 U.S.C. §1396d(a)(13), 42 C.F.R. §440.170(d)); medical and "other remedial care recognized under state law" if furnished by a licensed practitioner (§1396d(a)(6), 42 C.F.R. §440.60); private duty nursing (42 U.S.C. §1396d(a)(8), 42 C.F.R. §440.80); "clinic" services, which may be preventive, diagnostic, therapeutic, rehabilitative or palliative services furnished on an outpatient basis (42 U.S.C. §1396d(a)(9), 42 C.F.R. §440.90); physical, occupational and related therapies including necessary equipment and supplies for treatment of speech, hearing and language disorders (42 U.S.C. §1396d(a)(11), 42 C.F.R. §440.110); "other diagnostic, screening, preventive, and rehabilitative" services (42 U.S.C. §1396d(a)(13), 42 C.F.R. §440.130); hospice services (42 U.S.C. §§1396d(a)(18), 1396(o)); personal care services (42 U.S.C. §1396d(24), 42 C.F.R. §440.167); home and community care (which may include a range of specific services as well as other services approved by HCFA as "cost-effective and necessary to avoid hospitalization" of a beneficiary (42 C.F.R. §440.180); durable medical equipment and prosthetic devices (42 C.F.R. §440.120(c)); case management services, which are defined broadly to cover multi-disciplinary patient assistance in "gaining access" not only to covered medical and health services but also needed educational, social or other services that are not in themselves reimbursable Medicaid services (42 U.S.C. §§1396d(a)(19), 1396n(g)(2)); a specialized package of services for individuals diagnosed with tuberculosis (42 U.S.C. §§1396d(a)(19), 1396a(z); respiratory care services (§1396d(a)(20), 1396e)(9), 42 C.F.R. §440.185); and personal care services (42 U.S.C. §1396d(a)(24), 42 C.F.R. §440.167).

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### **§103. Prevention, Testing, Counseling, Education, and Referral Services**

The purpose of this section is to define the range of services that health plans are expected to provide to enrollees that relate to the primary prevention of HIV and to reduce the risk of HIV transmission to others. Secondary prevention services (services designed to prevent people living with HIV from progressing in their illness or from developing opportunistic infections) are covered separately under **§104**.

The model language in this section covers three types of services:

- Prevention services which include risk assessments to determine the presence of risk factors associated with HIV transmission, education activities concerning HIV and HIV risk reduction, as well as prescription drugs that are designed to prevent perinatal transmission of HIV, transmission associated with an occupational exposure to HIV, and transmission and seroconversion of infants exposed to HIV at birth.
- Testing and counseling services that include the actual HIV test, as well as various components of a counseling program including pre- and post-test counseling and education. This counseling should include education related to risk reduction for persons who test negative for HIV, as well as counseling and education related to health care and treatment options for persons who test HIV positive.
- Referral services include referrals to contractors within a health plan's network for substance abuse, mental health, and prevention services, referrals for non-covered mental health and substance abuse services to community-based providers that are not part of the health plan's network, and referrals to persons who are HIV-positive to programs operated by the state or local public health agency to conduct partner notification activities.

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*The following section provides an illustrative enumeration of services that experts consider relevant and necessary to HIV prevention, counseling, testing, education and referral.*

#### **§103. Prevention, Testing, Counseling, Education, and Referral Services**

**L,G (a) Prevention services**—Services relating to prevention of HIV are the following items and services:<sup>3</sup>

- L,G (1)** risk assessment to determine the presence of risk factors for HIV as defined in **§112**<sup>4</sup> ;
- L,G (2)** education concerning HIV and HIV risk reduction;<sup>5</sup>
- L,G (3)** testing and counseling as defined in subsection (b) of this section;<sup>6</sup>
- L,G (4)** prescribed drugs:
  - G (A)** to prevent transmission in the case of perinatal exposure<sup>7</sup>,
  - G (B)** for occupational exposure to HIV<sup>8</sup>; and
  - G (C)** for exposed infants beginning at birth<sup>9</sup>.
- L,G (5)** family planning services and supplies<sup>10</sup>; and
- G (6)** referral services described in subsection (c) of this section.

**L,G (b) Testing and counseling services**—Testing and counseling services are the following services<sup>11</sup>:

- L,G (1)** laboratory tests described in **§105** to determine the presence of HIV/AIDS, as set forth in applicable guidelines enumerated in **§109**;
- L,G (2)** counseling services<sup>12</sup>, consisting of:
  - G (A)** counseling at the time of testing and at the time of receipt of test results regarding HIV/AIDS and risk reduction;
  - G (B)** individualized, multi-session HIV risk-reduction counseling to assist an enrollee initiate or sustain behaviors or practices that eliminate or reduce the risk of acquiring or transmitting HIV;
  - G (C)** counseling HIV-infected enrollees regarding notifying sex and needle-sharing partners of the risk of infection and the need to seek counseling and testing services;
  - G (D)** counseling regarding decreasing the risk of perinatal transmission;
  - G (E)** counseling HIV-infected enrollees regarding treatment options.

<sup>3</sup> **Commentary:** The services enumerated in this section are considered to be primary preventive services to the extent that they prevent transmission of HIV infection (e.g., through promotion of condom use or timely diagnosis and treatment of HIV infection in pregnant women). The services are also considered to be secondary preventive services to the extent that they promote diagnosis early in the course of HIV infection and initiation of treatment to achieve and maintain maximum viral load reduction and delay and mitigate opportunistic infections and other AIDS-defining conditions.

<sup>4</sup> **Commentary:** For applicable guidelines see **§§109(a) and (b)**.

<sup>5</sup> **Commentary:** For applicable guidelines, see **§§109(a)-(e)**. There is a growing body of evidence based on randomized controlled trials that personalized one-on-one counseling aimed at risk reduction reduces high-risk behaviors and reduces new infection among high-risk persons.

**Commentary for Medicaid Purchasers:** In the case of Medicaid-eligible enrollees under age 21, this education and counseling would be considered an element of the health education and anticipatory guidance that are part of mandatory Early and Periodic Screening, Diagnosis and Treatment (EPSDT) services (42 U.S.C. §1396d).

<sup>6</sup> **Commentary:** For applicable guidelines see **§§109(a)-(d)**.

<sup>7</sup> **Commentary:** For applicable guidelines see **§109(f)**.

<sup>8</sup> **Commentary:** For applicable guidelines see **§109(h)**.

<sup>9</sup> **Commentary:** assumes coverage at the time of birth of infants born to HIV-infected women, to permit antiretroviral prophylaxis for the infant to begin as soon as possible after birth, preferably within 12-24 hours. For applicable guidelines see **§109(f)**.

<sup>10</sup> **Commentary:** For a definition of family planning services and supplies see forthcoming sample purchasing specifications for reproductive health services.

**Additional Commentary for Medicaid Purchasers:** In the case of Medicaid, condoms would be included in the term “family planning services and supplies.” Other purchasers may wish to specify condoms separately.

<sup>11</sup> **Commentary:** For applicable Medicaid law, see **Commentary 3**.

<sup>12</sup> **Commentary:** For applicable guidelines see **§§109(a)-(e) and (h)**.

- G (c) Referral Services** — Referral services are referrals:
- (1) to providers of substance abuse and mental illness treatment and prevention services that are either:
    - (A) members of Contractor’s provider network; or
    - (B) maintain a contractual affiliation status with Contractor as referral providers, regardless of their network membership status<sup>13</sup>;
  - (2) to appropriate and available sources of care in the community for treatment in the case of substance abuse and mental health services that are not covered under this Agreement; and
  - (3) of HIV-infected enrollees to partner services programs if offered by the public health agency in Contractor’s service area.

#### **§104. Medical Management Services**

The purpose of this section is to list all of the types of services and qualified health care professionals that the health plan will be expected to provide related to the medical management (i.e. primary and specialty medical care) of people living with HIV. Please note that the contract may include a separate list of medical management services for all enrollees. This section lists all those services that the health plan is expected to provide specifically to manage HIV disease.

This section is primarily a list of services. It is, however, one of the most critical elements of the contract because consumer advocates will want to make sure that the full range of services are built into the contract. While the listing provided in the model language is comprehensive, consumer advocates are encouraged to determine if their Medicaid program offers additional optional services that have not been included in this listing. Further, a state Medicaid agency may state that not all of these services are ordinarily covered by their program. Examples of this are FDA approved vitamin supplements and medical nutrition services—which may be overlooked when the state is negotiating the contract for services to be provided to all enrollees. Consumer advocates should make the case, and when possible provide documentation from published studies, that all of these services are necessary to appropriately manage the care of people living with HIV. An important piece of evidence justifying these services are CDC or HRSA (federal agencies with extensive HIV/AIDS expertise) policy statements supportive of such services.

<sup>13</sup> **Commentary:** Certain providers may not have network membership status but may nonetheless maintain a formal contractual affiliation with a Contractor for purposes of referral services.



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*The following section sets forth the range of medical management services for persons with HIV/AIDS that have been identified by experts and that Purchasers may wish to consider for inclusion.*

#### **§104. Medical Management Services**

**L,G,K** (a) **Medical management services**—Services relating to the medical management of HIV/AIDS<sup>14</sup> are:

- L** (1) services of medical and health professionals;
- L** (2) inpatient and outpatient hospital care including hospital emergency room services;
- L** (3) federally qualified health center services<sup>15</sup> and other ambulatory services offered by federally qualified health centers;
- L** (4) services of nursing facilities and rehabilitation institutions;
- L** (5) laboratory services enumerated in **§105**;
- L** (6) prescribed drugs and biologicals in accordance with **§106**;
- L** (7) FDA approved vitamin supplements;

**L,G** (8) vaccines enumerated in guidelines set forth in **§109(j)** to prevent opportunistic infections as well as other vaccines recommended by the Advisory Committee on Immunization Practices under guidelines set forth in **§109(k)**.

**L,G** (9) home and community-based services enumerated in **§107**;

**L** (10) case management services enumerated in **§108(a)**;

**G** (11) adherence services enumerated in **§108(b)**;

**L** (12) medical nutrition services;

**K** (13) services and benefits that are covered under this Agreement, when furnished as part of a clinical trial relating to HIV/AIDS<sup>16</sup>;

(14) services for the treatment of mental illness and addiction disorders (**reserved**);

**L** (15) hospice and palliative services;

**L** (16) durable medical equipment;

**L** (17) home health care and private duty nursing care;

**L** (18) preventive, restorative and emergency dental care;

**L** (19) vision care<sup>17</sup>;

**L** (20) hearing care, including hearing aids and devices to aid hearing;

<sup>14</sup> **Commentary:** “Medical management” refers to the diagnostic, treatment, ancillary medical and supportive social services that are needed, in the view of experts in HIV/AIDS, to manage HIV infection as a chronic condition. The services enumerated in this section constitute the minimum elements of medical management of HIV infection. When offered as a continuum of care that is tailored to the HIV/AIDS status and psychosocial circumstances of an HIV-infected individual, these services promote desired treatment outcomes (delaying and mitigating loss of immune function, suppressing or delaying emergence of drug-resistance strains of HIV virus, and delaying and mitigating severity of opportunistic infections and other AIDS-defining conditions.) For a comprehensive reference and clinician’s practice guideline on medical management of HIV/AIDS, see John Bartlett, 1998 Medical Management of HIV Infection (1998 Johns Hopkins University, Department of Infectious Diseases, Baltimore, MD.) (<http://www.hopkins-aids.edu>). The website should be consulted regularly for updates.

**Commentary for Medicaid Purchasers:** for applicable Medicaid law, see **Commentary 3**.

<sup>15</sup> **Commentary for Medicaid Purchasers:** Federally Qualified Health Centers (FQHCs) are community- based, multi-disciplinary ambulatory health care centers that provide primary and certain specialty health care services to medically underserved communities and populations. FQHCs include centers in medically underserved urban and rural areas and health care services for individuals who are homeless. FQHC services are a mandatory service under federal Medicaid and Medicare law. 42 U.S.C. §§1395x(aa)(3); §1396a(a)(10) and §1396d(a)(2)(C). The term “federally qualified health center services” (FQHC) refers to physicians services and ancillary services, services of nurse practitioners and physicians assistants and ancillary services, services of clinical psychologists and social workers when furnished by a federally qualified health center as defined in §1395x(aa)(4). FQHC services in the case of Medicare also include preventive primary services that a Center is required to furnish under §§329,330 and 340 of the Public Health Service Act. §1395x(aa)(3). In certain cases FQHC services also include home health services.

<sup>16</sup> **Commentary:** Access to investigational HIV/AIDS drugs and combination therapies is considered by experts in HIV/AIDS to be an important option. While the drugs used in such trials are provided without cost to participants, enrollee access to trials may be impeded if they are denied other covered services simply because they are participating in a trial. The guidelines identified at **§109(g)** include a toll-free telephone number (1-800- 874-2572) that may be called to determine availability of drug trials that would be appropriate for an HIV-infected enrollee.

<sup>17</sup> **Additional Commentary for Medicaid Purchasers:** In the case of Medicaid, eyeglasses are a mandatory benefit for children under age 21. Most states cover eyeglasses at least to some extent in the case of adults. Medicaid purchasers may wish to include eyeglasses in their purchasing agreements or may wish to continue direct coverage for eyeglasses outside of their managed care contracts.

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- L** (21) intravenous and aerosolized therapy;
- L,G** (22) individualized counseling services described in **§103(b)**;
- L** (23) habilitative and rehabilitative services, including occupational, speech, and physical therapy;
- L** (24) medical devices for the administration of therapies; and
- L** (25) other medical, remedial, and palliative care permitted under state law<sup>18</sup>.

#### **§105. Laboratory Services**

The purpose of this section is to describe and list the types of laboratory services that the health plan will be expected to provide to enrollees. Two critical components should be embodied in this section: First, to describe all of the laboratory services that are currently needed by people living with HIV; and, second, to build in flexibility to add additional laboratory services that may be developed during the period of the contract or that may become more commonly prescribed by a qualified provider.

The model language in this section covers a broad range of tests, including tests to determine the presence of HIV, tests for opportunistic infections associated with HIV, pregnancy tests and obstetric tests related to the monitoring for perinatal transmission or complications among pregnant women living with HIV, tests related to gynecological manifestations of HIV, and tests for infectious conditions associated with HIV, such as tuberculosis and sexually transmitted diseases.

Importantly, the model language references the guidelines cited in **§109** which will be revised and updated over time. The language also includes laboratory tests deemed appropriate by an experienced HIV provider, as defined in **§112**.

<sup>18</sup> **Commentary for Medicaid and other Purchasers Under Medicaid:** “any other medical care permitted under state law” is an optional service for categorically needy adults but would be a mandatory service for enrollees under age 21 if medically necessary. (42 U.S.C. §1396d). This service would include such alternative therapies (e.g., acupuncture) as may be furnished under the medical practice laws of the state in which the Agreement is in effect. In the case of other public and private Purchasers, this subsection should be viewed as a placeholder for the enumeration of other services.

*The following section identifies laboratory testing services that have been identified by experts as relevant and necessary for the diagnosis, treatment and management of HIV/AIDS*

**§105. Laboratory Services**

**L,G,K(a) Covered Services**—The following laboratory services for the testing, diagnosis and medical management of HIV/AIDS covered under this Agreement are<sup>19</sup>:

**L** (1) tests to:

**G** (A) determine the presence of HIV, and

**G** (B) monitor the progression of HIV/AIDS and the effectiveness of medical management, in accordance with the guidelines enumerated in **§109**; and

**G,K** (2) Such other laboratory tests deemed appropriate under the guidelines enumerated in **§109** or in the opinion of experienced HIV providers, as defined in **§112**.

**§106. Prescription Drugs and Biologicals**

The purpose of this section is to describe those prescription drugs and biologicals that the health plan will be expected to provide to HIV-infected enrollees under the terms of the contract.

Consumer advocates generally recognize the important role that prescription drugs play in the treatment of HIV disease. The goal of this section of the contract should be to require the health plan to provide all FDA-approved medications. In an effort to manage their costs, health plans may try to limit access to a certain pharmaceutical for a specific purpose. This section of the contract should clearly create an expectation on the health plan that they must provide all prescription drugs that are prescribed for the purposes for which they were approved by the FDA.

Off-label uses of medications are uses for a medication beyond the scope of the original approval. Pharmaceutical companies often avoid seeking expanded uses for pharmaceuticals because of a desire to avoid the time and expense of taking a medication through the FDA approval process after it was originally approved. Off-label uses for medications are common for all conditions, but this is especially true for HIV disease. To address the issue of documenting common accepted off-label uses for medications, the model language calls on health plans to make a prescription drug available for purposes as described in a variety of pharmacy listings. These listings are compiled by pharmacists and medical professionals and undergo a scientifically-based review process before uses are added to these compendia.

To further address the needs of people living with HIV, for whom the standard of care is changing rapidly, the model language calls on the health plan to provide prescription medications when they are certified as medically necessary by an experienced HIV provider.

<sup>19</sup> For applicable Medicaid law, see **commentary 3**.

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The model language also calls for a prohibition on substitution of prescribed medications without the explicit authorization of the prescribing physician or provider. In an effort to control costs, health plans may routinely substitute medications for lower cost alternatives. The potential for complications from substitutions increases substantially when individuals are taking multiple medications. This contract language does not prohibit substitutions—and some substitutions may provide a valid and appropriate way for health plans to manage costs. The policy that consumer advocates should ensure is written into the contract, however, is that in the case of persons being treated for HIV disease, the health plan must obtain the explicit authorization from the prescribing physician or provider before making any substitutions.

*The following section provides illustrative language for coverage of prescribed drugs and biologicals identified by experts as necessary for the treatment and management of HIV/AIDS.*

#### **§106. Prescription Drugs and Biologicals**

- L (a) In General**<sup>20,21</sup>—A prescribed drug and biological is covered under this Agreement regardless of whether Contractor covers the drug for members enrolled by other Purchasers if the drug or biological is one that is:
- (1) approved by the Food and Drug Administration (FDA); and
  - (2) prescribed:
    - (A) for the indication for which it is approved by the FDA, or
    - (B) for an indication for which it is listed in one of the following compendia:
      - (i) American Hospital Formulary Service Drug Information;
      - (ii) United States Pharmacopeia-Drug Information;
      - (iii) American Medical Association Drug Evaluations; or
      - (iv) the DRUGDEX Information System.

<sup>20</sup> **Commentary:** The pharmacy benefit described in this section is drafted to respond to the well-recognized need for maximum flexibility in prescribing antiretroviral combination drug therapies and other medications for HIV-infected individuals on a case-by-case basis, taking into consideration the stage of infection in the individual (or exposure in the case of perinatally- or occupationally-exposed individuals); evidence of treatment failure or drug resistance, variations in pharmacokinetics, the multiplicity of combination drug therapy options and emerging new drug therapies.

<sup>21</sup> **Commentary for Medicaid Purchasers:** The extent to which the full scope of coverage described in this section is required under Medicaid law for all Medicaid beneficiaries is unclear. Under Medicaid law, “prescribed drugs” are an optional benefit for categorically needy individuals except that any drug found to be medically necessary for a beneficiary under age 21 would be mandatory. (42 U.S.C. 1396a(10), 42 U.S.C. §1396d(a)(12), §1396d(r)). All states now include prescribed drugs in their state Medicaid plans. Medicaid law requires that all FDA-approved drugs available under rebate agreements (which are virtually all currently-approved drugs) be covered; a state may exclude only drugs in certain named categories and drugs that are not prescribed for “medically indicated” uses, defined as either uses approved by the FDA or “off-label” uses that are supported in at least one of four named compendia. (42 U.S.C. §1396r-8(d), 1396(a)). The Health Care Financing Administration (HCFA) has advised state Medicaid directors that states must cover AZT (now referred to as Zidovudine, ZDV) for the prevention of perinatal transmission of HIV. (Letter of Sally K. Richardson, Director, Center for Medicaid and State Operations, to state Medicaid directors, Dec. 5, 1994). HCFA has also advised state Medicaid directors that FDA-approved protease inhibitors must be covered. In the same advisory letter, HCFA also advised states that if Medicaid beneficiaries who are HIV-infected are enrolled in managed care and if the state’s managed care contract includes drugs, “these [protease inhibitor] drugs must be available in managed care formularies.” State Medicaid agencies are also advised to determine what benefit restrictions might apply to the drugs and to consider whether “capitation rates should be adjusted to account for the introduction of new drugs such as protease inhibitors.” (Letter of Sally K. Richardson, Director, Center for Medicaid and State Operations to state Medicaid directors, June 19, 1996). At least one court that has considered this issue has enjoined a state from failing to cover HIV-related drugs used in accordance with accepted medical practice (Reagan v. Weaver, 886 F.2d.194 (8th Cir., 1989)). This specification is drafted to follow Medicaid law (coverage for FDA-approved uses or uses supported by one of the four compendia) except that an additional basis for coverage has been added, i.e., certification of a drug’s “medical necessity” by a Contractor or an experienced HIV provider.

**K (b) Additional coverage**—Drugs not described under subsection (a)(2)(A) or (B) will be considered covered under this Agreement if certified as medically necessary by an individual who conducts utilization review and who is an experienced HIV/AIDS provider as defined in **§112**.

**G,K (c) Substitution prohibited**

- G,K (1)** Contractor shall ensure that drugs prescribed under this section are dispensed as prescribed unless the prescribing physician expressly authorizes modification of the prescription.
- (2) Notwithstanding subparagraph (1) of this subsection, Contractor may substitute generic drugs where available.

**§107. Home and Community-based Services**

Home and community-based services include a broad range of services that may enable an individual to continue to live in their own home or to live in a community (non-institutional) setting. These services should include:

- personal care services that assist the individual with activities of daily living.
- homemaker/home health aide services that assist the individual to perform activities necessary to continue to reside in their home.
- respite services which provide for caretakers to be relieved from twenty-four hour responsibility for monitoring and caring for the person living with HIV. It is especially important to ensure that the eligible caretaker be broadly defined to include an enrollee's partner or (non-biological) family members.
- transportation services that enable the individual to obtain prevention or medical management services.

Presently, many state Medicaid programs still pay for home and community-based services on a fee-for service basis, and these services will not be part of the managed care contract. If recent trends continue toward capitating an ever greater number of services, however, these contract provisions will be increasingly important.

*The following section sets forth illustrative language enumerating home and community based services identified as relevant and necessary by persons with expertise in the care and management of HIV/AIDS.*

**§107. Home and Community-based Services**

**L,G (a) Home and community-based services**<sup>22</sup>—Home and community-based services are the following services furnished to an enrollee in the enrollee’s home or in a community setting<sup>23</sup>:

- (1) personal care services<sup>24</sup>;
- (2) homemaker/home health aide services<sup>25</sup>;
- (3) respite care for the enrollee’s partner or family caretaker<sup>26</sup>; and
- (4) transportation necessary to enable an enrollee to obtain prevention or medical management services<sup>27</sup>.

**§108. Case Management and Adherence Services**

The purpose of this section is to create expectations for the health plan to provide the described range of case management and adherence services.

Case management services are recognized by most consumer advocates as an essential element of a care program for people living with HIV. While definitions of the role of a case manager vary, in this context, case management should be defined broadly to encompass medical case management, which involves the coordination of the medical care plan for a person living with HIV, as well as other social case management roles, such as coordinating or assisting an enrollee with accessing other medical and social support programs. For example, an individual with HIV may be eligible for a health plan on the basis of receiving Medicaid, but they also qualify for Medicare, housing assistance or other services. Consumer advocates should strive to work with state Medicaid agencies to recognize the value to the health plan of providing a single source for the coordination of all of the service needs of the individual.

It is important to specify that adherence services are a covered benefit because they may be overlooked by a health plan in designing their care plan, but which directly relate to the potential for success of any treatment plan. Adherence services should be described to include monitoring for adherence, and counseling and educating an individual in strategies to improve or promote adherence with a treatment plan.

22 **Commentary:** In communities where Ryan White CARE Act-funded providers offer these services, Contractors may wish to purchase the services from these providers or consult with Ryan White Care Act grantees to identify appropriate providers.

**Commentary for Medicaid Purchasers:** For applicable law, see **Commentary 3**.

23 **Commentary:** Purchasers may wish to specify that Contractors enter into agreements with Ryan White CARE Act grantees for the provision of one or more home and community care services. In the case of Medicaid agencies, on November 25th, 1998, Sally Richardson, Director of the HCFA Center for Medicaid and State Operations, sent a letter to state Medicaid directors regarding strategies to implement coordination between the Medicaid program and the Ryan White Comprehensive AIDS Resources Emergency Act (CARE). Among other options for consideration, the letter encourages the development of managed care contract language that “ensures that traditional providers such as Ryan White grantees will be considered for inclusion in managed care organizations and/or that services provided to beneficiaries be coordinated with Ryan White grantees.” Letter from Sally Richardson to state Medicaid directors, November 25th, 1998. <http://www.hcfa.gov/medicaid/smd11256.htm>.

24 42 U.S.C. § 1396d(a).

25 42 U.S.C. § 1396d(a)

26 42 U.S.C. § 1396d(a)

27 42 C.F.R. §§ 431.53 (transportation as an administrative cost), 440.170(a) (transportation as an optional service).

### Section III: An Explanation and Description of Model Contract Language

*The following section provides illustrative language relating to case management and adherence services, which have been identified by experts as relevant and necessary to the proper care and management of HIV/AIDS.*

#### **§108. Case Management and Adherence Services**

**L,G,K** (a) **Case management services**<sup>28</sup>—Case management services for enrollees with HIV/AIDS, or perinatally exposed infants, are the following items and services<sup>29</sup>:

**K** (1) an initial and periodic<sup>30</sup> assessment of an enrollee's medical, prevention, social, substance abuse, mental health, transportation, housing, and other needs conducted on a face-to-face basis by a case manager in consultation with the enrollee's primary care physician and other providers involved in the care of the enrollee and in consultation with the enrollee or enrollee's representative;

**K** (2) development and maintenance of a written case management plan for the enrollee based on the assessment under paragraph (1) that is made available to the enrollee and any treating or consulting provider;

**K** (3) arranging necessary referrals;

**L** (4) assistance to an enrollee in gaining timely access to necessary medical, social, and preventive health

services regardless of coverage under this Agreement;

**K** (5) assistance to an enrollee in applying for federal, state, or local benefits or assistance for needed services not covered under this Agreement;

**K** (6) assistance to an enrollee in initiating and sustaining practices that prevent the transmission of HIV; and

**G** (7) assistance to family members involved in the care of an individual with HIV/AIDS<sup>31</sup>.

(b) **Adherence services**<sup>32</sup>—Adherence services for enrollees with HIV/AIDS are:

(1) monitoring enrollee adherence to a prescribed course of treatment; and

(2) counseling an enrollee about adherence to a prescribed treatment, and activities that assist an enrollee initiate and sustain practices that promote adherence to a course of treatment<sup>33</sup>.

<sup>28</sup> **Commentary:** The case management services enumerated in this section constitute an individualized, multi-disciplinary social service that is intended to promote effective care for those HIV-infected enrollees who may need assistance in coordinating complex medical management regimens or provider referrals or whose adherence to treatment may be enhanced by identifying appropriate support services (e.g., housing assistance for enrollees who are homeless or subject to domestic violence; special education and early intervention programs for HIV-infected children, state and federal public assistance programs). The case management services specified in this section are in addition to the traditional institutional discharge planning and case management done under managed care as part of utilization management. This model of case management has been developed by and evaluated for, among others, Ryan White CARE Act providers. Case management has been shown to decrease hospitalization and enhance adherence to medication regimens in individuals with severe, disabling mental illness. (CT Bush, MW Langford, P Rosen, W Gott. Operation Outreach: intensive case management for severely psychiatrically disabled adults. *Hosp. Community Psychiatry*. 1990; 411:6477-649; USPHS/HRSA/HIV/AIDS Bureau, *Evaluation of HIV Case Management: Invited Research and Evaluation Papers* (July, 1998). HIV case management experts consider face-to-face provision of services an important quality assurance standard (as opposed to case management by telephone). Note that this language does not obligate a payor to finance services enumerated under a case management plan that are not otherwise covered services under this Agreement.) Persons who decline medical management of their conditions should be able to receive case management services.

**Additional Commentary for Medicaid Purchasers:** Multi-disciplinary case management of this scope is an optional Medicaid service (42 U.S.C. §1396n(g)) but is mandatory when found to be medically necessary in the case of enrollees under age 21. (42 U.S.C. §1396d).

<sup>29</sup> For applicable Medicaid law, see **Commentary 3**.

<sup>30</sup> **Commentary:** Guidelines in §109 do not indicate the frequency for case management assessments. Experts in the medical management of persons with HIV/AIDS suggest assessments on a semi-annual basis or more often as determined by an individual's case manager, or whenever there is a major change in an individual's HIV status or psychosocial circumstances (e.g., a child's or adolescent's entry into out-of-home care).

<sup>31</sup> **Commentary:** USDHHS, *A Guide: Family Centered Comprehensive Care for Children with HIV Infection* (August, 1991); Boland, Epstein and Taylor, *Building Quality: Indicators for Family Centered Care in HIV Health Services for Children, Youth and Families* (National Pediatric HIV Resource Center and New England SERVE, Boston, MA, 1994); Richard Conviser, *Caring for Families with HIV: Case Studies of Pediatric HIV/AIDS Demonstration Projects* (USDHHS, 1991).

<sup>32</sup> **Commentary:** HIV experts consider that assistance to HIV-infected individuals as needed to promote adherence is necessary because suboptimal adherence (e.g., not taking all prescribed medicines at indicated times) may lead to treatment failure and emergence of drug resistance.

<sup>33</sup> **Commentary:** Counseling and other strategies to promote adherence to drug treatment is considered by HIV experts to be critical to achieving acceptable treatment outcomes and avoiding or minimizing the emergence of drug-resistant HIV strains. Intensive counseling and assistance, provided on an emergency or urgent care basis by individuals with demonstrated experience in adherence services, may be needed for certain enrollees who, for psychological or other reasons, find adherence difficult.



### Section III: An Explanation and Description of Model Contract Language

#### §109. Guidelines

The purpose of this section is to ensure that the health plan is aware of and required to comply with numerous clinical practice guidelines related to the treatment of people living with HIV developed by appropriate health professionals. Importantly, the language in §101(a)(1) requires health plans to comply with the guidelines in this section as they are updated. This provides flexibility to ensure that enrollees are not subject to outdated treatment standards that were current only when the contract was first negotiated.

Requiring health plans to comply with these guidelines is critical. Unlike other health conditions which are well understood and for which treatment and care recommendations are firmly established and rarely change, the standard of care for HIV disease changes frequently and unpredictably. Therefore, no contract terms are complete for ensuring the appropriate care of people living with HIV, unless the health plan is explicitly required to factor in and comply with changing treatment recommendations and practices.

Further, treatment of all patients is highly individualized. These guidelines do not make firm determinations about a course of treatment, and all are subject to the best medical judgement of the treating provider and personal decisions of the patient. Nonetheless, these guidelines have been developed to weigh a large volume of scientific evidence and make recommendations that have received the consideration and best judgement of leading physicians, consumers, and others.

#### G §109. Guidelines<sup>34</sup>

- (a) U.S. Preventive Services Task Force. Guide to Clinical Preventive Services, 2<sup>nd</sup> ed. (Virginia: International Medical Publishing, 1996)<sup>35</sup>.
- (b) Centers for Disease Control and Prevention (CDC). *HIV Counseling, Testing, and Referral Standards and Guidelines* (Atlanta, Georgia. May 1994)<sup>36</sup>.
- (c) Centers for Disease Control and Prevention (CDC). *U.S. Public Health Service Recommendations for Human Immunodeficiency Virus Counseling and Voluntary Testing for Pregnant Women. MMWR 1995;44(RR-7): 1-14* <sup>37</sup>.
- (d) Centers for Disease Control and Prevention (CDC). *HIV Prevention Case Management: Guidance*. Atlanta, Georgia. September 1997 <sup>38</sup>.
- (e) Centers for Disease Control and Prevention (CDC). Health Resources and Services Administration (HRSA), National Institute on Drug Abuse (NIDA), Substance Abuse and Mental Health Services Administration (SAMSHA), *HIV Prevention Bulletin: Medical Advice for Persons who Inject Illicit Drugs, May 9, 1997*<sup>39</sup>.
- (f) Centers for Disease Control and Prevention (CDC). Public Health Service Task Force Recommendations for the Use of Antiretroviral Drugs in Pregnant Women Infected with HIV-1 for Maternal Health and for Reducing Perinatal HIV-1 Transmission in the United States. *MMWR 1998;47(RR-2)*<sup>40</sup>.

<sup>34</sup> **Commentary:** All guidelines enumerated in this section except those identified at subsection (a) are available at the CDC website [http://www.cdc.gov/nchstp/hiv\\_aids/pubs.htm](http://www.cdc.gov/nchstp/hiv_aids/pubs.htm). The website should be consulted regularly for updates. Current treatment guidelines can be obtained at <http://www.hivatis.org>.

<sup>35</sup> **Commentary:** This guide, prepared by a U.S. Public Health Service Task Force, contains evidence-based guidelines for HIV risk-assessment and for periodic HIV screening (counseling and testing) of at-risk individuals and for HIV counseling and education for all individuals. <http://www.odphp.osophs.dhhs.gov/pubs/guidecps>

<sup>36</sup> **Commentary:** See **Commentary 34** for website address. This two-part document was developed by CDC, with review by experts in HIV prevention, to provide standards and guidelines for CDC grantees in administering HIV counseling and testing programs and for providers of counseling and testing services in such programs.

<sup>37</sup> **Commentary:** See **Commentary 34** for website address (guidelines are located under the MMWR Index). This document contains recommendations of the U.S. Public Health Service on offering HIV counseling and testing to all pregnant women; topics addressed include test interpretation, and counseling on treatment and breastfeeding.

<sup>38</sup> **Commentary:** See **Commentary 34** for website address. This document contains CDC standards for HIV prevention grantees for provision of multi-session risk reduction counseling as a component of prevention case management. Topics addressed include indications for such counseling, screening and counseling standards and related matters.

<sup>39</sup> **Commentary:** See **Commentary 34** for website address. This document contains joint recommendations of four federal health agencies regarding counseling injection drug users (non-medical users) on methods to minimize the risk of HIV acquisition or transmission associated with injection drug use.

<sup>40</sup> **Commentary:** See **Commentary 34** for website address (guidelines are located under the MMWR Index). This document reflects recommendations of a Public Health Service task force whose participants were clinical and public health experts on perinatal HIV transmission. Topics addressed include the use of antiretroviral therapy in pregnancy, antiretroviral chemoprophylaxis to reduce perinatal HIV transmission, and monitoring of HIV-infected women and their exposed infants.



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- (g) Centers for Disease Control and Prevention (CDC). *Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection. MMWR 1998; 47(RR-4)*<sup>41</sup>.
- (h) Centers for Disease Control and Prevention (CDC). *Public Health Service Guidelines for the Management of Health-Care Worker Exposures to HIV and Recommendations for Postexposure Prophylaxis. MMWR 1998. 47(RR-7)*<sup>42</sup>.
- (i) Centers for Disease Control and Prevention (CDC). *Report of the NIH Panel to Define Principles of Therapy of HIV Infection and Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents. MMWR 1998;47(RR-5)*<sup>43</sup>.
- (j) Centers for Disease Control and Prevention (CDC). *1997 USPHS/IDSA Guidelines for the Prevention of Opportunistic Infections in Persons Infected with Human Immunodeficiency Virus. MMWR 1997;46 (RR- 12)* <sup>44</sup>.
- (k) Centers for Disease Control and Prevention. *Recommendations of the Advisory Committee on Immunization Practices: Use of Vaccines and Immune Globulins in Persons with Altered Immunocompetence MMWR 1993; 42 (RR-4)* <sup>45</sup>
- (l) Centers for Disease Control and Prevention. *Prevention and Treatment of Tuberculosis Among Patients Infected with Human Immunodeficiency Virus: Principles of Therapy and Revised Recommendations. MMWR 1998; 47 (RR-20)* <sup>46</sup>.
- (m)Centers for Disease Control and Prevention. *HIV Partner Counseling and Referral Services: Guidance Atlanta, GA. Dec. 1998* <sup>47</sup>.
- (n) Centers for Disease Control and Prevention. *1993 Revised Classification System for HIV Infection and Expanded Surveillance Case Definitions for AIDS Among Adolescents and Adults. MMWR 1992; 41 (RR-17)*<sup>48</sup>

<sup>41</sup> **Commentary:** See **Commentary 34** for website address. This document contains guidelines developed by the Working Group on Antiretroviral Therapy and Medical Management of HIV-Infected Children which was convened by the National Pediatric and Family HIV Resource Center (NPHRC), HRSA and the National Institutes of Health (NIH). The recommendations in the document are based on published and unpublished data on treatment of HIV infection in adults and children and where definitive data were unavailable, the clinical experience of members of the Working Group. Topics addressed include diagnostic testing, treatment recommendations (including testing for monitoring and modifying treatment) and treatment adherence for infants, children and adolescents.

<sup>42</sup> **Commentary:** See **Commentary 34** for website address. This document contains recommendations of a federal interagency working group (CDC, Food and Drug Administration, NIH, with review by expert consultants) for post-exposure prophylactic antiretroviral treatment, testing and counseling of health care workers who have been occupationally exposed to HIV.

<sup>43</sup> **Commentary:** See **Commentary 34** for website address. This two-part document consists of a statement of principles in the treatment of HIV infection, developed by a panel of experts convened by the NIH Office of AIDS Research, and clinical guidelines for antiretroviral therapy, developed by a panel convened by the Department of Health and Human Services (DHHS) and the Henry J. Kaiser Family Foundation. The clinical guidelines include indications of the strength of evidence for each guideline and also stipulate that the guidelines are not intended to substitute for the opinion of a physician “who is expert in caring for HIV-infected persons” (as primary care practitioner or through consultation). Topics addressed include considerations for initiating therapy in asymptomatic and symptomatic individuals with HIV infection (including acute HIV infection), choice of drugs and drug combinations, criteria for modifying treatment regimens, and ongoing testing associated with treatment. See <http://www.hivatis.org>.

<sup>44</sup> **Commentary:** See **Commentary 34** for website address. This document contains recommendations of a working group of representatives from federal agencies, universities, professional societies, community health-care providers and patient advocates, convened by the U.S. Public Health Service (USPHS) and the Infectious Diseases Society of America (IDSA). Topics addressed include disease-specific recommendations for prevention and treatment of opportunistic infections associated with HIV infection in adults, adolescents and children and in pregnant women. Recommendations are rated on the strength of published and unpublished data considered by the working group. The guidelines were made available for public comment in the *Federal Register* and *MMWR* and the final document was approved by USPHS, IDSA, the American College of Physicians, the American Academy of Pediatrics, the Infectious Diseases Society of Obstetrics and Gynecology, the Society of Healthcare Epidemiologists of America and the National Foundation for Infectious Diseases.

<sup>45</sup> **Commentary:** See **Commentary 34** for website address (guidelines are located under “HIV Prevention Guidelines , 1982-Present”)

<sup>46</sup> See **Commentary 34** for website address (guidelines are located under the MMWR Index).

<sup>47</sup> See **Commentary 34** for website address.

<sup>48</sup> **Commentary:** See **Commentary 34** for website address (guidelines are located under “HIV Prevention Guidelines, 1982-Present”).

### **§110. Coverage Determinations**

The purpose of this section is to describe how health plans are expected to determine whether a service or benefit is covered—and which they are obligated to provide. This section also serves to prohibit health plans from undertaking certain activities when making coverage determinations. While the strength of a contract stems from the sum of its parts, this section is one of the more important parts of the contract. Making sure that health plans make coverage decisions in a consistent and appropriate manner, based on the medical condition of the enrollee, should be one of the highest priorities of consumer advocates.

Frequently, consumer concerns with managed care stem from their experiences and those of others where services have been denied. The reasons for denials of a service are many. In some cases, a service truly may not be necessary. In other cases, a provider may not have adequately demonstrated to the health plan that a particular service is necessary. In other cases, however, denials have been made because the coverage determination section was poorly written, and the health plan was permitted more flexibility in making coverage determinations than the payor (whether it is Medicaid or some other public or private payor) intended. (See *The Difference Between Contract Law and Statutory Law* on page 26. This describes how lack of specificity in a contract can give a health plan more freedom to act in ways contrary to what the state Medicaid agency expects.)

Further complicating this issue, many providers participate in multiple provider networks, wherein each has different standards and processes for making coverage determinations. This can lead to providers either prescribing services which are not covered and then having the health plan fail to authorize them or to providers “dumbing down” their practices and only prescribing services that are generally accepted by the many health plans with which they participate.

In general, a service is covered if it is described in other parts of the contract as being a covered benefit by the health plan and it has been determined to be medically necessary. Determining medical necessity is the crux of the issue.

In advocating to strengthen the contract provisions related to coverage determinations, consumer advocates are encouraged to focus on how medical necessity is defined and who determines whether a service meets the standard for being medically necessary. The following principles should guide your advocacy in this area:

- **One consistent definition of medical necessity.**  
It is important that when Medicaid contracts with health plans they do not negotiate on the provisions of this section, meaning they do not allow each health plan to change the language and set their own standards for medical necessity—all health plans within a state Medicaid program should be subject to the same provisions.
- **Qualified and experienced providers need to be decision makers.**  
Trained and qualified health care professionals with expertise in the prevention and care of people living with HIV should be the persons who determine whether a service is medically necessary. In the past, some health plans have developed rigid standards that do not take into account the unique circumstances of people living with HIV, or the variations and needs of individual enrollees. Further, some health plans have employed unqualified or under-experienced individuals, and persons who may not be health care professionals to make coverage determinations.

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- **Decisions must be consistent with relevant clinical practice guidelines.**

Decisions regarding the medical necessity of a service must be based on clinical practice guidelines. As stated previously, the standard of care for HIV is changing rapidly and it is difficult for individual providers and health plans to stay current on recommendations for the prevention and care of people living with HIV. The guidelines referenced in the model contract language were developed by panels of experts, including health care providers and consumers, with a diversity of experience. In most cases, these guidelines provide the most current consensus statement of how to care for people living with HIV.

- **Decisions must be made on the basis of medical evidence and judgement of treating providers.**

If a determination involves an issue that is not covered in the guidelines, then health plans should base their decisions on medical evidence based on: the enrollee's health status and medical record, clinical evidence of HIV, the opinions of providers responsible for the care of the enrollee, findings from clinical trials, and opinions of clinicians and researchers that have been published in peer-reviewed publications.

There is more to this section of the contract than simply determining if a service is necessary. The model language also addresses circumstances indicating when a service is considered medically necessary without being subject to utilization review either before or after a service has been provided. These services include prevention services related to a risk assessment for HIV exposure and HIV counseling and testing services; prescription drugs; and services by an out-of-network primary care provider when the health plan does not have an experienced provider available within the enrollee's geographic service area.

This section also prohibits health plans from requiring pre-authorization (prior approval) from the health plan before an enrollee seeks emergency medical care or care for an urgent medical condition.

Finally, the model contract language for this section prohibits health plans from denying care for the medical management of HIV because: the services are otherwise available through a public health clinic; have been ordered by a court or an agency of the government; are for an enrollee with co-morbid conditions (such as substance abuse), or is living in adverse social circumstances or living arrangements (such as persons who are homeless); or the enrollee is participating in a clinical trial or is receiving an experimental drug under an expanded access program.

## **Utilization Review**

To understand what is meant by managed care, it is necessary to understand the principle of utilization review. Managed care is premised on the idea that without careful controls on services, health care resources will be wasted through the prescribing of services and benefits that are not truly necessary. Utilization review encompasses the range of policies and procedures that a health plan employs to determine which services are necessary—and avoid paying for services that are not.

Health plans can create rules that require individuals to receive pre-certification or pre-authorization before they receive a service. For example, a common feature of managed care is the requirement that a primary care provider must give referrals—and specialty care cannot be received without a referral. This is a strategy by the health plan to avoid paying for unnecessary specialty care. Similarly, most

health plans require persons to get a non-emergency hospitalization pre-certified or approved in advance. This is also a utilization review technique.

Health plans may also conduct utilization review analysis after services have been provided and paid for. This is done to look for patterns of specific physicians ordering more services than other physicians. This type of practice has the potential to penalize HIV providers for providing necessary care.

Some utilization review practices of a health plan may be harmful if they are applied to people living with HIV. For this reason, the model language exempts prevention services, prescription drugs and consultations with an experienced provider from either pre-or post utilization review.

*The following section sets forth illustrative language regarding coverage decision-making in the case of persons with HIV/AIDS, which Purchasers may wish to include in whole or in part in their agreements.*

**§110. Coverage Determinations**

**K (a) Medical necessity of services for prevention, testing, counseling, referral and medical management of HIV/AIDS**—In making coverage determinations under this Part, Contractor shall utilize medical and health professionals with training and expertise in the prevention and medical management of HIV/AIDS and shall make determinations in a manner that is consistent with the requirements of this section.

**K (b) Determinations of medical necessity**

(1) **Basic rule**—In determining whether an item or service covered under this Agreement will be covered as medically necessary for the prevention or medical management of HIV/AIDS, Contractor shall base such determinations on the guidelines enumerated in **§109**, using personnel who have expertise in the prevention, and management of HIV/AIDS.; and

(2) **Determinations**—In the case of coverage determinations involving conditions and procedures that are not addressed in the guidelines enumerated in **§109**, Contractor shall rely on the following evidence:

- (A) the enrollee’s health status and health-related behaviors;<sup>49</sup>
- (B) clinical evidence of HIV/AIDS;
- (C) the enrollee’s medical record and accompanying supporting documents;
- (D) the opinion of any medical or health professional responsible for the care and management of the enrollee;

- (E) findings from clinical drug trials or from studies published in journals which have been reviewed by relevant experts in the field of HIV/AIDS; and
- (F) the opinions of peer reviewers with expertise in the medical management of persons with HIV and HIV-related conditions.

**K (c) Services considered medically necessary without additional pre- or post-utilization review**—The following items and services shall be considered medically necessary and therefore exempt from both pre- and post-service utilization review procedures otherwise employed by Contractor to determine medical necessity:

- (1) services enumerated in **§103 (a)(1)-(5)** (certain prevention services)<sup>50</sup>;
- (2) drugs prescribed in accordance with the provisions of **§106**; and
- (3) consultation by an enrollee (under a standing order of the primary care provider) or provider on the enrollee’s behalf with an experienced HIV provider who has in effect a consultation Agreement with the enrollee’s primary care provider as described in **§202(a)(2)**.

**L,G,K (d) Use of prospective utilization management and prior authorization**—In reviewing the medical necessity of care and services furnished under this Part, Contractor shall exempt care and services from prospective utilization management or prior authorization in cases involving:

<sup>49</sup> **Commentary:** Experts indicate that in assessing an individual’s health status and need for care, health professionals should take into account whether the individual is at risk for HIV/AIDS or presents a risk of infecting others.

<sup>50</sup> **Commentary:** Certain services enumerated in this section are exempted from prior authorization for reasons relating to primary prevention of HIV/AIDS. Perceived delays or barriers to HIV testing could discourage earliest possible identification of the illness.

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**L** (1) emergency medical conditions<sup>51</sup>;

**K** (2) urgent medical conditions<sup>52</sup>; and

(3) post-exposure prophylaxis for enrollees who are health care workers<sup>53</sup>.

**K,L** (e) **Prohibited bases for denial of coverage of HIV medical management services**—Contractor shall not deny, terminate or reduce coverage of items and services enumerated under this Part solely on the grounds that such services are

**K** (1) available:

(A) free of charge or at a discount through a public or private provider that is legally obligated to furnish such service either free of charge or in accordance with a schedule of charges that has been adjusted for family income, or

(B) from a provider described in **§202(f)**;

**L** (2) ordered by a court or administrative agency with jurisdiction over the enrollee;

**K** (3) for an enrollee with co-occurring conditions or living in adverse social circumstances or living arrangements<sup>54</sup>;

**K** (4) for an enrollee who is participating in a clinical trial or is under treatment with a drug available under an FDA Treatment Investigational New Drug Application (or similar application for expanded access distribution); or

**L** (5) specified in a plan of care developed for a child or adolescent by a child welfare agency under Title IV-B of the Social Security Act or by an education agency or early intervention agency under the Individuals with Disabilities Education Act (IDEA).

**51 Commentary for Medicaid Purchasers:** In the case of Medicaid (or Medicare) contracts the term “emergency medical condition” in the managed care context means “a medical condition manifesting itself by acute symptoms of sufficient severity (including severe pain) such that a prudent layperson, who possesses an average knowledge of health and medicine, could reasonably expect the absence of immediate medical attention to result in (i) placing the health of the individual (or with respect to a pregnant woman, the health of the woman or the unborn child) in serious jeopardy, (ii) serious impairment of bodily functions, or (iii) serious dysfunction of any bodily organ or part. (§1852(d)(3) of the Social Security Act). According to experts in the field, in the context of HIV/AIDS, an emergency medical condition would include symptoms of serious opportunistic infection associated with AIDS. For a discussion of opportunistic infections associated with HIV infection, see **§109(j)**. For infants born to HIV- infected pregnant women in labor who received no antiretroviral therapy during pregnancy, ZDV should be initiated as soon as possible. See guidelines at **§109(f)**.

**52 Commentary:** There is no federal definition of the term “urgent.” For illustrative approaches taken by state Medicaid agencies see S. Rosenbaum et. al., *Negotiating the New Health System: A Nationwide Study of Medicaid Managed Care Contracts* (2d ed.) (The George Washington University, Washington D.C., 1998).

**53 Commentary:** CDC guidelines regarding exposure of health care workers stress that occupational exposures should be considered urgent medical conditions, with immediate administration of post-exposure prophylaxis if indicated. See **§109(h)**.

**54 Commentary:** Examples of prohibited grounds for denial would be homelessness, pregnancy, addiction, or mental illness.

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#### **§111. Consumer Protections: Timelines for Review of Requests for Treatment, Grievances and Appeals of Adverse Coverage or Treatment Determinations, and Other Matters (Reserved)**

In recent years, consumer advocates have focused considerable attention on strengthening the mechanisms within managed care programs to hold individual providers and health plans accountable for providing a high level of service to their enrollees. As a strategy for improving accountability, consumer advocates have focused on developing standards for how long it is reasonable to make a person wait in order to receive a service. Consumer advocates have also worked to promote the creation of grievance programs that allow a Medicaid beneficiary an opportunity to make a formal complaint to the health plan, and if the complaint is not resolved, to an independent body.

It is also necessary to set timelines and other standards governing how grievance programs should operate. While provisions related to these consumer protections are not included here, they are important consumer protections. Consumer advocates are encouraged to advocate for the establishment of timeliness and other consumer protection standards within their state Medicaid programs.

#### **§112. Definitions**

The definitions section of a contract may seem like a mundane technicality, but it is not. Since the goal of consumer advocacy is to create a legally enforceable document, it is important that there is a high level of specificity about what is meant by various provisions. The model contract language contains definitions for terms that are used throughout the contract.

Use these terms as guidance for making sure there is clarity between both the state Medicaid program and the health plan regarding all of these contract elements.



**Section III:** An Explanation and Description of Model Contract Language

*The following section provides illustrative definitions.*

**§112. Definitions**

**G (a) Adolescent**—an individual aged 11 through 20<sup>55</sup>.

**G (b) AIDS**—Acquired Immunodeficiency Syndrome, which is a specific group of diseases, conditions or laboratory findings that are indicative of severe immunosuppression related to infection with the human immunodeficiency virus (HIV)<sup>56</sup>.

**G (c) HIV infection**—infection with the Human Immunodeficiency Virus, the etiologic agent for AIDS.

**G (d) HIV-related condition**—conditions associated with HIV infection, as enumerated in the CDC guidelines under **§109**.

**K (e) Experienced HIV provider**<sup>57</sup>—a licensed physician, nurse practitioner, or physician assistant who has:

- (1) maintained an active HIV/AIDS medical practice by providing continuous and direct medical care to at least \_\_\_ individuals with a full spectrum of HIV/AIDS; and
- (2) has completed at least \_\_\_ hours of continuing medical education on topics related to the care and management of individuals with HIV/AIDS<sup>58</sup>.

**G (f) HIV risk factor**—the presence or history in an individual of one or more of the following factors<sup>59</sup>:

- (1) injection drug use;
- (2) for men, sex with other men;
- (3) failure to use condoms whenever engaged in sexual activity that poses a risk of transmission of HIV and that involves an individual whose HIV infection status is positive or unknown;
- (4) exchange of sex for money or drugs;
- (5) a sexually transmitted disease;
- (6) exposure to the blood or body fluids of an individual with HIV infection;
- (7) participation in sexual activity with multiple sex partners;
- (8) participation in sexual activity with an individual with one or more of the risk factors enumerated in this subsection;
- (9) any other behavior, condition or circumstance that is recognized by the Centers for Disease Control and Prevention as providing a route of transmission of HIV; or

<sup>55</sup> **Commentary:** This age range for adolescence is that of the American Medical Association (Guidelines for Adolescent Preventive Medicine, GAPS). While definitions of adolescence may depend on state law, the term as it is used here is meant to identify those children whom medical experts consider to be adolescents.

<sup>56</sup> **Commentary:** See guidelines on the AIDS case definition in **§109(n)**.

<sup>57</sup> **Commentary:** As used in these sample purchasing specifications, the term “experienced provider” is a term of art. It is assumed that any health care provider furnishing any covered physical or mental health benefit to an enrollee will have the requisite skill and experience to furnish competent care.

<sup>58</sup> **Commentary:** Currently there is no uniform definition of an experienced HIV provider or any national certification for this type of provider. Moreover, the definition of an experienced provider may vary from community to community depending upon a number of factors, such as the nature of the epidemic and the population affected and the types of providers within the community’s health care delivery system. However, experts suggest as minimum experience threshold an active ongoing caseload of at least 25 individuals with HIV/AIDS over the preceding 24 months, either in regular practice or as part of a supervised post-graduate training program. In the case of urban areas with a high incidence of HIV/AIDS and a delivery system that includes an academic health center, providers should be considered experienced only if they have maintained an ongoing caseload of at least 50 patients with HIV/AIDS over the preceding 24 months. The education requirement may be met if the medical or health professional has completed at least 12 hours of CME over the past 12 months. Persons interested in the definition of experienced providers may wish to consult the definitions developed by the states of Maryland, New York and Tennessee. See *Negotiating the New Health System: A Nationwide Study of Medicaid Managed Care Contracts*, op cit. Ch. 3. See also, J. Rawlings-Secunda and N. Kaye, op cit.

<sup>59</sup> **Commentary:** While not factors contributing to the actual transmission of HIV, homelessness, alcohol or drug abuse, tuberculosis, hepatitis C, and history of incarceration are factors associated with HIV.



(10) for women, sex with men with a known risk factor<sup>60</sup>.

- K (g) Medically necessary**—a service or benefit that is necessary to prevent, diagnose, treat or manage HIV/AIDS or, in an individual with HIV/AIDS, to maintain an optimal health and functional level.
- L (h) Minor enrollee**—an enrollee who has not attained [drafter insert the legal age of majority under state law].
- K (l) Specialist**—a licensed physician who, as measured by added education and training, has a demonstrated expertise in one or more areas of health and medical care practice and relevant experience in the care and management in HIV/AIDS.

### **§113. Information for Purchaser**

The information section of the contract sets out requirements for health plans to share information, as requested, by the state Medicaid agency, in order to determine that the health plan is meeting the terms of the contract and complying with the Medicaid statute and other relevant state and federal statutes.

As consumer advocates focus greater attention on improving accountability of health plans, pressure will increase on state Medicaid programs to strengthen their monitoring of their contractors. For this reason, it is important that this section is written to ensure that the Medicaid agency can access the records and materials they are likely to need in order to ensure compliance with the terms of the contract.

<sup>57</sup> **Commentary:** The population at risk for HIV/AIDS is shifting from men who have sex with other men to persons who are injection drug users or who have sexual relations with drug users. This is relevant in the design of HIV prevention programs and activities by managed care organizations.

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*The following section provides illustrative language regarding information that Purchasers may wish to consider specifying in their agreements.*

**§113. Information for Purchaser**

- K (a) Submissions required**—Upon request, Contractor shall make available to the Purchaser the current version of each of the following documents:
- (1) Contractor’s provider manual and any other directives, guidelines, or protocols relating to the provision or coverage of items or services under this Agreement;
  - (2) The subcontract or other written Agreement between Contractor and participating laboratories, pharmacies, providers and case managers;
  - (3) Contractor’s enrollee handbook or other written information given to enrollees regarding items and services covered under this Agreement; and
  - (4) Contractor’s operations manual and any other directive, guideline, or protocol setting forth the standards and procedures used by the Contractor relating to prior authorization determinations and to coverage and medical necessity determinations.

### **Section III:** An Explanation and Description of Model Contract Language

#### **Part 2. Service Delivery and Health Care Quality Measurement and Improvement**

Part 2 addresses the expectations of the state Medicaid agency with regard to the systems that the health plan must put in place to ensure that enrollees receive all of the medically necessary services to which they are entitled, as described in Part 1.

#### **§201. Enrollment and Disenrollment**

The purpose of this section is to describe how the health plan is expected to manage the care of people living with HIV while they are being enrolled or disenrolled from a health plan. In particular, the model language in this section addresses three issues: how the health plan should ensure continuity of care when enrolling persons living with HIV who are already receiving care; how the health plan should handle disenrollment of persons living with HIV who have third party coverage, meaning coverage from a source other than the health plan; and how the health plan should handle disenrollment for a person living with HIV who has no other source of health insurance coverage.

Issues related to enrollment and disenrollment are particularly important to people living with HIV because circumstances may arise very rapidly (such as an acute illness or a reaction to a prescription medication) that, in an otherwise healthy person, do not hold the same potential to produce a serious health care crisis.

**Section III:** An Explanation and Description of Model Contract Language

*The following section offers illustrative language for Purchasers to consider related to enrollment and disenrollment of individuals with HIV/AIDS.*

**§201. Enrollment and Disenrollment**<sup>61</sup>

**K (a) Safeguards against the interruption of care for individuals receiving services related to HIV/AIDS at the time of enrollment**

—In the case of an individual who at the time of enrollment is receiving services for the prevention or medical management of HIV/AIDS, Contractor shall continue to cover and pay for such services furnished by enrollee’s current providers without interruption, to the extent that such services are covered under this Agreement, until the primary care provider selected by the enrollee has:

- (1) assessed the enrollee;
- (2) reviewed the enrollee’s care, and
- (3) prescribed or arranged for uninterrupted treatment in accordance with the standards enumerated in **§110** (relating to coverage), and in consideration of the individual’s need for case management services defined in **§108**<sup>62</sup>.

**L,K (b) Safeguards against the interruption of care at the time of disenrollment for individual’s receiving HIV/AIDS services**

—In the case of an individual who ceases to be an enrollee, who has other third party coverage, and who, at the time of disenrollment, is receiving services enumerated under **Part 1** for HIV/AIDS, Contractor shall:

- K (1)** continue to provide the services to the individual until the earlier of:
  - (A) the last day of the enrollee’s enrollment period under the terms of this Purchasing Agreement ends; or
  - (B) the day on which another provider or managed care organization assumes responsibility for the care of the individual; and

**L,K (2)** transfers the individual’s medical records in a confidential manner to the responsible provider or managed care organization.

**L,K (c) Safeguards against the interruption of care for individuals without third party coverage who are receiving HIV/AIDS services at the time of disenrollment**

—In the case of an individual who ceases to be an enrollee, who has no other third party coverage, and who, at the time of disenrollment, is receiving medical management services for HIV/AIDS, Contractor shall

- K (1)** continue to provide the services to the individual until the end of enrollee’s enrollment period under the terms of this Purchasing Agreement;
- K (2)** assist the enrollee identify alternative sources of payment, including the state AIDS Drug Assistance Program (ADAP) under the Ryan White CARE Act and find alternative sources of care if enrollee requests such help; and

**L,K (3)** transfer enrollee’s records in a confidential manner to a new provider who has enrollee’s consent to obtain such records.

**K (d) Medical Management of enrollees whose treating providers leave the network**

—In the event that the enrollee’s primary care provider or other professional involved in the management and treatment of enrollee’s case terminates membership in Contractor’s network, Contractor shall assist enrollee to identify another provider (either within the network or on a contractual, non-network affiliation basis) who is willing and able to immediately assume care of the enrollee on an uninterrupted basis.

<sup>61</sup> **Commentary:** The guidelines in **§109** do not address the issue of enrollment and disenrollment. This section has been drafted to provide Purchasers with illustrative specifications regarding issues that arise in the development of enrollment and disenrollment specifications. Purchasers might wish to pay particular attention to the recommendation of HIV experts regarding the obligations of Contractors in situations involving new enrollees with HIV as well as the disenrollment of persons receiving HIV-related care. Of special interest is the sample specification regarding continuation of treatment until the treatment has been reviewed and any necessary adjustment been made by the individual’s new primary care provider.

<sup>62</sup> **Commentary:** The guidelines set forth in **§109** do not address the issue of adherence to medical management plans. Several states do include provisions in their contracts regarding the effect of existing case plans on subsequent Contractor conduct. See, e.g., State of New Jersey entry, Table 3.1, in *Negotiating the New Health System* (2d Ed.), op cit.

## **§202. Provider Selection**

The purpose of this section is to specify duties to be placed on the health plan related to giving an enrollee a choice of primary care providers. Consumer advocates are well aware that choice of providers is critical because it is essential that an individual feel comfortable and able to work in partnership with their primary care provider. For people living with HIV, however, it has also been shown that provider experience affects survival.

The model language recognizes the importance of an experienced HIV provider. It calls for an enrollee to be allowed to choose an experienced HIV provider as their primary care provider. If the health plan does not have an experienced HIV provider available, then it must allow its enrollees with HIV to choose either a primary care provider who has entered into a consulting relationship with an experienced HIV provider, or a specialist provider.

Even though consumer advocates recognize the value of having a choice among primary care providers, it is a reality that some enrollees will not choose a primary care provider, and the health plan will be forced to assign them to a primary care provider. This is called default enrollment (or default assignment). The model language for this section requires the health plan, in cases of default enrollment for persons who are known to the health plan to be living with HIV, to assign the enrollee to: the enrollee's existing provider (if they are in the health plan's network), a primary care provider who is an experienced HIV provider, or a primary care provider who has a consultation agreement in effect with an experienced HIV provider. For cases where the primary care provider must establish a consultation agreement with an experienced HIV provider, the model language also defines what is meant by a consultation and how a primary care provider can fulfill this requirement.

## **How Important is Provider Experience?**

A study was published in the *New England Journal of Medicine* showing that, after adjusting for severity of illness and year of diagnosis, people with AIDS treated by the most experienced providers (based on three levels of provider experience) had a 31% lower risk of death than persons treated by the least experienced providers.

*New England Journal of Medicine* 1996; 334: 701-6

Enrollees will want or need to change primary care providers for a variety of reasons. The model language requires the health plan to allow an enrollee to change health plans at least once within the first 90 days after enrolling, at least once annually (called an open season), or at the time when they are first diagnosed with HIV/AIDS.

The model language also calls for health plans to permit and pay for individuals to refer themselves for HIV testing and counseling for a set number of times per year (to be established by the state Medicaid agency). It also calls for health plans to inform enrollee's of this right through the member handbook and other marketing materials.

Finally, this section of the model language addresses access to prevention and care services by minors. This language would ensure that minors are permitted to consent to and receive prevention and care services as permitted under state and federal law.

**Section III:** An Explanation and Description of Model Contract Language

*The following section presents illustrative language related to the selection of providers by enrollees with HIV/AIDS.*

**§202. Provider Selection**<sup>63</sup>

- K (a) Selection of primary care provider**—Contractor shall permit enrollees with HIV or HIV-related conditions to select one of the following types of primary care providers:
- (1) an experienced HIV provider, as defined in **§112**, who is a member of Contractor’s provider network and who has entered into a written agreement with the Contractor to perform the functions required of a primary care provider;
  - (2) a primary care provider who has entered into a written consultation agreement with an experienced HIV provider, as described in subsection (c), which
    - (A) sets forth the terms of the consultation arrangement, and
    - (B) includes a standing order that provides the member with direct access to the consultation services offered by an experienced HIV provider as specified in **§110(c)(3)** as well as other consulting specialists; or
  - (3) a specialist, as defined in **§112**, who is a member of Contractor’s provider network and who, with respect to the member, has entered into a written agreement with the Contractor to perform the functions required of a primary care provider.
- K (b) Default assignment to a primary care provider**—In the case of an individual whose HIV/AIDS status is known to the Contractor at the time of enrollment and provider selection and who fails to select a primary care provider, Contractor, in assigning such individual to a primary care provider, shall make an assignment only to a provider described in subsection (a) of this section.
- K (c) Consultation arrangements with experienced providers**—In order to meet the requirements of this Agreement, Contractor shall:
- (1) identify experienced HIV providers (either within Contractor’s provider network or outside of the network) who agree to furnish consultation services to network providers;
  - (2) enter into written agreements with such experienced providers that specify their obligation to make consultation services available to both primary care providers and patients with HIV/AIDS who request such services;
  - (3) provide a level of compensation for such consultation services that is sufficient to ensure the availability of consultation services required as defined in this Agreement;
  - (4) furnish the names, addresses and telephone numbers of experienced HIV providers who have entered into such consultation agreements to enrollees who request it and to all primary care providers in Contractor’s provider network; and
  - (5) require as a condition of participation in Contractor’s provider network that a primary care provider who is not an experienced provider as defined in **§112**:
    - (A) enter into written consultation arrangement with an experienced provider identified by Contractor, and
    - (B) permit patients with HIV/AIDS for whom the primary care provider is responsible direct access to the consulting provider without prior authorization.

<sup>63</sup> **Commentary:** This section has been drafted to provide Purchasers with illustrative specifications regarding issues that arise in the development of provider selection standards. Particular attention should be paid to the recommendation of HIV experts that patients with HIV/AIDS have the option of selecting either an experienced provider or a provider that maintains a consultative relationship with an experienced provider. The specification explains what is meant by a consultative relationship and sets forth the duties of Contractors to assist in the development of such relationships. The complexity and rapid evolution of HIV treatment options and the risk of inadequate treatment resulting in treatment failure and emergence of drug-resistant strains of HIV have resulted in recommendations that “[w]hen possible, the treatment of HIV-infected patients should be directed by a physician with extensive experience in the care of these patients. When this is not possible, the physician treating the patient should have access to such expertise through consultations.” (Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents, at **§109 (i)**). Investigators have reported the death rates of AIDS patients with the most experienced physicians to be nearly one-third lower than death rates of patients whose physicians had the least experience in treating the condition. MM Kitiyata et al. Physician’s experience with the acquired immunodeficiency syndrome as a factor in patients’ survival. *NEJM* 1996; 97:323-330. Strathdee S et al. “HIV+ IDUs eligible for antiretrovirals: what are the barriers to receiving therapy despite universal access?.” Fifth conference on Retroviruses and Opportunistic Infections 1998, Abstract 132. Laine C et al. “The relationship of clinic experience with advanced HIV and survival of women.” *AIDS* . 1998;12(4):417-424. Markson, LE et al., “Repeated emergency department use by HIV-infected persons: effect of clinic accessibility and expertise in HIV Care.” *Journal of Acquired Immune Deficiency Syndromes & Human Retrovirology*. 1998; 17(1):35-41.

### Section III: An Explanation and Description of Model Contract Language

- K (d) Consultation defined**—For purposes of this Agreement, the term consultation shall mean the following:
- (1) oral communication with either a primary care provider or an enrollee under the care of such provider, on either a face-to-face basis or by telecommunication, and within a reasonable time period after a request for oral consultation services is made;
  - (2) review of medical records;
  - (3) at least one face-to-face medical consultation (including physical examinations and diagnostic procedures that the experienced HIV provider considers to be medically necessary) annually with members who are under the care of primary care providers to whom the provider furnishes consulting services;
  - (4) provision of timely and ongoing written and oral advice regarding the management of HIV/AIDS; and
  - (5) when requested by Contractor, a primary care provider, or an enrollee, a written opinion regarding the medical necessity of items and services furnished under this Agreement that sets forth the factual basis on which such opinion is based.

- K (e) Changing primary care providers**—Contractor shall permit an enrollee who is diagnosed with HIV/AIDS following his or her enrollment into Contractor’s plan to switch to a primary care provider described in subsection (a):
- (1) at the time that the diagnosis is initially made;
  - (2) at least once during the 90-day period following such selection and at least annually thereafter; and
  - (3) at any time for cause.

- L,K (f) Self-referral for testing and counseling**—Contractor shall:

- L,K (1)** at least \_\_\_ times per year<sup>64</sup>, allow an enrollee to obtain HIV testing and counseling as defined in **§103(b)(1)** and **(2)(A)** on a covered basis from the agency or entity within Contractor’s service area that receives funding under the Ryan White CARE Act, a CDC HIV prevention grant, or other public funding dedicated to HIV testing and counseling, sexually transmitted disease or family planning services or prenatal care, regardless of the entity’s or agency’s network status;
- K (2)** reimburse such provider or agency for testing and counseling services that are furnished regardless of provider’s network status at rates that are at least as favorable as the Contractor would make payment to a participating provider in Contractor’s network; and
- K (3)** include in its member handbook and marketing materials a clear statement of each enrollee’s right to self-refer on a covered basis \_\_\_ times per year to such agency for HIV testing and counseling services.

- L (g) Access to HIV prevention and medical management services by minor enrollees: consent to services**—In the case of an enrollee with HIV/AIDS who is a minor as defined in **§112**, Contractor shall permit the enrollee to consent to receive HIV prevention or medical management services to the extent permitted under state and federal law<sup>65</sup>.

<sup>64</sup> **Commentary:** Self-referral is recommended by HIV experts to minimize barriers to early identification of HIV infection. No specific number of out-of-network encounters with local health agencies that are not members of Contractor networks is specified in the guidelines in **§109**. Experts in HIV prevention recommend permitting at least one self-referral annually.

**Commentary for Medicaid purchasers:** Certain state Medicaid agencies have elected to define family planning services, in their managed care contracts, to include HIV counseling and testing and to permit Medicaid managed care enrollees to refer themselves for these services. See Rosenbaum S et al., *Negotiating the New Health system: A Nationwide Study of Medicaid Managed Care Contracts* (2d ed.) (The George Washington University, Washington D.C., 1998). These provisions are consistent with the statutory requirement that managed care organizations permit Medicaid enrollees to self-refer for family planning services. (42 U.S.C. 1396a(a)(23)(B), 42 U.S.C. 1396d(a)(4)(C)). More generally, the Balanced Budget Act of 1997 requires each Medicaid managed care organization to provide assurances that the organization “offers an appropriate range of services and access to preventive and primary care services for the population expected to be enrolled...” (42 U.S.C. (13969-2(b)(5)(A)).

<sup>65</sup> **Commentary:** All states by law permit minors to consent to diagnosis and treatment of an STD although not all states classify HIV infection as an STD. At least 13 states by law specifically permit adolescents to consent to HIV testing; and seven states also by statute expressly permit minors to consent to treatment. K. Hein, Annotation: adolescent HIV testing—who says who signs? *AJPH* 1997; 87:1277-1278. Other types of services to which minors may consent, which could reasonably include HIV services, are prenatal care and delivery (27 states and the District of Columbia) and contraceptive services (23 states and the District of Columbia). Allan Guttmacher Institute, Teenagers’ Right to Consent to Reproductive Health Care (<http://www.agi-usa.org/pubs/ib21.html>)

## Section III: An Explanation and Description of Model Contract Language

### §203. Provider Network

The purpose of this section is to specify duties that the state Medicaid agency is placing on health plans with regard to their provider networks. These provisions are important because access to care for people living with HIV has the potential to be restricted unless the Medicaid agency ensures that experienced HIV providers and other providers who provide care to people living with HIV are not unfairly discriminated against or excluded from participating in a particular health plan on the basis of their providing care to people living with HIV. This section is also important for creating expectations for health plans with regard to the training of all network providers about HIV/AIDS.

Key elements of this section include provisions to require health plans to:

- establish provider networks that include experienced HIV providers and other providers in adequate numbers and with a broad range of skills and expertise.
- establish provider networks that include specialist providers, pharmacies, laboratories, hospitals with experience in caring for people living with HIV, medical nutritionists qualified to counsel persons living with HIV, and trained HIV counselors.
- form formalized relationships with Ryan White CARE Act providers to deliver or coordinate services.

- create a manual for each participating provider that describes what services are covered under this contract, how issues will be handled related to confidentiality, reporting, access, enrollment, and that instructs providers on how to establish consultation agreements with experienced HIV providers that are required for primary care providers who are not experienced HIV providers.

This section also prohibits health plans from disenrolling or excluding providers from the provider network solely on the grounds that they provide services to people living with HIV. It also prohibits health plans from withholding compensation or otherwise basing compensation decisions to participating providers solely on the basis of a provider's use of resources in providing prevention or care services to people living with HIV.

Finally, this section of the contract also describes expectations for health plans with regard to the training of all providers in their provider network with regard to HIV/AIDS.



### Section III: An Explanation and Description of Model Contract Language

*The following subsection offers illustrative language for Purchasers' consideration regarding the composition, capabilities and selection of provider networks competent to treat HIV/AIDS.*

#### **§203. Provider Network**<sup>66</sup>

**K** (a) **In general**—Contractor shall establish a provider network:

- (1) that includes the types of providers described in subsection (b);
- (2) that is of sufficient size, range and skill to be able to furnish the care and services that are enumerated in this Agreement in a manner that is consistent with accepted standards of health care practice for persons with HIV/AIDS; and
- (3) whose members are accessible to persons with HIV/AIDS in accordance with the Americans with Disabilities Act and §504 of the Rehabilitation Act of 1973 which, in the case of primary care providers, shall be measured by the maintenance of a consulting agreement with an experienced HIV provider.

**L,K** (b) **Network membership**—Contractor's provider network shall contain the following providers:

- K** (1) primary care providers who maintain consultative relationships with experienced HIV providers;
- K** (2) experienced HIV providers as defined in **§112** on either a full membership or consultative status in accordance with the requirements of **§202**;

**K** (3) specialty medical and health care providers representing the full range of physical and mental health, substance abuse, dental, and clinical subspecialties that are required in order to furnish the care and services enumerated in Part 1 of this Agreement in a manner that is appropriate to the prevention, treatment and management of HIV/AIDS;

**K** (4) pharmacies (both retail and mail order)<sup>67</sup>;

**L** (5) laboratories that are certified under the Clinical Laboratory Improvement Act (CLIA), §353 of the Public Health Service Act, (42 U.S.C. §263a) to perform the tests described in **§105** of this Agreement;

**K** (6) one or more hospitals (either as part of the network or under special arrangements) that have demonstrated experience in furnishing care to individuals with HIV/AIDS as demonstrated by:

- (A) the establishment and operation of a comprehensive program of care for individuals with HIV/AIDS;
- (B) the provision of regular training to hospital medical and non-medical staff relating to the treatment of individuals with HIV/AIDS; or
- (C) the granting of admitting privileges to experienced HIV providers.

<sup>64</sup> **Commentary:** Certain enrollees with HIV infection for whom drug treatment is prescribed may need or elect to receive covered drugs, vitamin supplements and biologicals by mail because they live in rural or underserved areas without pharmacies within a reasonable distance, because they are homebound, because of confidentiality concerns about receiving HIV drugs at a pharmacy in their neighborhood or for other reasons. Note that both retail and mail order services are included; it is not intended that enrollees be limited to mail-order pharmacy services.

**Section III:** An Explanation and Description of Model Contract Language

- L,K** (7) centers of excellence in the care and management of persons with HIV/AIDS that are recognized under state law<sup>68</sup>;
- K** (8) medical nutritionists on a direct care or consultative basis with demonstrated experience in counseling patients with HIV/AIDS; and
- K** (9) trained HIV counselors, educators and case managers on either a direct or consultative basis<sup>69</sup>.
- K** (c) **Ryan White CARE Act providers**—Contractor shall use its best efforts to enter into network agreements with any provider in Contractor’s service area that receives funding under the Ryan White CARE Act and that furnishes or arranges for one or more of the types of care and services enumerated in Part 1 of this Agreement<sup>70</sup>.
- K** (d) **Provider manuals**—Contractor shall furnish each network provider, as well as non-network providers, with the following material:
- (1) a standard agreement form for use in entering into written consultation agreements with experienced HIV providers, as required in **§202(c)**, that addresses the elements specified in such section; and
  - (2) a provider manual that is updated as needed, describes the coverage, service, confidentiality, reporting, access, enrollment, and network requirements of this Agreement, instructs providers on the required elements of the experienced provider consultation program described in **§202(c)** and the procedures for developing such a consultation arrangement, and identifies experienced hospitals in the network as described in **§203(b)**.
- K** (e) **Prohibited use of resource consumption measures in selecting or retaining providers**<sup>71</sup>—Contractor shall not exclude or disenroll a provider from Contractor’s provider network solely on the grounds that the provider:
- (1) Conducts or orders to be conducted HIV tests consistent with **§103** of this contract;
  - (2) prescribes drugs and biologicals consistent with **§106** of this contract; or
  - (3) provides medical care to persons with HIV/AIDS.
- K** (f) **Compensation of providers participating in Contractor’s provider network**—Contractor shall not reduce compensation to, withhold compensation from, or otherwise impose financial penalties upon a provider participating in Contractor’s provider network solely on the basis of a provider’s use of resources in connection with the prevention, or medical management of HIV/AIDS.

<sup>68</sup> **Commentary:** Purchasers and Contractors, particularly with regard to rural areas with few or no experienced HIV providers may also wish to consider the Tennessee HIV “Centers of Excellence” voluntary model, which was developed through a consensus process involving medical providers specializing in HIV/AIDS care, consumers, advocates, managed care organizations and the state Health Department. MCOs are encouraged but not required to enter into fee-for-service contracts under which the Centers would serve as primary care physicians for individuals with HIV infection. Criteria for designation as a Center include an actively managed patient base of at least 50 individuals with HIV, a commitment to furnish provider AIDS education and medical and non-medical service capacity. The development and other elements of this model are described in J Rawlings-Sekunda and N. Kaye, op cit. New York State will require its MCOs to contract with designated AIDS centers, a hospital designation that has been in existence in the state since 1985.

<sup>69</sup> **Commentary:** In areas where CDC prevention grantees or Ryan White CARE Act providers offer these services, Contractor may consult with such providers to identify such specialists.

<sup>70</sup> **Commentary:** Medicaid agencies are directed to the November 25, 1998 letter from Sally Richardson that encourages use of Ryan White CARE Act providers in managed care network. See note 20 *supra*, for website address. Contractors should contact their state health agencies to obtain the names and locations of Ryan White CARE Act grantees in their service areas.

<sup>71</sup> **Commentary:** Subsections (e) and (f) are intended to minimize disincentives for providers to furnish appropriate HIV services or for providers to accept individuals with HIV/AIDS into their practices.

### Section III: An Explanation and Description of Model Contract Language

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**K (g) Training of providers**<sup>72</sup>—Contractor shall certify that each primary care provider participating in Contractor’s provider network receives information or training on at least an annual basis on the following topics:

- (1) the incidence and prevalence of HIV/AIDS in the Contractor’s service area and the population groups at risk of HIV residing in the area;
- (2) risk factors for HIV and information about preventing transmission of HIV;
- (3) universal precautions;
- (4) diagnosis of primary HIV infection;
- (5) in the case of primary care providers, risk assessment, testing and counseling duties as described in **§103**;
- (6) provisions related to confidentiality under **§208**; and
- (7) applicable HIV referral and reporting requirements under the laws of the state of *[drafter insert name of state]*.

<sup>72</sup> **Commentary:** The Contractor may wish to consult with CDC-funded HIV prevention programs (in local or state public health agencies) and Ryan White CARE Act grantees to identify appropriate clinical training opportunities (materials, personnel, programs) as well as the availability of epidemiological data and other types of information on which provider training is recommended.

### Section III: An Explanation and Description of Model Contract Language

#### **§204. Delivery of Care and Access to Covered Services**

The purpose of this section is to ensure that network providers (and other providers affiliated with the health plan) comply with various provisions related to the delivery of care and access to services.

This section is important because it addresses access problems that have sometimes caused barriers to good care for people living with HIV. Key elements of the model contract language include:

- access to an HIV risk assessment and HIV testing (and pre- and post-test counseling).
- access to case management services, including home access or access to case management services at an alternative site when warranted by the enrollee's health condition.
- service timelines that provide a framework for setting waiting time standards when accessing various services. The model contract language does not set specific standards, and reasonable standards will vary greatly from state to state. This will depend on the number of providers in a geographic service area, the size of the geographic service area, and the population density of the state (i.e. is the state predominately urban or rural). Commentaries provide some guidance on baseline standards. Consumer advocates are encouraged to consult with other consumer advocates and examine timeline standards set for roughly comparable states in order to establish timeline standards for your own state.

- language access provisions are not included at this time. Language access, however, is an important issue and will directly impact the quality of care received by people living with HIV. As with some other sections marked “reserved”, the Center for Health Services Research and Policy is developing sample purchasing specifications that relate to access standards generally and cultural competence, in particular. Consumer advocates are encouraged to visit the Center's website at [www.gwumc.edu/chpr](http://www.gwumc.edu/chpr).

#### **Federal and State Governments Mandate Language Access**

Federal and state laws have addressed the issue of access to health care services for persons who have limited English proficiency (LEP). The following Federal laws provide the most relevant requirements on access to health care services for Medicaid beneficiaries:

**Title VI of the Civil Rights Act of 1964** creates rights for persons to be free of discrimination or being excluded from receiving benefits on the basis of race, color, or national origin under any program or activity that receives Federal financial assistance. The Office for Civil Rights within the Department of Health and Human Services has interpreted this to require the provision of qualified interpreter services and translated materials at no cost to patients.

**The Hill Burton Act** was enacted to encourage the construction and modernization of nonprofit community hospitals and health centers. As an obligation of receiving Federal funds, the Act requires recipients to comply with a community service obligation that has been construed to require recipients to address the needs of LEP patients.

### **Section III:** An Explanation and Description of Model Contract Language

**Medicaid** regulations require state programs to comply with Title VI of the Civil Rights Act of 1964. HCFA requires states to “communicate with beneficiaries both orally and in writing in a language understood by the beneficiary and to provide interpreters at Medicaid hearings.”

Certain states have also taken the lead in ensuring that health care services are accessible by their residents in a language that they can understand. While not an exhaustive list, California, Illinois, and New York have all been leaders in this area.

In particular, California’s law (Dymally-Alatorre Bilingual Services Act, California Government Code § 7290 et seq.) is viewed as a model for other states. Among other requirements, the law requires hospitals to:

- develop policies on the provision of interpreter services and review them annually;
- ensure the availability of interpreter services, “to the extent possible,” 24-hours a day to patients who are part of a language group that comprises at least five percent of the population of the geographic area served by the hospital;
- post multi-lingual notices of the availability of interpreters and how to obtain an interpreter, and directions on how to complain to state authorities about interpreter services; and
- notify employees of the requirement to provide interpreters to all patients who request them.

The law also defines interpreters as individuals who are fluent in English and a second language, and who can speak accurately, read and readily interpret a second language, and who have the ability to translate the names of body parts and describe symptoms and injuries competently in both languages.

Excepted from *Ensuring Linguistic Access in Health Care Settings: Legal Rights and Responsibilities*, Jane Perkins, Harry Simon, Francis Cheng, Kristi Olson, and Yolanda Vera (1998). An Executive Summary or a copy of the report may be obtained through the Kaiser Publication Line by calling 800-656-4533.

**Section III:** An Explanation and Description of Model Contract Language

*The following section offers illustrative language for Purchasers' consideration related to delivery and access of HIV/AIDS services.*

**§204. Delivery of Care and Access to Covered Services**<sup>73</sup>

**K** (a). **In general**—Contractor shall ensure that in furnishing services covered under this Agreement, network and affiliated providers comply with the performance standards in this section.

**L,G,K** (b). **Prevention, testing and counseling services**—In delivering services enumerated in **§103**, Contractor shall ensure that consistent with **§103** (relating to prevention services), network providers:<sup>74</sup>

(1) conduct an HIV risk assessment:

**L,G** (A) as part of the initial visit and regularly thereafter as part of any covered routine health exam (including, for Medicaid enrollees under age 21, periodic and interperiodic screens furnished pursuant to the Early and Periodic Screening, Diagnosis and Treatment Program (EPSDT)), and

**G,K** (B) during an encounter related to pregnancy, reproductive health, mental illness or addiction disorder, sexually transmitted disease, tuberculosis, bacterial pneumonia in persons under 50, cervical intra epithelial neoplasia, or any other conditions suggestive of HIV infection.<sup>75</sup>

**G,K** (2) conduct HIV antibody tests and pre- and post-test counseling in the case of an enrollee who:

**G** (A) has one or more HIV risk factors as defined in **§112**; or

**G** (B) is a woman who is pregnant or considering becoming pregnant;

**G** (C) has experienced occupational exposure to HIV, or

**G** (D) requests a test;

**K** (3) dispense a reasonable number of condoms at the time of testing and counseling an enrollee at risk for HIV; and

**G** (4) make a reasonable effort to contact an enrollee who tests positive for HIV infection but who does not return for the test results.

**K** (c) **Case management services**<sup>76</sup>—Contractor shall ensure that:

(1) the case management plan described in **§108**:

(A) is developed by a case manager participating in Contractor's provider network in consultation with the enrollee and, with the written consent of the enrollee, the enrollee's primary care physician, other treating providers, a member of the enrollee's family, or other caregiver, and

(B) includes a description of all services for which the periodic assessment under subsection (a)(1) indicates a need (whether or not such services are covered under this Agreement);

(2) covered case management services are delivered at alternative sites such as an enrollee's home, shelter or other locations indicated by the enrollee's health.

**K,L** (d) **Service timelines**—In furnishing services covered under this Agreement Contractor shall ensure that:

**K** (1) testing and counseling occurs within \_\_\_ calendar days of the time of request;<sup>77</sup>

<sup>73</sup> **Commentary:** The guidelines in **§109** do not address the issue of access. These specifications have been developed because of the importance under the Balanced Budget Act of 1997 (P.L. 105-33) of including access measures in purchasing specifications as part of the state's quality assurance system. These access standards address both prevention and treatment requirements in order to ensure maximum plan involvement in prevention activities.

<sup>74</sup> For applicable Medicaid law, see **Commentary 3**.

<sup>75</sup> **Commentary:** Experts note that conditions such as unexplained weight loss, thrush, chronic fatigue and chronic diarrhea may be suggestive of HIV infection.

<sup>76</sup> **Commentary:** See **Commentary** on case management at **§108**.

<sup>77</sup> **Commentary:** The guidelines in **§109** do not address timelines for requested testing and counseling from request. Experts in the field suggest that the test should occur within 5 calendar days of request.

### Section III: An Explanation and Description of Model Contract Language

- K** (2) positive results of HIV tests are communicated to enrollees on a face-to-face basis within \_\_ calendar days of receipt of test results<sup>78</sup>;
- K** (3) drugs in the prescribed dosage and form are dispensed and received within \_\_\_ hours of the time that enrollee presents the prescription<sup>79</sup>;
- L** (4) a 72-hour supply of any drug is immediately made available to an enrollee during the time period that a full prescription is pending<sup>80</sup>;
- K** (5) a case management plan is:
  - (A) developed within \_\_ calendar days<sup>81</sup> after an individual whose HIV/AIDS status is known at the time of enrollment enrolls under this Agreement or within \_\_ calendar days<sup>82</sup> after an enrollee is diagnosed with HIV infection or an HIV-related condition; and
  - (B) modified within \_\_ calendar days<sup>83</sup> after a significant change in the medical condition or housing status of an enrollee with a written case management plan; and
- K** (6) in the case of an HIV infected enrollee who is pregnant and who has an addiction disorder, treatment is arranged within \_\_ hours of request<sup>84</sup>;
- K** (7) appointments for newborns are made with the infant's primary care provider within \_\_ calendar days of hospital or birthing center discharge<sup>85</sup>;
- K** (8) appointments for urgent medical conditions are provided within \_\_ hours of request<sup>86</sup>; and
- L** (9) no prior authorization is required for the care of enrollees when the contractor or a member of contractor's network has a reasonable basis for suspecting an emergency medical condition.
- (e) **Language access** (Reserved).

<sup>78</sup> **Commentary:** The guidelines in §109 do not specify timelines for reporting test results. Experts in the field recommend that individuals receive positive test results within 14 days of the date on which blood is drawn. Negative results also can be communicated by telephone.

<sup>79</sup> **Commentary:** The guidelines enumerated in §109 do not prescribe time lines for dispensing prescribed drugs. Experts in the area of HIV suggest a time line of 72 hours. Note that in the case of contracts that permit the use of mail order pharmacies, a Purchaser should indicate maximum time limits for the transmission of mail order prescriptions to a member. Purchasers should consider specifying the use of overnight mail arrangements where necessary to meet the 72- hour timeline.

<sup>80</sup> **Commentary for Medicaid Purchasers:** Under specialized Medicaid prior authorization rules for prescription drugs, a 72-hour emergency supply of a drug must be dispensed while waiting for a prior authorization (which must be made and transmitted within 24 hours of the request for authorization). (42 U.S.C. §1396r-8(d)(5)).

<sup>81</sup> **Commentary:** The guidelines listed in §109 do not specify time periods for developing a case management plan following enrollment. Experts in HIV medical management recommend a time period of between 30 and 60 days.

<sup>82</sup> **Commentary:** The guidelines listed in §109 do not specify time periods for developing a case management plan for persons diagnosed with HIV/AIDS. Experts in HIV medical management recommend a time period of between 60 and 90 days.

<sup>83</sup> **Commentary:** The guidelines listed in §109 do not specify timelines for such modifications. Experts in HIV medical management recommend a timeline of between 14 and 30 days.

<sup>84</sup> **Commentary:** The guidelines in §109 do not set forth treatment timelines for treatment of pregnant women with addiction disorders. Experts in the field recommend that treatment should be initiated within 24 hours.

<sup>85</sup> **Commentary:** While the guidelines listed in §109 do not specifically address services following discharge of an HIV-exposed neonate, they provide guidance on timing of services following birth in order to maximize the opportunity to prevent the onset of HIV infection or opportunistic infection (particularly *Pneumocystis carinii* pneumonia, PCP) and achieve appropriate treatment outcomes in infants infected at birth. These timelines include provision of an initial HIV test within forty-eight hours of birth, antiretroviral therapy/prophylaxis for the first six weeks of life and initiation of PCP prophylaxis six weeks after birth. In light of these and other considerations, experts in the field recommend that a first post-discharge visit occur at least within seven to fourteen days.

<sup>86</sup> **Commentary:** The guidelines in §109 do not specify a definition of "urgent" or a timeline for urgent medical conditions. Experts recommend that conditions that require attention within 24 hours be considered urgent and recommend the use of a 24-hour window for urgent care appointments.

### Section III: An Explanation and Description of Model Contract Language

#### §205. Public Health Reporting

The purpose of this section is to ensure that the health plan and its contractors comply with relevant state and federal public health laws.

Currently, an AIDS diagnosis is a reportable condition in the United States. Health care providers are required to report such cases to the state public health authority. The U.S. Centers for Disease Control and Prevention (CDC) collects data from state public health authorities to conduct nationwide monitoring of the AIDS epidemic. In some places, cases of HIV are also required to be reported. This has been a controversial issue within the HIV community. The model contract language does not substantively address the policy issues related to HIV surveillance, including name based reporting. Rather, these provisions simply ensure that the health plan require its contractors to comply with existing laws.

*The following section provides illustrative language related to the reporting of data required for public health surveillance purposes.*

#### §205. Public Health Reporting<sup>87</sup>

- L (a) Case and test result reporting by providers including clinical laboratories**—Contractor shall ensure that Contractor shall ensure that, regardless of their location in or outside of [drafter insert name of state], each provider (including clinical laboratories) that has entered into a service agreement with the Contractor reports cases of HIV and AIDS to the [drafter insert name of state] public health agency, in accordance with the laws and regulations of such state, and in a form, timeline, and manner prescribed by the [drafter insert name of state health agency], in any case in which the test sample is drawn in [drafter insert name of state] or the care is furnished in [drafter insert name of state]<sup>88</sup>.
- L (b) Access to data for case surveillance**—Contractor and each clinical laboratory, and other provider participating in Contractor’s provider network shall:
- L (1)** make available to *[drafter insert name of public health agency with HIV/AIDS monitoring responsibilities in the area served by the Contractor]* upon request and in a manner consistent with the confidentiality provisions of this Agreement individual medical and other information with respect to an enrollee with HIV/AIDS necessary to enable the Agency to:
    - L (A)** carry out its HIV/AIDS case surveillance responsibilities under *[drafter insert applicable state law or regulation]*; and
    - L (B)** conduct HIV-related investigations of public health importance under *[drafter insert applicable state law or regulation]*.

<sup>87</sup> **Commentary:** These public health reporting requirements have been developed by experts to provide Purchasers with illustrative specifications relating to the provision of information to public health authorities regarding HIV. Purchasers may wish to pay particular attention to reporting of the results of laboratory tests, particularly in cases in which Contractors use out-of-state laboratories over which a state may have limited practical control. Frequently laboratories are critical sources of data for public health surveillance activities. Note that public health reporting is distinguished from any Medicaid claims reporting that may be required in a comprehensive or specialty Medicaid services contract.

<sup>88</sup> **Commentary:** For a fuller explication of public health data and reporting, as well as other data and reporting specifications, see forthcoming data and information specifications, which may be obtained in draft form from CHPR.



**L (c) Perinatal exposure**—Contractor shall ensure that providers caring for pregnant women with HIV report cases of infants exposed perinatally to HIV to the local public health agency consistent with *[drafter insert applicable state law or regulation]*.

**§206. Memoranda of Understanding (Reserved)**

The purpose of this section is to define parameters for Memoranda of Understanding (MOU) between health plans and other entities. An MOU is a legal document signed by two parties that describes how two parties will work collaboratively, and covers issues such as what and how information will be shared and how parties will be compensated, if at all, for various services. As with some other sections marked reserved, the Center for Health Services Research and Policy is developing sample purchasing specifications that relate to Memoranda of Understanding. Consumer advocates are encouraged to visit the Center's website at [www.gwu.edu/~chsrp](http://www.gwu.edu/~chsrp).

### Section III: An Explanation and Description of Model Contract Language

#### §207. Quality Improvement and Measurement

The purpose of this section is to place requirements on health plans with regard to quality improvement and quality assurance activities. The model contract language requires the health plan to conduct one or more clinical performance studies to assess issues of timeliness in providing services, accessibility to enrollees, and effectiveness of services provided, but it leaves it up to the health plan to determine which area upon which to focus. The health plan is also required to submit its clinical study plan to the state Medicaid agency for approval.

Consumer advocates are encouraged to use this language as a starting point for ensuring that health plans assess the quality of their HIV/AIDS services. Consumer advocates are also encouraged to work with non-HIV/AIDS advocates to focus on quality improvement and quality assurance strategies for all enrollees.

The model language also requires the health plan to make available the results of their clinical performance studies to the state Medicaid agency, the state public health agency, or enrollees, on request.

*The following section offers illustrative language for Purchasers' consideration related to quality measures in the area of HIV/AIDS.*

#### §207. Quality Improvement and Measurement

- K (a) Clinical performance studies**<sup>89</sup>—Contractor shall conduct, or arrange for the conduct of, one or more clinical studies to measure the timeliness, accessibility to enrollees, or effectiveness of [drafter insert agreed-upon topics from the following options]:
- (1) HIV testing of all pregnant enrollees no later than the second prenatal encounter;
  - (2) HIV testing, with counseling of enrollees diagnosed with a sexually transmitted disease;
  - (3) antiretroviral therapy for enrollees diagnosed with HIV as recommended in the guidelines enumerated **§109**;
  - (4) prophylactic treatment of enrollees diagnosed with HIV for *Pneumocystis carinii* pneumonia or other opportunistic infections;
  - (5) viral load testing and CD4 monitoring of enrollees diagnosed with HIV;
  - (6) assessment of adolescent enrollees for HIV risk factors;
  - (7) assessment of adult enrollees for HIV risk factors;
  - (8) compliance by providers participating in Contractor's provider network with the requirements relating to the timeliness of provision of the HIV prevention and medical management services specified in [drafter insert reference comparable to the illustrative language in **§103** and **§104** of Part 1] of the Agreement; and

<sup>89</sup> **Commentary:** Performance measures for HIV prevention and care are under development or consideration. The Institute of Medicine (IOM) has recommended the development and adoption of performance measures for prenatal HIV testing. *Reducing the Odds*, op cit. Field-tested performance measures will be appended to future revisions of these specifications as they become available.

**Commentary for Medicaid purchasers:** State Medicaid agencies must maintain programs to review services covered for beneficiaries for "appropriateness" and "quality of care." (42 U.S.C. §1396a(a)(33)); in addition, the 1997 Balanced Budget Act requires states to establish "quality assessment and improvement strateg[ies]" for their Medicaid managed care programs, addressing beneficiary access to covered services "within reasonable time frames" as well as "other aspects of care and service directly related to the improvement of quality of care." (42 U.S.C. §1396(c)).

(9) measures of satisfaction among members who have HIV/AIDS.

**K (b) Performance reporting**<sup>90</sup>—Contractor shall make the results of performance studies related to HIV/AIDS available to the Purchaser and, upon request, to the state public health agency and enrollees without charge.

**K (c) Study plan**—Prior to commencing its study, Contractor shall submit its study plan to Purchaser for review and approval.

### **§208. Confidentiality of Enrollee HIV Status**

The purpose of this section is to require health plans to comply with state and federal law in the handling of information that identifies the HIV status of enrollees.

#### **Medical Privacy is Critical to People Living with HIV**

Ensuring that a person's HIV status--and other contents of their medical record--are maintained confidentially is critical to creating an environment where people will feel safe in coming forward for health care treatment. Protecting privacy, while also making sure that biomedical researchers and other researchers have access to the information they need to search for a cure for HIV is a complex task. Indeed, the Congress has struggled with this issue for many years--and so far, no comprehensive medical privacy law has been enacted.

As authorized by the Health Insurance Portability and Accountability Act of 1996 (HIPPA), the Department of Health and Human Services issued a proposed rule to institute new federal privacy protections for electronically transmitted personally identifiable health information. The Department is expected to issue a final rule in 2000—and it will take effect two years after it is issued. While consumer advocates believe this regulation is a positive step forward, it does not cover all personally identifiable health information. Therefore, there remains a need for congressional action.

At the state level, several states have passed laws that create even tighter restrictions around the release of a person's HIV status than other medical information. As states move to develop HIV surveillance systems which are necessary to track the HIV epidemic, whether through a system of unique identifiers or a name-based reporting system, new attention is being focused on protecting the privacy of personal HIV-related information.

<sup>90</sup> **Commentary:** Note that reporting on performance measures is distinguished from public health reporting which is considered necessary for case surveillance and epidemiological data collection.

### **Section III:** An Explanation and Description of Model Contract Language

It is beyond the scope of this publication to provide a detailed discussion of all of the issues surrounding medical records privacy. The following principles should be kept in mind whenever grappling with issues around the privacy of an individual's personally-identifiable information:

- Individuals should have a legally-defined right to privacy with respect to individually identifiable health information, including genetic information.
- The use or disclosure of individually identifiable health information absent an individual's informed consent should be prohibited, except in limited circumstances.
- Individual should have the right to access his or her own health information and the right to amend such information.
- Strong and effective remedies for violations of privacy protections need to be established.
- Efforts to protect individual privacy should not unnecessarily impede important biomedical and epidemiological research.

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*The following section offers illustrative language for Purchasers' consideration related to patient and enrollee confidentiality.*

#### **§208. Confidentiality of Enrollee HIV Status**

- L(a) Compliance with legal requirements**—Contractor shall comply with applicable state and federal law regarding the confidentiality of enrollee HIV status in carrying out the terms of this Agreement.

### **Section III:** An Explanation and Description of Model Contract Language

#### **§209. Information for Enrollees**

The purpose of this section is to give enrollees the right to access information that they may need.

In particular, the model language specifies that the enrollee be informed in the member handbook that their personal health care information related to their HIV status or HIV-related services will be treated in a confidential manner. It also requires the health plans to inform enrollee's in the member handbook of the confidentiality rights of minors, as provided by state and federal law.

This section also contains important rights for enrollees or prospective enrollees to access information in a confidential manner with regard to a health plan's procedures for protecting the confidentiality of an enrollee's personally identifiable health care information, as well as a list of covered services, and a list of experienced HIV providers, specialists, and primary care providers who treat people living with HIV in consultation with an experienced HIV provider.

**Section III:** An Explanation and Description of Model Contract Language

*The following section offers illustrative language for purchasers' consideration related to information that should be furnished to enrollees.*

**§209. Information for Enrollees**

**L,K (a) Member handbook**—Contractor shall include in its member handbook the following information:<sup>91</sup>

- (1) a statement that patient medical information relating to the provision of HIV services is confidential and that it may be disclosed only in a manner consistent with state and federal law;
- (2) a statement of rights of minors, in accordance with state and federal law, to confidentiality of all encounters or communications relating to services covered under this Agreement for HIV/AIDS;
- (3) a complete and accurate description of all care and services related to HIV/AIDS that are covered under this Agreement as well as the conditions under which the Contractor may pre-authorize care and services;
- (4) complete and accurate information regarding the ability of enrollees with HIV/AIDS to select PCPs who are experienced providers, as defined in **§112** of this Agreement, or who are affiliated with such providers; and
- (5) complete and accurate information regarding the ability of enrollees to self-refer for services identified as described in **§202** of this Agreement.

**K (b) Confidential information**—Contractor shall ensure that an enrollee or prospective enrollee may obtain the following information on a confidential basis through member services and through enrollment forms or other written materials:

- (1) a description of procedures available to enrollees and their treating providers to protect the confidentiality of enrollee medical information;
- (2) a list of services that are covered under this Agreement; and
- (3) a list of participating experienced HIV providers and specialists and primary care providers who have consultative relationships with experienced HIV providers as described in **§202(a)(2)**.

<sup>91</sup> **Commentary for Medicaid purchasers:** The 1997 Balanced Budget Act includes a general requirement that managed care organizations provide specified information to enrollees including covered services and the "identity, locations, qualifications and availability" of the plan's primary care and specialist providers. (42 U.S.C. §1396u-2(a)(5)(B)(ii), (iv)).

**§210. Information for Purchaser**

The purpose of this section is to require the health plan to make available to the state Medicaid agency, the health plan’s provider manual, guidelines and protocols; subcontracts with providers participating in the health plan’s network, the enrollee handbook; and any directives or guidelines from the health plan to their provider network related to the prevention and care of HIV/AIDS.

*The following section provides illustrative language regarding information for Purchasers.*

**§210. Information for Purchaser**

**K(a) Submissions required**—Contractor shall make available to Purchaser upon request a copy of the following documents:

- (1) Contractor’s provider manual and any other directives, guidelines, or protocols relating to the provision or coverage of items or services under this Purchasing Agreement;
- (2) the subcontract or other written agreement between Contractor and participating laboratories, pharmacies, providers and case managers;
- (3) Contractor’s enrollee handbook or any other written information given to enrollees regarding items and services covered under this agreement; and
- (4) Contractor’s directives, coverage and treatment guidelines, and instructions to network and affiliated providers relating to the prevention, diagnosis and management of HIV and related conditions.

**Section III:** An Explanation and Description of Model Contract Language



# **SECTION IV**

**Additional Resources**

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## **Internet Resources**

One of the benefits of the rapid adoption of Internet access by many AIDS services organizations and millions of individuals across the country is that this has become a popular medium for transmitting new information--and sharing voluminous materials, for which printing costs always limit the capacity to distribute materials widely.

The following are web sites for organizations that conduct extensive Medicaid policy analysis or advocacy. Local and national HIV/AIDS organizations are also an excellent resource for information. Due to space limitations, we are not listing their web sites here, but we urge you to contact other HIV/AIDS organizations--or visit their web sites.

**National Association of People with AIDS**                      [www.napwa.org](http://www.napwa.org)

**Henry J. Kaiser Family Foundation**                      [www.kff.org](http://www.kff.org)

### **Federal Government Resources**

Centers for Disease Control and Prevention (CDC)                      [www.cdc.gov](http://www.cdc.gov)  
Health Care Financing Administration (HCFA)                      [www.hcfa.gov](http://www.hcfa.gov)  
Health Resources and Services Administration (HRSA)                      [www.hrsa.gov](http://www.hrsa.gov)  
Substance Abuse and Mental Health Services  
Administration (SAMHSA)                      [www.samhsa.gov](http://www.samhsa.gov)

### **Non-governmental Resources**

Bazelon Center for Mental Health Law                      [www.bazelon.org](http://www.bazelon.org)  
Center on Budget and Policy Priorities                      [www.cbpp.org](http://www.cbpp.org)  
Center for Health Care Strategies                      [www.chcs.org](http://www.chcs.org)  
Center for Health Services Research and Policy  
(Formerly the Center for Health Policy Research)                      [www.gwu.edu/~chsrp/](http://www.gwu.edu/~chsrp/)  
Families USA                      [www.familiesusa.org/medicaid](http://www.familiesusa.org/medicaid)  
National Academy for State Health Policy                      [www.nashp.org](http://www.nashp.org)  
National Health Law Program (NHeLP)                      [www.healthlaw.org/medicaid.shtml](http://www.healthlaw.org/medicaid.shtml)  
Urban Institute                      [www.urban.org/socwelfare.htm#medicaid](http://www.urban.org/socwelfare.htm#medicaid)



## State Medicaid Directors

The following are provided to help you contact the Medicaid agency in your state:

### ALABAMA

Medicaid Director  
Mr. W. Dale Walley  
Acting Commissioner  
Alabama Medicaid Agency  
501 Dexter Avenue  
P.O. Box 5624  
Montgomery, AL 36103-5624  
(334) 242-5600  
(800) 362-1504  
Fax Number(334) 242-5097  
E-Mail - Almedicaid@medicaid.state.al.us

### ALASKA

Medicaid Director  
Mr. Robert Labbe  
Director  
Division of Medical Assistance  
Department of Health and Social Services  
P.O. Box 110660  
Juneau, AK 99811-0660  
(907) 465-3355  
Fax Number (907) 465-2204  
E-Mail - Blabbe@health.state.ak.us

### AMERICAN SAMOA

Medicaid Director  
Mr. Niuatoa A. Puleyasi  
State Medicaid Officer  
Department of Health  
LBJ Tropical Medical Center  
Pago Pago, AS 96799  
011-684-633-4590  
Fax Number 011-684-633-1869

### ARIZONA

Medicaid Director  
Ms. Phyllis Beidess  
Director  
Arizona Health Care Cost Containment System  
(AHCCCS)  
801 East Jefferson Street  
Phoenix, AZ 85034  
(602) 417-4680  
Fax Number (602) 252-6536  
E-Mail - PXBiedess@ahcccs.state.az.us

### ARKANSAS

Medicaid Director  
Mr. Ray Hanley  
Director  
Division of Medical Services  
Department of Human Services  
P.O. Box 1437, Slot 1100  
Little Rock, AR 72203-1437  
(501) 682-8292  
TDD (510) 682-6789  
Fax Number (501) 682-1197  
E-Mail - Ray.Hanley@medicaid.state.ar.us

### CALIFORNIA

Medicaid Director  
Mr. J. Douglas Porter  
Deputy Director  
Medical Care Services  
Department of Health Services  
714 P Street, Room 1253  
Sacramento, CA 95814  
(916) 654-0391  
Fax Number (916) 657-1156  
E-Mail - Dporter@hw1.cahwnet.gov

**Appendix B:** State and Regional Contacts

**COLORADO**

Medicaid Director     Mr. Richard Allen  
Executive Director  
Department of Health Care Policy and Financing  
1575 Sherman Street  
Denver, CO 80203-1714  
(303) 866-5401  
Fax Number (303) 866-2803  
TDD (303) 866-3883  
E-Mail - Richard.allen@state.co.us

**CONNECTICUT**

Medicaid Director     Mr. David Parella  
Deputy Commissioner  
Department of Social Services  
25 Sigourney Street  
Hartford, CT 06106-5116  
(860) 424-5116  
Fax Number (860) 424-5114  
E-Mail - David.Parrella@PO.state.ct.us

**DELAWARE**

Medicaid Director     Mr. Philip Soule, Sr.  
Director  
Medical Assistance Program  
Department of Health and Social Services  
P.O. Box 906, Lewis Building  
1901 North DuPont Highway  
New Castle, DE 19720  
(302) 577-4901  
Fax Number (302) 577-4577  
E-Mail - Psoule@state.de.us

**DISTRICT OF COLUMBIA**

Medicaid Director     Mr. Herb Weldon  
Deputy Director  
Medical Assistance Administration  
Department of Health  
2100 Martin Luther King Jr. Avenue, S.E.  
Suite 302  
Washington, DC 20020  
(202) 727-0735  
Fax Number (202) 610-3209  
E-mail: Poffner.doh@dcgov.org

**FLORIDA**

Medicaid Director     Mr. Rick Lutz  
Agency for Health Care Administration  
2727 Mahan Drive, Bldg. 3  
Tallahassee, FL 32308  
(850) 922-6463  
Fax Number (850) 488-3560  
E-Mail - Lutzr@sdhc.state.fl.us

**GEORGIA**

Medicaid Director     Dr. William Taylor  
Department of Medical Assistance  
2 Peachtree Street, N.W.  
Suite 4043  
Atlanta, GA 30303-3159  
(404) 656-4479  
Fax Number (404) 651-6880  
E-Mail - Wtaylor@dma.state.ga.us

**GUAM**

Medicaid Director     Ms. Ma Theresa Arcangel  
Acting Administrator  
Bureau of Health Care Financing  
Department of Public Health and  
Social Services  
P.O. Box 2816  
Agana, GU 96910  
(671) 735-7269  
Fax Number (671) 734-5910

**HAWAII**

Medicaid Director     Mr. Chuck C. Duarte  
Administrator  
Med-Quest Division  
Department of Human Services  
P.O. Box 399  
Honolulu, HI 96809-0339  
(808) 692-8056  
Fax Number (808) 692-8173  
E-Mail - Chuck@l-one.com

## State Medicaid Directors

### IDAHO

Medicaid Director

Mr. Joe Brunson  
Administrator  
Division of Medicaid  
Department of Health and Welfare  
Americana Building  
P.O. Box 83720  
Boise, ID 83720-0036  
(208) 364-1802  
Fax Number (208) 364-1811  
E-Mail - Allynkp@mmis.state.id.us

### ILLINOIS

Medicaid Director

Mr. A. George Hovanec  
Administrator  
Medical Operations  
Department of Public Aid  
201 South Grand Avenue, East  
Third Floor  
Springfield, IL 62763-0001  
(217) 782-2570  
Fax Number (217) 782-5672  
E-Mail - Aidd2062@mail.idpa.state.il.us

### INDIANA

Medicaid Director

Ms. Kathleen D. Gifford  
Assistant Secretary  
Medicaid Policy and Planning  
Family and Social Services Administration  
Room W382  
402 W. Washington Street  
Indianapolis, IN 46204-2739  
(317) 233-4455  
Fax Number (317) 232-7382  
E-Mail: Kgifford@fssa.state.in.us

### IOWA

Medicaid Director

Mr. Donald Herman  
Director  
Division of Medical Services  
Department of Human Services  
Hoover State Office Building  
Fifth Floor  
Des Moines, IA 50319-0114  
(515) 281-8621  
Fax Number (515) 281-7791  
E-Mail - Dherman@dhs.state.ia.us

### KANSAS

Medicaid Director

Ms. Ann E. Koci  
Commissioner  
Adult and Medical Services  
Department of Social and Rehabilitation Services  
Docking State Office Building  
Room 628 South  
915 S.W. Harrison Street  
Topeka, KS 66612  
(785) 296-5217  
Fax Number (785) 296-4813  
E-Mail - AEK@srskansas.org

### KENTUCKY

Medicaid Director

Mr. Larry McCarthy  
Deputy Commissioner  
Department for Medicaid Services  
Third Floor  
275 East Main Street  
Frankfort, KY 40621  
(502) 564-4321  
Fax Number (502) 564-0509  
E-Mail - Lmccarthy@mail.state.ky.us

### LOUISIANA

Medicaid Director

Mr. Thomas D. Collins  
Director  
Bureau of Health Services Financing  
Department of Health and Hospitals  
P.O. Box 91030  
Baton Rouge, LA 70821-9030  
(504) 342-3891  
Fax Number (504) 342-9508  
E-Mail - TCOLLINS@dhhmail.dhh-state.la.us

### MAINE

Medicaid Director

Mr. Francis T. Finnegan, Jr.  
Director  
Bureau of Medical Services  
Department of Human Services  
State House Station 11  
Augusta, ME 04333-0011  
(207) 287-2093  
Fax Number (207) 287-2675  
E-Mail - fran.finnegan@state.me.us

## Appendix B: State and Regional Contacts

### MARYLAND

Medicaid Director Ms. Debbie Chang  
Deputy Secretary for Health Care Financing  
Department of Health and Mental Hygiene  
201 West Preston Street  
Baltimore, MD 21201  
(410) 767-4664  
Fax Number (410) 333-7687  
E-mail - Dchang@dhhm.md.state.us

### MASSACHUSETTS

Medicaid Director Mr. Mark Reynolds  
Acting Commissioner  
Division of Medical Assistance  
600 Washington Street  
Boston, MA 02111  
(617) 210-5690  
Fax Number (617) 210-5697  
E-Mail - MReynolds@nt.dma.state.ma.us

### MICHIGAN

Medicaid Director Mr. Robert M. Smedes  
Chief Executive Officer  
Medical Services Administration  
Department of Community Health  
400 S. Pine St.  
Lansing, MI 48909  
(517) 335-5001  
Fax Number (517) 335-5007  
E-Mail - Smedes@state.mi.us

### MINNESOTA

Medicaid Director Mary B. Kennedy  
Medicaid Director  
Assistant Commissioner Health Care  
Minnesota Department of Human Services  
444 Lafayette Road  
St. Paul, MN 55155-3852  
(612) 282-9921  
Fax Number (612) 297-3230  
E-Mail - mary.kennedy@state.mn.us

### MISSISSIPPI

Medicaid Director Ms. Helen Wetherbee  
Executive Director  
Division of Medicaid  
Office of the Governor  
Suite 801, Robert E. Lee Building  
239 North Lamar Street  
Jackson, MS 39201-1399  
(601) 359-6050  
Fax Number (601) 359-6048  
E-Mail - Exhaw@medicaid.state.ms.us

### MISSOURI

Medicaid Director Mr. Gregory A. Vadner  
Division of Medical Services  
Department of Social Services  
615 Howerton Court  
P.O. Box 6500  
Jefferson City, MO 65102-6500  
(573) 751-6922  
Fax Number (573) 751-6564  
E-Mail - Victornine@aol.com

### MONTANA

Medicaid Director Ms. Nancy Ellery  
Administrator  
Division of Health Policy and Services  
Department of Public Health and Human Services  
1400 Broadway  
Helena, MT 59601  
(406) 444-4141  
Fax Number (406) 444-1861  
E-Mail: Nellery@state.mt.us

### NEBRASKA

Medicaid Director Cec Brady  
Acting Administrator  
Medicaid Division  
Nebraska Department of Health  
and Human Services  
301 Centennial Mall South  
Fifth Floor  
Lincoln, NE 68509-5026  
(402) 471-9147  
Fax Number (402) 471-9092



## State Medicaid Directors

### NEVADA

Medicaid Director

Ms. Myla Florence  
Administrator  
Nevada State Welfare Division  
2527 North Carson Street  
Carson City, NV 89710  
(775) 687-4128  
Fax Number (775) 687-5080

### NEW HAMPSHIRE

Medicaid Director

Ms. Lee Bezanson  
Medicaid Director  
Medicaid Administration Bureau  
Department of Health and Human Services  
6 Hazen Drive  
Concord, NH 03301-6521  
(603) 271-4353  
Fax Number (603) 271-4376

### NEW JERSEY

Medicaid Director

Ms. Margaret A. Murray  
Director  
Division of Medical Assistance  
and Health Services  
Department of Human Services  
P.O. 712  
Trenton, NJ 08625-0712  
(609) 588-2600  
Fax Number (609) 588-3583

### NEW MEXICO

Medicaid Director

Mr. Charles J. Milligan  
Director  
Medical Assistance Division  
New Mexico Human Services Department  
P.O. Box 2348  
Santa Fe, NM 87504-2348  
(505) 827-3106  
(888) 997-2583 Toll free client information  
Fax Number (505) 827-3185  
E-mail: Charles.milligan@state.nm.us

### NEW YORK

Medicaid Director

Ms. Donna Farlow  
Deputy Director  
NYS Department of Health  
Office of Medicaid Management  
Empire State Plaza  
Room 1466, Corning Tower Building  
Albany, NY 12237  
(518) 474-3018  
Fax Number (518) 486-6652  
E-mail: Dbf02@health.state.ny.us

### NORTH CAROLINA

Medicaid Director

Mr. Paul R. Perruzzi  
Director  
Division of Medical Assistance  
Department of Health and Human Services  
1985 Umstead Drive  
P.O. Box 29529  
Raleigh, NC 27626-0529  
(919) 857-4011  
Fax Number (919) 733-6608  
E-mail: Dick.Perruzzi@ncmail.net

### NORTH DAKOTA

Medicaid Director

Mr. David J. Zentner  
Director  
Division of Medical Assistance  
Department of Human Services  
600 East Boulevard Avenue  
Bismarck, ND 58505-0261  
(701) 328-3194  
Fax Number (701) 328-1544  
E-mail: sozend@state.nd.us

## Appendix B: State and Regional Contacts

### NORTHERN MARIANA ISLANDS

Medicaid Director Ms. Maria A. V. Leon Guerrero  
Medical Administrator  
Department of Public Health and  
Environmental Services  
Commonwealth of the Northern Mariana Islands  
P.O. Box 409 CK  
Saipan, MP 96950  
(670) 234-8931  
Fax Number 670-

### OHIO

Medicaid Director Ms. Barbara Edwards  
Deputy Director  
Office of Medicaid  
Department of Human Services  
30 East Broad Street  
31st Floor  
Columbus, OH 43266-0423  
(614) 644-0140  
Fax Number (614) 752-3986  
E-Mail: Medicaid@odhs.state.oh.us

### OKLAHOMA

Medicaid Director Mr. Michael Fogarty  
State Medicaid Director  
Oklahoma Health Care Authority  
4545 North Lincoln Boulevard  
Suite 124  
Oklahoma City, OK 73105  
(405) 530-3373  
Fax Number (405) 530-3478  
E-mail: Fogartym@ohca.state.ok.us

### OREGON

Medicaid Director Mr. Hersh Crawford  
Director  
Senior and Disabled Services Division  
Department of Human Resources  
500 Summer Street, N.E. 2nd. Floor  
Human Resources Building, Third Floor  
Salem, OR 97310-1015  
(503) 945-5767  
Fax Number (503) 373-7689  
E-mail: herschel.crawford@state.or.us

### PENNSYLVANIA

Medicaid Director Ms. Christine M. Bowser  
Acting Deputy Secretary  
Medical Assistance Programs  
Department of Public Welfare  
Health and Welfare Building, Room 515  
Harrisburg, PA 17120  
(717) 787-1870  
Fax Number (717) 787-4639  
E-mail - christineb@dpw.state.pa.us

### PUERTO RICO

Medicaid Director Ms. Margarita Latorre  
Medicaid Director  
Office of Economic Assistance  
to the Medically Indigent  
Department of Health  
G.P.O. Box 70184  
San Juan, PR 00936  
(809) 765-1230  
Fax Number (809) 250-0990

### RHODE ISLAND

Medicaid Director Mr. John Young, C.P.M.  
Associate Director  
Division of Medical Services  
Department of Human Services  
600 New London Avenue  
Cranston, RI 02920  
(401) 462-3113  
Fax Number (401) 462-6338  
E-mail: Jyoung@gw.dhs.state.ri.us

### SOUTH CAROLINA

Medicaid Director Dr. Jay Samuel Griswold, Ph.D.  
Director  
Department of Health and Human Services  
P.O. Box 8206  
Columbia, SC 29202-8206  
(803) 898-2504  
Fax Number (803) 898-4515  
E-mail: Griswold@dhhs.state.sc.us

## State Medicaid Directors

### SOUTH DAKOTA

Medicaid Director

Mr. David M. Christensen  
Program Administrator Medical Services  
Department of Social Services  
Richard F. Kneip Building  
700 Governors Drive  
Pierre, SD 57501-2291  
(605) 773-3495  
Fax Number (605) 773-5246  
E-mail: Dave.Christensen@state.sd.us

### TENNESSEE

Medicaid Director

Mr. Brian Lapps, Sr.  
Director of Operations  
Department of Finance and Administration  
729 Church Street  
Nashville, TN 37247-6501  
(615) 741-0213  
Fax Number (615) 741-0882  
E-mail: Blapps@mail.state.tn.us

### TEXAS

Medicaid Director

Ms. Linda K. Wertz  
State Medicaid Director  
Health and Human Services Commission  
P.O. Box 13247  
Austin, TX 78711  
(512) 424-6549  
Fax Number (512) 424-6547  
E-mail: Linda.wertz@hhsc.state.tx.us

### UTAH

Medicaid Director

Mr. Rod Betit  
Executive Director  
Department of Health  
Division of Health Care Financing  
P.O. Box 14100  
Salt Lake City, UT 84114-1000  
(801) 538-6111  
Fax Number (801) 538-6306

### VERMONT

Medicaid Director

Mr. Paul Wallace-Brodeur  
Director  
Office of Health Access  
Department of Social Welfare  
103 South Main Street  
Waterbury, VT 05676  
(802) 241-3985  
Fax Number (802) 241-2974  
E-mail: Paulw@wpgate1.ahs.state.vt.us

### VIRGINIA

Medicaid Director

Mr. Dennis G. Smith  
Director  
Department of Medical Assistance Services  
600 East Broad Street  
Suite 1300  
Richmond, VA 23219  
(804) 786-8099  
Fax Number (804) 371-4981  
E-mail: DSmith@dmas.state.va.us

### VIRGIN ISLANDS

Medicaid Director

Ms. Priscilla Berry-Quetel  
Director  
Bureau of Health Insurance  
and Medical Assistance  
Department of Health  
210-3A Altona  
Suite 302 Frostco Center  
Charlotte Amalie, VI 00802  
(809) 774-4624  
Fax Number (809) 774-4918

### WASHINGTON

Medicaid Director

Mr. Tom Bedell  
Acting Assistant Secretary  
Medical Assistance Administration  
P.O. Box 45080  
Olympia, WA 98504-5080  
(360) 902-7807  
Fax Number (360) 902-7855  
E-mail: Bedeltw@dshs.wa.gov

## **Appendix B:** State and Regional Contacts

### **WEST VIRGINIA**

Medicaid Director      Ms. Elizabeth Lawton  
Commissioner  
Bureau for Medical Services  
Department of Health and Human Resources  
7012 MacCorkle Avenue, SE  
Charleston, WV 25304  
(304) 926-1703 (ask for Ms. Lawton's Secty)  
Fax Number (304) 926-1833  
E-mail: ELawton@wvdhhr.org

### **WISCONSIN**

Medicaid Director      Ms. Peggy Bartels  
Administrator  
Division of Health Care Financing  
Department of Health and Social Services  
One West Wilson Street, Room 350  
Madison, WI 53701  
(608) 266-8922  
Fax Number (608) 266-1096  
E-mail: BARTEPL@dhfs.state.wi.us

### **WYOMING**

Medicaid Director      Mr. James Shepard  
Administrator  
Division of Health Care Financing  
Department of Health  
North Building, Room 259B  
6101 Yellowstone Road  
Cheyenne, WY 82002  
(307) 777-7531  
Fax Number (307) 777-6964  
E-mail: Jshepa@missc.state.wy.us

### **HCFA Regional AIDS Contacts**

The Health Care Financing Administration (HCFA) has regional offices throughout the country that help it to administer the Medicaid program. In each regional office, there is a designated HIV/AIDS Contact Person(s). These individuals can serve as an important resource for you:

**Region I: This region covers Connecticut, Maine, Massachusetts, Rhode Island, and Vermont**

Raymond Porter, 617/565-1260

**Region II: This region covers New Jersey, New York, and Puerto Rico**

Michael Melendez, 212/264-9121

**Region III: This region covers Delaware, District of Columbia, Maryland, Pennsylvania, Virginia, and West Virginia**

Theresa Rubin, 215/861-4215

**Region IV: This region covers Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, and Tennessee**

Michael McDaniel, 404/562-7413

Linda Lattimore, 404/562-7429

**Region V: This region covers Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin**

Renee Graxirena, 312/353-3876

**Region VI: This region covers Arkansas, Louisiana, New Mexico, Oklahoma, and Texas**

Tina Cheatham, 214/767-6497

**Region VII: This region covers Iowa, Kansas, Missouri, and Nebraska**

Gail Brown, 816/426-6317 x3319

Jackie Glaze, 816/426-3406

**Region VIII: This region covers Colorado, Montana, North Dakota, South Dakota, Utah, and Wyoming**

Cynthia Gillaspie, 303/844-4725

**Region IX: This region covers Arizona, California, Hawaii, and Nevada**

Bruce Campbell, 415/744-3588

**Region X: This region covers Alaska, Idaho, Oregon, and Washington**

Linda Miles, 206/615-2343

## Appendix B: State and Regional Contacts

### State AIDS Directors

State governments have individuals responsible for coordinating AIDS programs for the state, including HIV prevention and care programs. These individuals can be an important resource.

#### ALABAMA

Jane B. Cheeks, MPH, Director  
Division of HIV/AIDS Prevention  
and Control, Alabama Department  
of Public Health  
RSA Towers, Suite 1400  
P.O. Box 3017  
Montgomery, AL 36130-3017  
(334) 206-5364 - phone  
(334) 206-2092 - fax  
jane.cheeks@adph.state.al.us

#### ALASKA

Wendy S. Craytor, MBA, MPH,  
Coordinator  
AIDS/STD Program, Division of  
Public Health, State of Alaska  
P.O. Box 240249  
Anchorage, AK 99524-0249  
(907) 269-8058 - phone  
(907) 561-0453 - fax  
wendyc@health.state.ak.us

#### ARIZONA

Christopher Brown, MBA, Chief  
Office of HIV/AIDS Services,  
Arizona Department of  
Health Services  
3815 N. Black Canyon Highway  
Phoenix, AZ 85015  
(602) 230-5819 - phone  
(602) 230-5973 - fax  
cbrown@hs.state.az.us

#### ARKANSAS

Gary Horton, Director  
AIDS/STD Division, Arkansas  
Department of Health  
4815 West Markham  
Slot 33  
Little Rock, AR 72205  
(501) 661-2503 - phone  
(501) 661-2082 - fax  
hort101w@cdc.gov

#### CALIFORNIA

Vanessa Baird, Acting Chief  
Office of AIDS, California  
Department of Health Services  
P.O. Box 942732  
Sacramento, CA 94234-7320  
(916) 323-7415 - phone  
(916) 323-4642 - fax  
vbaird@dhs.ca.gov

#### COLORADO

Karen Ringen, Executive Director  
Governor's AIDS Council, Colorado  
Department of Health  
4300 Cherry Creek Drive South  
DCEED-STD-A3  
Denver, CO 80246-1530  
(303) 692-2719 - phone  
(303) 691-7736 - fax  
karen.ringen@state.co.us

Nancy Spencer, Program Manager  
for Field Services, Colorado  
Department of Health  
4300 Cherry Creek Drive South  
DCEED-STD-A3  
Denver, CO 80246-1530  
(303) 692-2741 - phone  
(303) 782-0904 - fax  
nancy.spencer@state.co.us

#### CONNECTICUT

Beth Weinstein, MPH, Director  
AIDS Division, Connecticut  
Department of Public Health  
410 Capitol Avenue  
MS 11 APV  
Hartford, CT 06134  
(860) 509-7832 - phone  
(860) 509-7853 - fax  
beth.weinstein@po.state.ct.us

#### DELAWARE

James C. Welch, RN, State AIDS  
Activities Coordinator  
HIV/STD/AIDS Program Director  
Delaware Health and Social  
Services, Division of Public Health  
P.O. Box 637  
Dover, DE 19903  
(302) 739-3032 - phone  
(302) 739-6617 - fax  
jwelch@state.de.us

#### FLORIDA

Thomas Liberti, Chief  
Bureau of HIV/AIDS, Florida  
Department of Health  
2020 Capitol Circle, SE  
Bin #A09  
Tallahassee, FL 32399-1715  
(850) 488-9768 - phone  
(850) 414-0038 - fax  
tom\_liberti@doh.state.fl.us

#### GEORGIA

Mark Schrader, Director  
STD/HIV Program, Division of  
Public Health, Department of  
Human Resources  
2 Peachtree Street, NW  
10th Floor, Room 400  
Atlanta, GA 30303-3186  
(404) 657-3100 - phone  
(404) 657-3133 - fax  
mvs@ph.dhr.state.ga.us

#### HAWAII

Peter Whiticar, STD/AIDS  
Program Manager  
Hawaii Department of Health  
3627 Kilauea Avenue  
Room 306  
Honolulu, HI 96816-2399  
(808) 733-9010 - phone  
(808) 733-9015 - fax  
whiticar@lava.net

#### IDAHO

Anne Williamson,  
Program Manager  
Idaho STD/AIDS Program. Bureau  
of Clinical and Preventive Services  
Department of Health and Welfare  
450 West State Street  
4th Floor  
P.O. Box 83720  
Boise, ID 83720-0036  
(208) 334-6526 - phone  
(208) 332-7346 - fax  
willia25@idhw.state.id.us

## State AIDS Directors

### ILLINOIS

Chet Kelly, Administrator  
AIDS Activity Section, Illinois  
Department of Public Health  
160 North LaSalle Street  
7th Floor South  
Chicago, IL 60601  
(312) 814-4846 - phone  
(312) 814-4844 - fax  
ckellych@idph.state.il.us

### INDIANA

Lori Phillips, Director  
Division of HIV/STD, Indiana  
State Department of Health  
2 North Meridian, 6-C  
Indianapolis, IN 46206  
(317) 233-7867 - phone  
(317) 233-7663 - fax  
lphillips@isdh.state.in.us

### IOWA

John Katz, STD/HIV  
Program Manager  
Iowa Department of Public Health  
Lucas State Office Building  
321 East 12th Street, 4th Floor  
Des Moines, IA 50319-0075  
(515) 242-5838 - phone  
(515) 281-4570 - fax  
jkatz@idph.state.ia.us

### IOWA [ continued ]

Patricia Young, RN, BS, CIC,  
STD/HIV Prevention Coordinator  
Iowa Department of Public Health  
Lucas State Office Building  
321 East 12th Street, 4th Floor  
Des Moines, IA 50319-0075  
(515) 242-5838 - phone  
(515) 281-4570 - fax  
pyoung@idph.state.ia.us

### KANSAS

Karl Milhon, AIDS Director  
Bureau of Disease Control,  
Kansas Department of Health  
and Environment  
109 SW 9th Street  
Suite 605  
Topeka, KS 66612-1271  
(785) 296-6036 - phone  
(785) 296-4197 - fax  
kmlilhon@kdhe.state.ks.us

### KENTUCKY

Patty Sewell, MPA, Director  
Kentucky HIV/AIDS Program  
275 East Main Street  
Frankfort, KY 40621  
(502) 564-6539 - phone  
(502) 564-9865 - fax  
patty.sewell@mail.state.ky.us

### LOUISIANA

Beth Scalco, BCSW,  
Administrative Director  
Office of Public Health,  
HIV/AIDS Program  
234 Loyola Avenue, 5th Floor  
New Orleans, LA 70112  
(504) 568-7474 - phone  
(504) 568-7044 - fax  
bscalco@dhhmail.dhh.state.la.us

### LOUISIANA [ continued ]

Maria Ludwick, MPH,  
Program Manager  
HIV Prevention Program Office,  
Office of Public Health  
325 Loyola Avenue, Room 315  
New Orleans, LA 70112  
(504) 568-7523 - phone  
(504) 568-8398 - fax  
ludw103w@cdc.gov

### MAINE

Sally-Lou Patterson, Director  
HIV/STD Programs, Maine  
Bureau of Health, Division of  
Disease Control  
State House Station #11  
Augusta, ME 04333-0011  
(207) 287-3747 - phone  
(207) 287-6865 - fax  
sallylou.patterson@state.me.us

Jeanette Talbot, Federal Grants  
Program Manager  
Maine Department Of  
Human Services  
11 State House Station  
221 State Street  
Augusta, Maine 04333-0011  
(207) 287-5060 - phone  
(207) 287-5031 - fax

### MARYLAND

Liza Solomon, Dr. PH, Director  
AIDS Administration, Maryland  
Department of Health and  
Mental Hygiene  
500 North Calvert Street  
Baltimore, MD 21202  
(410) 767-5013 - phone  
(410) 333-6333 - fax  
solomonl@dhhm.state.md.us

### MASSACHUSETTS

Jean McGuire, PhD, Director  
AIDS Bureau, Department of  
Public Health  
250 Washington Street  
3rd Floor  
Boston, MA 02108-4619  
(617) 624-5300 - phone  
(617) 624-5399 - fax  
jean.mcguire@state.ma.us

### MICHIGAN

Loretta Davis-Satterla, Director  
Division of HIV/AIDS & STD  
Michigan Department of  
Community Health  
3423 N. Martin Luther King Jr. Blvd.  
P.O. Box 30195  
Lansing, MI 48909  
(517) 335-8468 - phone  
(517) 335-9611 - fax  
davis-satterLa@state.mi.us

### MINNESOTA

Jill DeBoer, AIDS/STD Director  
Disease Prevention and Control  
Minnesota Department of Health  
717 Delaware Street SE  
Box 9441  
Minneapolis, MN 55440-9441  
(612) 676-5143 - phone  
(612) 676-5739 - fax  
jill.deboer@health.state.mn.us

### MISSISSIPPI

Craig W. Thompson, Director  
Division of STD/HIV, Mississippi  
Department of Health  
P.O. Box 1700  
Jackson, MS 39215-1700  
(601) 576-7711 - phone  
(601) 576-7909 - fax  
craigthompson@msdh.state.ms.us

## Appendix B: State and Regional Contacts

### MISSOURI

Mary Hayes, Acting AIDS Director  
Bureau of STD/HIV Prevention  
Missouri Department of Health  
1730 East Elm Street  
P.O. Box 570  
Jefferson City, MO 65102-0570  
(573) 751-6141 - phone  
(573) 751-6417 - fax  
mhayes@mail.health.state.mo.us

Mary Menges, Bureau Chief  
HIV Care, Missouri Department  
of Health  
1730 East Elm Street  
P.O. Box 570  
Jefferson City, MO 65102-0570  
(573) 751-6107 - phone  
(573) 751-6447 - fax  
mengem@mail.health.state.mo.us

### MONTANA

Sally Klein, RN, MBA, STD/HIV  
Section Supervisor  
Department of Public Health and  
Human Services  
1400 Broadway  
Helena, MT 59620-2951  
(406) 444-9028 - phone  
(406) 444-6842 - fax  
sklein@mt.gov

### NEBRASKA

Sandra Klocke, Administrator  
HIV/AIDS Prevention/Planning  
Health and Human Services  
System  
P.O. Box 95044  
Lincoln, NE 68509-5044  
(402) 471-0193 - phone  
(402) 471-7049 - fax  
doh0401@vmhost.cdp.state.ne.us

### NEBRASKA [ continued ]

Russell Wren, Ryan White  
Program Coordinator  
Health and Human  
Services System  
P.O. Box 95007  
Lincoln, NE 68509-5007  
(402) 471-0362 - phone  
(402) 471-6426 - fax  
wrenj@msn.com

### NEVADA

Richard Whitley, Acting AIDS  
Program Manager  
HIV/AIDS Program Office, Bureau  
of Disease Control and Intervention  
State Health Division  
505 E King Street, Room 304  
Carson City, NV 89710  
(775) 684-5900 - phone  
(775) 684-5999 - fax  
rwhitley@govmail.state.nv.us

### NEW HAMPSHIRE

David Ayotte, Program Chief  
STD/HIV Program, Division of  
Public Health Services  
Health and Welfare Building  
6 Hazen Drive  
Concord, NH 03301  
(603) 271-4576 - phone  
(603) 271-4934 - fax  
dayotte@dhs.state.nh.us

### NEW JERSEY

Carmine J. Grasso,  
Program Manager  
Intervention and Care Services  
Unit, Division of AIDS Prevention  
and Control, New Jersey  
Department of Health  
P.O. Box 363  
50 East State Street  
Trenton, NJ 08625  
(609) 984-6125 - phone  
(609) 292-4244 - fax  
cg1@doh.state.nj.us

### NEW JERSEY [ continued ]

Steve Saunders, Director  
Prevention Education and Quality  
Assurance, Division of AIDS  
Prevention and Control, New  
Jersey Department of Health  
P.O. Box 363  
50 East State Street  
Trenton, NJ 08625  
(609) 984-6050 - phone  
(609) 292-4244 - fax  
ess@doh.state.nj.us

### NEW MEXICO

Don Torres, Chief  
HIV/AIDS/STD Bureau, New  
Mexico Department of Health  
1190 St Francis Drive  
Runnels South 1150  
Santa Fe, NM 87505  
(505) 476-8451 - phone  
(505) 476-3637 - fax  
dont@doh.state.nm.us

### NEW YORK

Gloria Maki, Executive  
Deputy Director  
AIDS Institute, New York State  
Department of Health  
Corning Tower, ESP, Room 412  
Albany, NY 12237-0658  
(518) 473-7542 - phone  
(518) 486-1315 - fax  
gjc01@health.state.ny.us

### NORTH CAROLINA

Evelyn Foust, CPM, MPH,  
Section Chief  
HIV/STD Prevention and Care  
North Carolina Department of  
Health and Human Services  
Division of Epidemiology  
P.O. Box 29601  
Raleigh, NC 27626-0601  
(919) 733-7301 - phone  
(919) 733-1020 - fax  
evelyn.foust@ncmail.net

### NORTH CAROLINA [ continued ]

Arthur Okrent, Branch Head  
HIV/STD Prevention and Care  
North Carolina Department of  
Health and Human Services  
Division of Epidemiology  
P.O. Box 29601  
Raleigh, NC 27626-0601  
(919) 715-3118 - phone  
(919) 733-1020 - fax  
arthur.okrent@ncmail.net

### NORTH DAKOTA

Ruth Vogel, TB/HIV/AIDS  
Program Manager  
North Dakota Department of Health  
Division of Disease Control  
600 East Boulevard  
Bismarck, ND 58505-0200  
(701) 328-3322 - phone  
(701) 328-1817 - fax  
rvogel@state.nd.us

### OHIO

Juliet C. Dorris-Williams, MSW,  
Program Chief  
HIV/STD Prevention, Ohio  
Department of Health  
35 East Chestnut, 7th Floor  
P.O. Box 118  
Columbus, OH 43266-0118  
(614) 728-9256 - phone  
(614) 728-0876 - fax  
jdorrisw@gw.odh.state.oh.us

Richard Aleshire,  
Program Administrator  
AIDS Client Resources, Family and  
Community Health Services, Ohio  
Department of Health  
246 N. High Street, 6th Floor  
PO Box 118  
Columbus, OH 43266-0118  
(614) 752-2427 - phone  
(614) 728-4622 - fax  
raleshir@gw.odh.state.oh.us



## State AIDS Directors

### OKLAHOMA

William Pierson, MBA, Chief  
HIV/STD Service, Oklahoma State  
Department of Health  
1000 NE Tenth and Stonewall  
Oklahoma City, OK 73117-1299  
(405) 271-4636 - phone  
(405) 271-5149 - fax  
billp@health.state.ok.us

### OREGON

Mark O. Loveless, MD, Director  
HIV/STD/TB Program,  
Oregon Health Division  
800 NE Oregon Street  
Suite 745  
Portland, OR 97232  
(503) 731-4029 - phone  
(503) 731-4608 - fax  
mark.o.loveless@state.or.us

### PENNSYLVANIA

Joseph Pease, MPH, Director  
Division of HIV/AIDS, Bureau of  
Communicable Diseases  
Pennsylvania Department of Health  
Health and Welfare Building  
P.O. Box 90  
Room 912  
Harrisburg, PA 17108  
(717) 783-0572 - phone  
(717) 772-4309 - fax  
jpease@health.state.pa.us

Janice P. Kopelman, LSW, MSW,  
Director  
Bureau of Communicable  
Diseases, Pennsylvania  
Department of Health  
Health and Welfare Building  
P.O. Box 90  
Room 912  
Harrisburg, PA 17108  
(717) 783-0479 - phone  
(717) 772-4309 - fax  
jkopelma@health.state.pa.us

### RHODE ISLAND

Paul G. Loberti, MPH,  
Chief Administrator  
Office of Communicable Diseases,  
Office of AIDS/STD/TB  
Rhode Island Department of Health  
3 Capital Hill  
Room 106  
Providence, RI 02908  
(401) 222-2320 or 2577 - phone  
(401) 272-3771 - fax  
PaulGLoberti@hotmail.com

### SOUTH CAROLINA

Lynda Kettinger, MPH, Director  
STD/HIV Division, Health and  
Environmental Control  
Mills-Jarret Complex  
Box 101106  
Columbia, SC 29211  
(803) 898-0749 - phone  
(803) 898-0573 - fax  
kettingld@columb.60.dhec.state.sc.us

### SOUTH DAKOTA

LaJean Volmer, Administrator  
STD/HIV Program, Office of  
Disease Prevention, South Dakota  
Department of Health  
615 East 4th Street  
Pierre, SD 57501  
(605) 773-3737 - phone  
(605) 773-5509 - fax  
lajeanv@doh.state.sd.us

### TENNESSEE

Chris Freeman, Director  
STD/HIV Programs,  
Cordell Hull Building, 4th Floor  
C.E.D.S  
426 5th Avenue North  
Nashville, TN 37247-4911  
(615) 741-7510 - phone  
(615) 741-3857 - fax  
cfreeman4@mail.state.tn.us

### TENNESSEE [ continued ]

Drema Mace, Director, AIDS  
Support Services  
Cordell Hull Building, 4th Floor  
426 5th Avenue North  
Nashville, TN 37247-4911  
(615) 532-8485 - phone  
(615) 741-3857 - fax  
dmace@mail.state.tn.usl

### TEXAS

Casey S. Blass, Director  
HIV/STD Health Resources Division  
Texas Department of Health  
1100 West 49th Street  
Austin, TX 78756-9987  
(512) 490-2515 - phone  
(512) 490-2538 - fax  
casey.blass@tdh.state.tx.us

### UTAH

Teresa Garrett, Director  
Bureau of HIV/AIDS/TB/Refugee  
Health, Utah Department of Health  
P.O. Box 142867  
Salt Lake City, UT 84114-2867  
(801) 538-6096 - phone  
(801) 538-9913 - fax  
tgarrett@doh.state.ut.us

### VERMONT

Leslie Westphal, AIDS Director  
Vermont Department of Health  
P.O. Box 70  
Burlington, VT 05402  
(802) 651-1532 - phone  
(802) 863-7314 - fax  
lwestph@vdh.state.vt.us

### VIRGINIA

Casey Riley, Director  
Bureau of STD/AIDS, Virginia  
Department of Health  
P.O. Box 2448  
Room 112  
Richmond, VA 23218  
(804) 786-6267 - phone  
(804) 225-3517 - fax  
criley@vdh.state.va.us

### WASHINGTON

Jack Jourden, Director  
Infectious Disease  
and Reproduction  
P.O. Box 47844  
Olympia, WA 98504-7844  
(360) 236-3444 - phone  
(360) 586-5440 - fax  
jxj0303@doh.wa.gov

Raleigh Watts  
HIV Client Services, Washington  
State Department of Health  
P.O. Box 47844  
Olympia, WA 98504-7844  
(360) 236-3477 - phone  
(360) 664-2216 - fax  
rrw1303@doh.wa.gov

### WEST VIRGINIA

Loretta Haddy, Director  
Division of Surveillance and  
Disease Control  
1422 Washington Street, East  
Charleston, WV 25301  
(304) 558-5358 - phone  
(304) 558-6335 - fax  
lhaddy@wvdhhn.org

## Appendix B: State and Regional Contacts

### WISCONSIN

James M. Vergeront, MD, Director  
AIDS/HIV Program,  
Division of Health  
1414 East Washington Ave. Rm 167  
Madison, WI 53703  
(608) 267-5287 - phone  
(608) 266-2906 - fax  
vergejm@dhfs.state.wi.us

### WYOMING

Terrance Foley  
Program Manager  
Wyoming Department of Health  
HIV/AIDS Prevention Program  
Hathaway Building, 4th Floor  
Cheyenne, WY 82002  
(307) 777-5932 - phone  
(307) 777-5402 - fax  
mbunne@miss.state.wy.us - e-mail

### WASHINGTON, D.C.

Ron Lewis, Administrator  
Agency for HIV/AIDS, Department  
of Human Services  
717 14th Street, NW, Suite 600  
Washington, DC 20005  
(202) 727-2500 - phone  
(202) 724-4678 - fax  
rlewis8116@aol.com

### AMERICAN SAMOA

Joseph Tufa, AIDS Coordinator  
AIDS Program, Public Health  
Division, Department of Health  
LBJ Tropical Medical Center  
P.O. Box F  
Pago Pago, AS 96799  
011 (684) 633-4071 - phone  
011 (684) 633-5379 - fax  
jtufa@lbj.peacesat.hawaii.edu

### GUAM

Josie O'Mallan  
Department of Public Health and  
Social Services  
Government of Guam  
P.O. Box 2816  
Agana, GU 96910  
011 (671) 735-7142 - phone  
011 (671) 734-5910 - fax

### MARSHALL ISLANDS

Justina R. Langidrik, MPH,  
Assistant Secretary of Health for  
Primary Health Care, Ministry of  
Health & Environment, Government  
of the Marshall Islands  
P.O. Box 16  
Majuro, Marshall Is. 96960  
011 (692) 625-3999 - phone  
011 (692) 625-3432 - fax  
jusmohe@ntamar.com

### MICRONESIA

Ben Jesse, National  
AIDS Coordinator  
Federated States of Micronesia  
Department of Health Services  
P.O. Box PS 70  
Palikir, Pohnpei, FM 96941  
011 (691) 320-2619 - phone  
011 (691) 320-5263 - fax

### N. MARIANA ISLANDS

Elsie S. Ramon, Manager  
Commonwealth Disease Control  
Program, Department of Public  
Health, Commonwealth of Northern  
Mariana Islands  
P.O. Box 409 CK  
Saipan, MP 96950  
(011) (670) 234-8950,  
ext. 2005 - phone  
(011) (670) 234-8931 - fax

### PALAU

Caleb Otto, MD  
Bureau of Health Services,  
Republic of Palau  
P.O. Box 100  
Koror, Palau, PW 96940  
011 (680) 488-1757 - phone  
011 (680) 488-1725 - fax

### PUERTO RICO

Dr. Orlando Lopez, Executive Dir.  
P.A.S.E.T.  
P.O. Box 70184  
Commonwealth of Puerto Rico  
San Juan, PR 00936  
(787) 274-5502 - phone  
(787) 274-5503 - fax

### U.S. VIRGIN ISLANDS

Stan Phillips, Director  
STD/HIV/TB Program  
Virgin Islands Department  
of Health  
48 Sugar Estate  
St. Thomas, U.S.V.I. 00802  
(340) 774-3168 - phone  
(340) 777-4001 - fax

## Glossary of Terms

**Adherence Services:** Services provided by a health plan that are designed to help an enrollee successfully complete a course of treatment. Such services may include educational interventions, support groups, or other activities that lead an enrollee to improve or maintain their ability to follow provider instructions with regard to when and how to take prescribed medications and/or to maintain prescribed diet, exercise, therapeutic, or other regimens.

**Administrative Fair Hearing:** A legal right established by the federal Medicaid law that allows a Medicaid beneficiary to appeal grievances or complaints with regard to the care they receive or the treatment they receive from their state Medicaid agency or their health plan to an independent federal judge. This is an important manner through which Medicaid beneficiaries can ensure that they receive the services provided under the Medicaid law.

**Administrative Procedures Act (APA):** A type of state law enacted by every state and the District of Columbia that defines the parameters within which state agencies, including the state Medicaid agency, must operate. In general, these laws require state agencies to provide for public notice and comment on all regulations and policies that are issued by state agencies. With the exception of Missouri and Nevada, where state APAs exempt the Medicaid program from complying with their requirements, APAs can be used as a tool by consumer advocates to obtain access to and provide comment on requests for proposals (RFPs), state plan amendments, and other policies before they are issued by the state.

**AID to Families with Dependent Children (AFDC):** Cash assistance program for low income women and children. To be eligible for Medicaid, individuals must have an income low enough to qualify for the program and then must fit into a limited number of categories of persons eligible to receive Medicaid. In the past, receipt of AFDC automatically made persons eligible for Medicaid. As part of federal welfare reform legislation that was enacted in 1996, AFDC was eliminated and a new program, called temporary assistance for needy families (TANF), was created. Some persons who had received AFDC became ineligible for TANF. Nonetheless, Congress did not change eligibility for Medicaid. All persons who would have qualified for AFDC remain eligible for Medicaid. Unlike in the past, AFDC-eligible Medicaid beneficiaries must apply for Medicaid separately from applying for TANF benefits.

**Auto-Assignment:** See default enrollment.

**Balanced Budget Act of 1997 (BBA):** A federal law enacted in the summer of 1997 that provided for the fiscal year 1998 appropriations and laid out a five-year spending framework for achieving a balanced federal budget. Included as part of this comprehensive legislation were provisions providing for the most significant reforms to Medicaid in the more than thirty year history of the program. Key reforms included provisions granting states new authority for requiring Medicaid beneficiaries to enroll in managed care programs, along with several new consumer protections. Also included in this legislation was the State Children's Health Insurance Program (CHIP) which provided additional funds to states to expand health insurance coverage to children in working families with low-incomes. Under CHIP, states are given the option of expanding Medicaid to extend coverage to these children or developing a new state program for extending health insurance coverage to these children.

## Appendix C: Glossary of Terms

**Beneficiary:** A person who receives benefits from a program. When talking about Medicaid, Medicaid beneficiaries are the people who receive health care services provided by Medicaid. These same individuals may be called enrollees when discussing their relationship to an individual health plan through which they receive health care coverage.

**Capitation:** A method of paying for health care services that is a common feature of many Medicaid managed care programs. Capitation involves paying a per person per month (pmpm) payment to a health plan for each of their members. The health plan receives this payment even if the individual does not use any health care services during the month. Medicaid programs have adopted capitated payment arrangements with health plans because they provide a way to limit their financial responsibility for the cost of care that their beneficiaries may require. In exchange for accepting the capitated payment, health plans accept responsibility for providing a defined set of benefits in the amount that is medically necessary. In this circumstance, Medicaid has paid a fixed rate for services, and the health plan is considered to be “at-risk” because they could be responsible for an unlimited amount of services—as long as they are medically necessary.

**Carve Out:** Practice of treating specific services or specific classes of beneficiaries differently from other services or beneficiaries. A service carve out generally means that a state Medicaid agency has decided to pay for or deliver that service differently than it does for most other services. For example, a Medicaid agency may pay for primary medical care on a capitated basis, but it will carve out substance abuse treatment by paying for this service on a fee-for-service basis. A population carve out involves the creation of a separate system of care for an entire population. For example, New York has created special needs plans for people living with HIV. While people living with HIV are allowed to participate in the main Medicaid managed care program, they can also get their care

through the special needs plans which are focused only on providing expert care to people living with HIV. A state may decide to use a carve out for many reasons. In some cases, such as substance abuse treatment, there could be a historical pattern of the under availability of this service, so they want to pay for the service separately to ensure that is made adequately available. In other cases, a state may determine that they could manage their costs more effectively by creating a specialized system for paying for that service. In the area of mental health, numerous for-profit managed behavioral care plans have developed that actively compete for mental health carve outs. Finally, a state may carve out a service or population because of the complexity of providing the service or serving the population well. For example, many states carve-out pharmacy benefits because the costs are unpredictable and high.

**Categorically Needy Eligible Beneficiary:** A type of Medicaid beneficiary who receives Medicaid on the basis of having a low income and falling into a legally defined eligibility category. The most common eligibility categories are: persons formerly eligible for AFDC or who receive Temporary Assistance for Needy Families benefits, persons receiving SSI, and persons over 65 who are blind or disabled and require long term care. Categorically eligible beneficiaries are considered mandatory beneficiaries. This means that for a state to receive federal Medicaid payments, they must provide health care coverage to all categorically needy eligible beneficiaries.

**Clinical Practice Guidelines:** Recommendations for health care providers on how to best provide health care to a specific population of individuals. These recommendations are generally given credibility by consensus that has been achieved among nationally respected physicians, health care providers, researchers, consumer advocates, and members of the affected population. In the case of HIV, it has been difficult to ensure that people living with HIV receive the highest

standard of care possible because most providers do not specialize in treating HIV disease—and the state of the art of HIV prevention and care is changing very rapidly. The clinical practice guidelines identified in the model contract language provide the most current scientific and community consensus on how to prevent and treat HIV disease. A major focus of consumer advocacy revolves around ensuring that all people living with HIV receive prevention and care services consistent with these guidelines.

**Consumer Assistance Program:** A program operated by a state Medicaid agency or other governmental agency to help people with Medicaid or other health insurance coverage by providing credible information about different health plans and health care providers, as well as assistance in resolving problems that they may have with their health plan or their health care provider. This assistance may include helping individuals to file a complaint or grievance or take advantage of other legal protections available to them. This type of program may also be called an ombudsprogram.

**Contractor:** Organization with whom a state Medicaid program is signing a legally enforceable contract to provide health care services to Medicaid beneficiaries. In most cases, the contractor is the same as the health plan.

**Coverage Determinations:** Process through which a health plan makes decisions regarding whether they are legally required to provide a service to an enrollee. An important element of managed care is that health plans have signed legally enforceable contracts with the state Medicaid agency to provide a defined set of health care benefits to the level that they are medically necessary. A coverage determination defines the practices or steps that a health plan can and cannot undertake when determining whether a service requested by an enrollee or a health care provider is medically necessary—and therefore, a covered service.

**Default Enrollment:** In Medicaid, beneficiaries have a choice of health plans. When beneficiaries fail to choose a health plan, the state Medicaid agency must select a health plan for the individual. This process is called default enrollment or auto assignment. Consumer advocates are encouraged to make sure that a state takes into account an existing provider relationship, if any.

**Enrollee:** A Medicaid beneficiary who has joined a specific health plan. Health plans may also call enrollees of their plan their members.

**Experienced HIV Provider:** A provider who has demonstrated her/his ability to care for people living with HIV on the basis of having received specialized training and continuing medical education in relation to HIV disease and who maintains an active practice of a specified number of patients living with HIV. In order to ensure that all people living with HIV get the highest quality of care possible, it is important to make certain that they either are treated by an experienced HIV provider or that they are treated by a provider who has an active consultation agreement in force with an experienced HIV provider. Published studies have shown that people living with HIV who are treated by experienced HIV providers live longer than people living with HIV who are treated by inexperienced HIV providers.

**Fee-for-Service Health Care Programs:** A way of paying for health care services that is being rapidly replaced by managed care programs. Fee-for-service health care systems have been called “traditional health insurance coverage”. Fee-for-service health care programs differ from managed care programs in that they pay for care on the basis of paying a set fee (or portion of a fee) for each health care service received by beneficiaries. This contrasts with managed care which pays a set fee to a health plan whether or not services are provided and expects the health plan to be at-risk for providing all of the services that an enrollee needs. Fee-for-service health care

## Appendix C: Glossary of Terms

has been considered inefficient because it creates incentives for providers to prescribe services that may not be necessary because they stand to gain financially if they provide more services. Consumers like aspects of fee-for-service, including the free choice of providers and limited number of rules. Historically, fee-for-service Medicaid has been less attractive than fee-for-service health care in the private market because Medicaid's payments are lower than for private health insurance, and many providers refuse to treat Medicaid beneficiaries. By contrast, Medicaid managed care programs contract with a network of providers who agree to accept all eligible Medicaid beneficiaries.

**Health Care Financing Administration (HCFA):** The federal agency that administers the Medicaid program. HCFA provides oversight of state Medicaid programs, administers federal payments to state Medicaid programs, and reviews and approves state plan amendments and waivers. HCFA is a part of the Department of Health and Human Services. In addition to administering Medicaid, HCFA operates the Medicare program, oversees the State Children's Health Insurance Program and regulates compliance with the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

**Health Maintenance Organization (HMO):** A type of managed care program that has been in existence since the early 1970s. HMOs accept a capitated payment and provide a defined set of benefits and services, generally through a closed network of care providers.

**Home and Community-Based Services:** Services that may enable an individual to continue to live in their own home or to live in a community (non-institutional) setting. Such services include personal care services that assist the individual with activities of daily living, homemaker/home health aide services that assist the individual to perform activities necessary to continue to reside in their home, respite services which provide for caretakers to be relieved from twenty-four hour responsibility for monitoring and caring for the person living

with HIV and transportation services that enable the individual to obtain prevention or medical management services.

**Independent Practice Association (IPA):** A type of managed care organization in which beneficiaries may select 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.

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

**Medicaid:** A health care program created by federal law that provides for states to operate their own health insurance program for specific categories of low-income individuals. While states have flexibility in structuring their programs, states must meet minimum federal standards and be subject to federal review and oversight. The federal government provides states with matching payments for Medicaid services and covers between 50% and 83% of the total program costs, depending on the state.

For people living with HIV and AIDS, Medicaid is the single largest source of health care. It provides health care to more than 90% of children living with AIDS and more than 50% of adults with AIDS.

**Medical Group:** An affiliation of a network of health care providers that markets the services of its providers collectively and which contracts with health plans to accept patients on a capitated basis. Because medical groups are generally large networks which refer patients to specialists within their own group, in some ways medical groups take on characteristics of a health plan. Medical groups differ from health plans in that they normally do not contract directly with a state Medicaid agency.



**Medical Necessity:** The criteria that determines whether or not a health plan is obligated to provide an enrollee with a specific service. How this term is defined in the contract between a state Medicaid agency and a health plan is one of the most critical factors in ensuring that enrollees have access to the services they need. In defining what is medically necessary, consumer advocates are encouraged to strive to make sure that determinations of medical necessity are consistent with current clinical practice guidelines, defer to the best judgement of the treating provider, and are consistent among health plans. Another important element of medical necessity relates to ensuring that habilitative services are provided. This means that a health plan cannot deny a service on the basis that even by providing it, the enrollee is unlikely to recover from a particular condition. In many cases, health care services are needed to prevent a further deterioration of a condition.

**Medically Needy Eligible Beneficiary:** A type of Medicaid beneficiary who receives Medicaid on the basis of meeting the Social Security Administration's definition of disability whose income disqualifies them for SSI, but when subtracting incurred medical expenses, their income falls below the SSI maximum income level. Unlike categorically needy eligible beneficiaries, medically needy eligible beneficiaries are an optional beneficiary category. State Medicaid programs can choose not to cover medically needy eligible beneficiaries without jeopardizing federal support for their Medicaid program. Many adults living with AIDS qualify for Medicaid on the basis of being medically needy.

**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 two years before they qualify for benefits. Medicare does not cover certain benefits that are highly important to people living with HIV and AIDS, such as prescription drugs. For persons who also meet the eligibility requirements for Medicaid, it is possible to

receive health care services through Medicare which are supplemented by Medicaid. These persons are called dually eligible beneficiaries. A significant number of people with AIDS receive health care services through Medicare, and after Medicaid, it is the next largest source of health care for people with AIDS.

**Ombudsprogram:** See consumer assistance program.

**Primary Care Case Management Organization (PCCM):** A type of managed care organization that contracts with a state Medicaid agency to serve as a gatekeeper by monitoring and approving all covered services. PCCMs are paid on a fee-for-service basis and undertake no risk for the cost of health care services.

**Primary Care Provider (PCP):** This is the provider an individual sees for most of their health care. This provider is responsible for coordinating an individual's care needs and must also authorize any specialty care (by giving the enrollee a referral).

**Private Right of Action:** A right of Medicaid beneficiaries, established by federal law, to sue the state Medicaid program in federal court in order to force them to comply with the terms of the federal Medicaid statute. This is an important legal remedy for Medicaid beneficiaries when grieving or complaining has failed to resolve problems related to access to care. In the 1980s, people with AIDS successfully used this legal protection to prevent state Medicaid programs from denying coverage for AZT on the basis of its cost. This protection also has been instrumental in a variety of other circumstances to ensure that Medicaid beneficiaries are provided with health care services consistent with the federal Medicaid statute.

**Quality Assurance:** An activity undertaken by a health plan, provider, or a state Medicaid agency to ensure that enrollees of the health plan or Medicaid beneficiaries actually

## Appendix C: Glossary of Terms

receive high quality care. An example of a quality assurance activity would be a training that a health plan conducts for all of its providers related to HIV clinical practice guidelines with the intention of ensuring that all of their providers treat all of their enrollees with HIV in a manner consistent with these guidelines. Quality assurance activities encompass a broad range of activities designed to monitor the performance of health plans or providers and make sure that this performance is consistent with current standards of care.

**Quality Improvement:** An activity undertaken by a health plan, provider, or state Medicaid agency to consistently improve performance against a specifically defined measure. For example, studying the number of enrollees who are counseled about antiretroviral therapy upon diagnosis or enrollment in order to increase the number of enrollees who receive such counseling is a type of quality improvement activity. Quality improvement is a facet of quality assurance, but it is focused on improvement against a predetermined baseline of performance.

**Request for Applications (RFA):** An announcement issued by a state Medicaid agency that notifies the public of its intention to enroll its Medicaid recipients into managed care and asks for health plans to submit applications to provide a specific set of services to a specified population of Medicaid beneficiaries. It will also describe how the state will review the applications that it receives and select health plans with which it would like to contract. Health plans that are interested in applying would develop a proposal that describes their expertise and capacity in providing such services, describes how they would structure a health care delivery system to provide the services identified, and outlines a cost proposal or a fee structure to serve the identified population.

**Request for Information (RFI):** This is similar to an RFA, only it indicates that a state Medicaid agency is at a preliminary stage in deciding how they will structure their managed care program. Health plans that respond to an RFI would develop

a similar application, only there is likely to be less specificity regarding how a health plan would structure its health care delivery system and it would provide little or no cost information.

**Request for Proposals (RFP):** An RFP is very similar to an RFA. In an RFA, the state Medicaid program may be more specific in the requirements it would impose on health plans with which it contracts, whereas an RFP may give a health plan more latitude for structuring a proposal. In short, where a state has used an RFP process, there is likely to be more variations in how health plans structure their programs and networks than in states that have contracted with health plans through an RFA process.

**Risk Adjustment:** A statistical method of paying health plans different capitated payments based on the composition of their enrollees and their predictable health care costs. Risk adjustment payment procedures would generally compensate providers of HIV services with a higher capitated payment than providers of other (often less costly) health care services.

**Social Security Administration (SSA):** The federal agency that administers the Social Security programs, including the supplemental security income (SSI) program.

**State Children's Health Insurance Program (CHIP):** A federal program that was established as part of the Balanced Budget Act of 1997 that provides federal funding to states to expand health insurance coverage to children in low-income working families. States can elect to expand coverage for this purpose by expanding eligibility for Medicaid or by creating a new state-operated program.

**State Plan Amendment:** A change in a state's operational outline for its Medicaid program that is submitted to the Health Care Financing Administration for review and approval. In order to receive federal matching payments for Medicaid, a state must submit a state plan that outlines how it will structure



and operate its own Medicaid program. Under the Balanced Budget Act of 1997, states that wish to mandate enrollment in Medicaid managed care no longer are required to receive permission through a waiver (in most cases), but they must still submit a state plan amendment which undergoes far less scrutiny and review.

**Supplemental Security Income (SSI):** Cash assistance program for people with disabilities. Receiving SSI makes an individual a categorically-eligible Medicaid beneficiary. The most common way that people with AIDS qualify for Medicaid is on the basis of receipt of SSI benefits.

**Temporary Assistance for Needy Families (TANF):** Cash assistance program for low income women and children that was created as part of federal welfare reform legislation that was enacted in 1996. All persons who receive TANF benefits are eligible for Medicaid.

**Title XIX of the Social Security Act of 1965:** The federal law that established the Medicaid program and defines the scope and terms of federal support for state Medicaid programs. All of the federal rights and protections that Medicaid beneficiaries have are contained in Title XIX. Title XIX is also called the federal Medicaid statute.

**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 or pre-authorization which requires the approval of the health plan 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; and imposing second opinion requirements in which the treating provider's decision is reviewed by another provider or health plan employee before the health plan will agree to pay for the service or procedure. Various utilization review practices can take place at different stages in the delivery process (i.e. before, during or after a service is provided).

**Waiver:** Title XIX gives the Secretary of Health and Human Services the authority to exempt states from complying with specific provisions of the law. When this exemption is granted it is called a waiver because the federal government is waiving provisions of the law. Generally, waivers have been granted to states in order to exempt them from provisions of the law related to freedom of choice of providers, and requirements that all services be provided throughout the state (statewideness) and that services be provided for all beneficiary categories (comparability). In some cases, waivers have also enabled states to expand eligibility to Medicaid.



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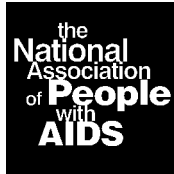
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