

# Trends in Serving People with HIV/AIDS Through Medicaid Managed Care

*3<sup>rd</sup> edition*

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by

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Special thanks also go to Joanne Rawlings-Sekunda, the author of the first two editions of this publication. She played an important role in designing the survey questions, and the structure she developed for the first two editions formed the framework for this report.

Finally, it can be difficult to translate the complexities of continually evolving program operations into standardized survey responses, despite the best efforts of all involved. The authors hope that the analysis provided here, based on survey responses, accurately reflects current state policies. However, any inaccuracies are solely the responsibility of the authors.

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## SIGNIFICANT FINDINGS

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Medicaid is the single largest source of funding for HIV/AIDS care and services in the United States. As a result, Medicaid policies have a significant bearing on how care is delivered to people with HIV/AIDS. This report uses survey data collected by the National Academy for State Health Policy in 1996, 1998, and 2000 from all 50 states and the District of Columbia<sup>1</sup> to examine state policies governing the enrollment of people with HIV/AIDS into risk-based Medicaid managed care programs and the care delivered to these enrollees. Four key findings emerged.

1. Most Medicaid agencies enroll at least some people with HIV or AIDS into managed care.
2. The greatest number of changes in state policies regarding the enrollment and care of people living with HIV or AIDS in risk-based Medicaid managed care occurred between 1996 and 1998—which was also the time of greatest advances in the treatment of HIV/AIDS.
3. States usually address the special needs of people with HIV or AIDS by developing policies that apply to all enrollees with special needs, not just enrollees living with HIV or AIDS.
4. When states do develop HIV or AIDS specific policies, those policies are most likely to focus on reimbursement for the care provided to enrollees with HIV/AIDS.

### **Most Medicaid agencies enroll some or all people with HIV or AIDS into risk-based managed care**

In all three years of the survey, most states reported that they enrolled some or all people with HIV or AIDS into Medicaid managed care. In 2000, 42 states reported enrolling some or all people with HIV or AIDS into risk-based managed care (Figure 1, next page). Among these 42 Medicaid agencies:

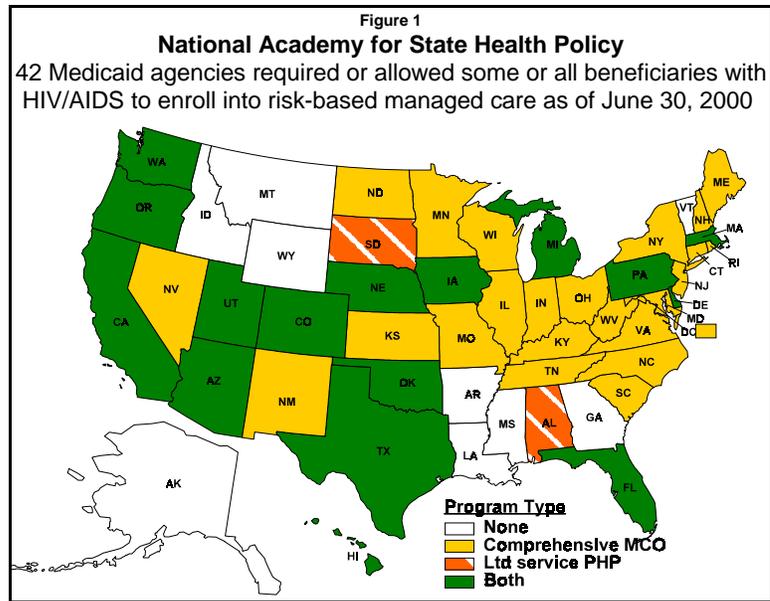
- Forty either required or allowed Medicaid beneficiaries with HIV and/or AIDS to enroll into comprehensive Managed Care Organizations (MCOs).

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<sup>1</sup>Throughout this paper, the 50 states and the District of Columbia are referred to collectively as “the states.” Consequently, the total number of “states” and Medicaid agencies is 51 (not 50).

- Eighteen either required or allowed Medicaid beneficiaries with HIV and/or AIDS to enroll into Prepaid Health Plans (PHPs) that delivered a limited set of services, such as only mental health services.

Finally, states were more likely to require beneficiaries with HIV or AIDS to enroll into PHPs than to require them to enroll into MCOs. All 18 states that enroll beneficiaries with HIV or AIDS into PHPs require at least some beneficiaries with HIV or AIDS to enroll in the program. Only 32 of the 40 states (80 percent) that enroll beneficiaries with HIV or AIDS into comprehensive MCOs require at least some beneficiaries with HIV or AIDS to enroll.



**The greatest number of changes in state policies regarding the enrollment and care of people living with HIV/AIDS in risk-based Medicaid managed care occurred between 1996 and 1998—which was also the time of greatest advances in the treatment of HIV/AIDS.**

In all three survey years some states changed their policies regarding the enrollment and care of people living with HIV/AIDS in risk-based Medicaid managed care. The extent of the changes, however, was much greater between 1996 and 1998 than between 1998 and 2000. This trend corresponds to trends in treatment of the disease. Revolutionary treatments (mostly new drug therapies) were introduced in 1995 and 1996, were widespread by 1998, and are now the standard of care.

- In 1996, 35 states enrolled Medicaid beneficiaries with HIV/AIDS into risk-based managed care (on either a voluntary or mandatory basis). By 1998, this number had increased to 44 states (an increase of nine states between 1996 and 1998). Between 1998 and 2000, however, this number only changed by two, declining to 42 states.
- In 1996, four states used payment mechanisms specifically designed to reimburse health plans for the higher than average cost of serving Medicaid beneficiaries with HIV/AIDS. By 1998, this number had increased to 15 states. Between 1998 and 2000, however, this number only changed by one, declining to 14 states.

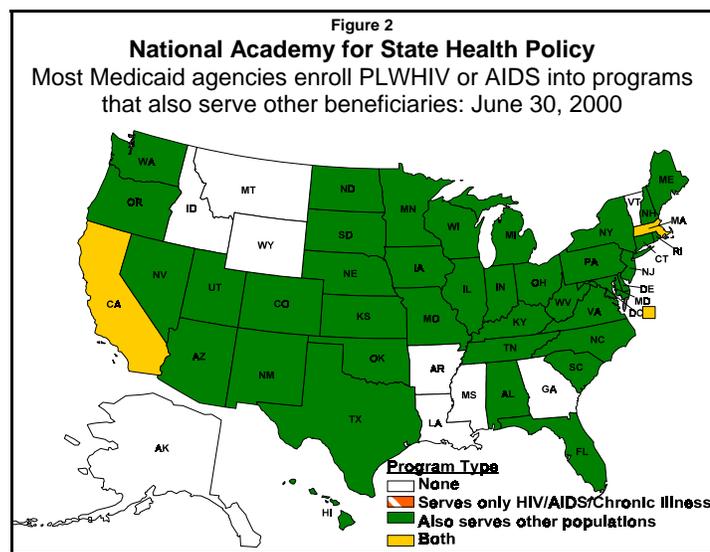
- In 1996, six states had HIV-specific contract requirements regarding the delivery of care. By 1998 this number had increased to 11 states. Between 1998 and 2000 this number remained unchanged.

It is important, of course, to bear in mind that these changes happened in a larger policy environment. Factors other than advances in treatment contributed to changes in Medicaid policies. For example, the decline in the number of states enrolling Medicaid beneficiaries into risk-based managed care between 1998 and 2000 occurred because two states that had enrolled beneficiaries with HIV or AIDS into risk-based managed care in 1998 no longer enrolled any Medicaid beneficiary into Medicaid managed care in 2000. These two states had dismantled their risk-based programs entirely and implemented or expanded Primary Care Case Management (PCCM) programs, a non-risk form of managed care. Since this report focuses on risk-based Medicaid managed care, it does not examine these phenomenon. Nor does it examine other Medicaid issues relevant to delivering care to beneficiaries with HIV or AIDS that are not related to managed care, such as changes to fee-for-service prescription drug coverage, the eligibility expansions that occurred in a few states, and disease management programs such as the HIV-specific programs operating in California, Florida, and New Mexico.

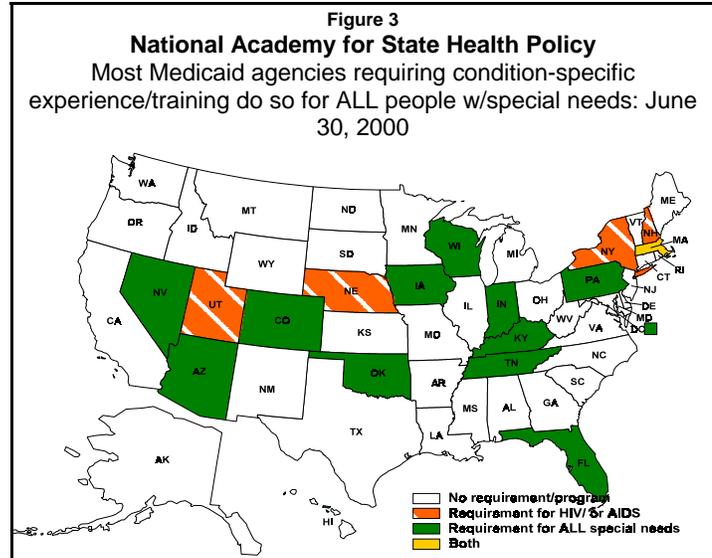
**States usually address the special needs of people with HIV/AIDS by developing policies that apply to all enrollees with special needs, not just enrollees living with HIV/AIDS.**

In many cases, states do not develop special policies specifically to meet the needs of people living with HIV/AIDS. Rather, states tend to establish policies to address the needs of all enrollees with special needs, including those with HIV/AIDS. States may take this more general approach because, although Medicaid serves most people with HIV/AIDS, probably less than one percent of Medicaid beneficiaries are people living with HIV/AIDS. In addition, Medicaid serves people with many other chronic illnesses or disabilities. Medicaid agencies need to design policies and programs that meet the needs of all of these people. For example, in 2000:

- All 42 Medicaid agencies with risk-based managed care enrolled people with HIV/AIDS into programs that served them along with other beneficiaries; two states enrolled them into programs specially designed to serve only people with HIV or AIDS (Figure 2).



- Five states had condition-specific risk-sharing arrangements in place to compensate health plans for the higher than average cost of serving enrollees with HIV/AIDS; 31 had general risk-sharing arrangements in place to compensate plans for the higher than average cost of serving Medicaid beneficiaries with HIV/AIDS—as part of a larger group of beneficiaries.

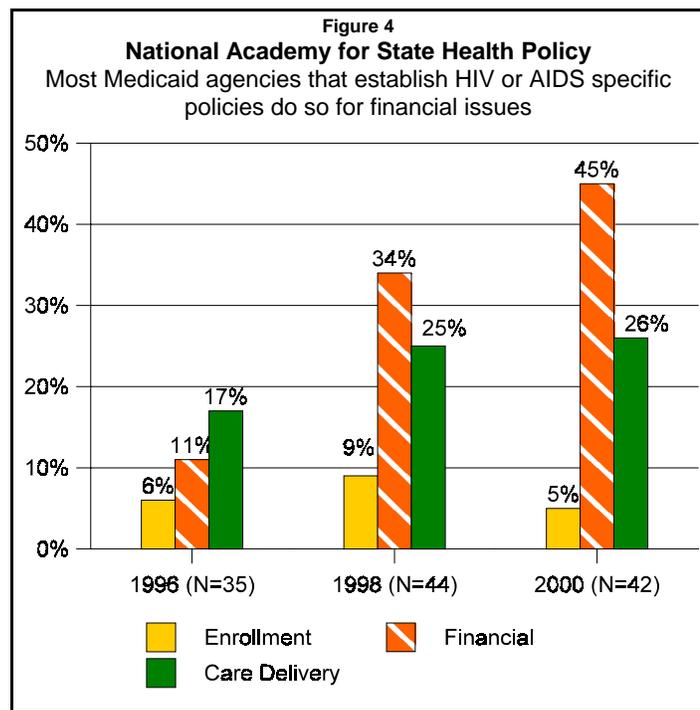


- Four Medicaid agencies required plans to provide enrolled Medicaid beneficiaries with HIV/AIDS with access to primary care providers experienced in the treatment of the condition; 15 states required plans to provide enrollees with special needs (including those with HIV/AIDS) with access to experienced providers (Figure 3).

One factor that may influence whether a state chooses to implement HIV- or AIDS-specific policies may be the relative incidence of AIDS within the state. For example, among the 11 states reporting HIV-specific contract requirements, seven are ranked in the top third of states in terms of the number of people living with AIDS at the end of 1999. (Note: This number ranges from a high of 54,971 people in New York to 44 in North Dakota.)

**When states do develop HIV or AIDS specific policies they are most likely to develop policies regarding payment for the care provided to enrollees with HIV/AIDS.**

While most states do not have special policies in place for Medicaid beneficiaries living with HIV/AIDS, when they do develop HIV/AIDS-specific policies they are most likely to develop specialized financial policies.



(Figure 4.) For example, as of June 30, 2000:

- Nineteen states had HIV/AIDS-specific financial arrangements (capitation payment adjusted for higher cost of treating HIV or AIDS, risk-sharing, or drug carve-out).
- Eleven states had HIV/AIDS specific contract requirements addressing service delivery.
- Two states enrolled people with HIV/AIDS into risk-based managed care programs specifically developed to serve them.

## INTRODUCTION

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Medicaid is the largest source of public funding for HIV/AIDS care and assistance in the United States. In Federal Fiscal Year (FY) 2001, Medicaid spent \$6.9 billion on HIV/AIDS care and assistance, about \$3.7 billion in federal funding and \$3.1 billion in state funding.<sup>2</sup> The federal share of Medicaid provides 26.6 percent of the total \$10 billion in federal funds spent on HIV/AIDS care and assistance and more than any other federal program, including the Ryan White CARE Act programs (which spent \$1.8 billion).<sup>3</sup> Also, Medicaid serves about 55 percent of all people with AIDS and up to 90 percent of all children with AIDS (about 218,000 people in FY 2002).<sup>4</sup>

Medicaid funds much of the care provided to most people with HIV/AIDS. It is important to remember, however, that the amount spent on HIV/AIDS care and assistance (about \$6.9 billion in FY 2001) is only a little over 3 percent of the total cost of providing Medicaid services to all beneficiaries (a projected \$226.1 billion for FY 2001).<sup>5</sup> The 218,000 individuals with AIDS who are covered by Medicaid is a small fraction of the total 36.6 million served by the program as of June 30, 2001, the most recent estimate available from the Centers for Medicaid & Medicare Services (CMS).<sup>6</sup> Although the 218,000 does not include the number of beneficiaries diagnosed with HIV who do not have AIDS, the number of those with HIV or AIDS would likely still be small when compared to the total number of Medicaid beneficiaries.

Because Medicaid pays for much of the care delivered to people with HIV/AIDS, Medicaid policies have a major impact on how care is delivered to people with HIV/AIDS. In 2000, 41 states and the District of Columbia<sup>7</sup> enrolled Medicaid beneficiaries living with HIV/AIDS into

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<sup>2</sup>Office of the Actuary. *2001 Medicaid AIDS Revised Costs*. (CMS: April 2001).

<sup>3</sup>Scott Foster, Piet Niederhausen, and Tim Westmoreland. *Federal HIV/AIDS Spending Fiscal Year 2001: A Budget Chartbook*. (Menlo Park, CA: The Henry J. Kaiser Family Foundation, June 2002).

<sup>4</sup>CMS. Fact Sheet: *Medicaid and Acquired Immunodeficiency Syndrome (AIDS) And Human Immunodeficiency Virus (HIV) Infection*. (CMS: January 2002). <http://www.cms.gov/hiv/hivfs.asp>. (Please note that the 218,000 does not include the number of people diagnosed with HIV who are receiving Medicaid.)

<sup>5</sup>Office of the Actuary. *National Health Expenditures Projections: 2001-2011*. (CMS: March 2002). Table 4. <http://www.cms.hhs.gov/statistics/nhe/default.asp>.

<sup>6</sup>CMS. *2001 Medicaid Managed Care Enrollment Report*. (CMS: Undated). <http://www.cms.gov/medicaid/managedcare/mmcss01.asp>.

<sup>7</sup>Throughout this paper, the 50 states and the District of Columbia are referred to collectively as “the states.” Consequently, the total number of “states” and Medicaid agencies is 51 (not 50).

risk based managed care programs.<sup>8</sup> As a result many Medicaid beneficiaries living with HIV/AIDS are likely to receive their care from health plans. This report is an update of 1996 and 1998 reports examining state policies governing how people with HIV/AIDS are served in risk-based Medicaid managed care. It also examines how these policies have changed since 1996 when the National Academy for State Health Policy (NASHP) published the first edition of this report.

There has been significant progress in treatment of the disease since the first edition of this report was produced in 1996, and these developments have affected Medicaid managed care policies. During this time, treatment standards have developed and become widely accepted. In particular, three developments have led to decreased numbers of death:

- combination therapy, which calls for the use of expensive antiretrovirals and/or protease inhibitors;<sup>9</sup>
- new treatments for the opportunistic infections that often accompany AIDS; and
- better methods to prevent the spread of HIV.

As a result of these advances HIV/AIDS is now often considered a chronic disease that physicians can manage with medications. However, due to a variety of reasons that include a lack of access to health insurance and/or an HIV infection that goes undiagnosed, not all people with HIV/AIDS are receiving these treatments.

States, while seeking to provide appropriate care for people with HIV/AIDS, must reconcile the complex health care needs of multiple populations within the parameters of one (or a few) programs.<sup>10</sup> This challenge is becoming even more difficult as many states face budget shortfalls and Medicaid costs continue to grow. In response some states are developing new tools to

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<sup>8</sup>Please refer to Appendix A for an overview of the types of managed care that Medicaid agencies can use and the authorities under which they can require Medicaid beneficiaries to enroll in managed care.

<sup>9</sup>Department of Health and Human Services, *Guidelines for Use of Antiretroviral Agents HIV-infected Adults and Adolescents*. Jan 2000, <http://www.hivatis.org>.

<sup>10</sup>According to the Centers for Medicare and Medicaid Services (CMS), Medicaid served over 33 million people in 2000. Medicaid is jointly funded by the federal and state governments to provide medical care to low-income persons. While each state establishes its own eligibility standards, eligible populations typically include: poor families, poverty-level pregnant woman, poverty-level children, poor elderly people, and SSI beneficiaries. Some or all of these populations may be enrolled in risk-based managed care programs in a particular state.

contain costs, and some are taking advantage of flexibility within federal requirements to tailor their programs to better meet their needs and situations. For example,

- Arizona and California have obtained Health Insurance Flexibility and Accountability (HIFA) waivers. HIFA is a newly developed Medicaid and State Children's Health Insurance Program (SCHIP) §1115 waiver approach. Waivers that meet certain requirements (that expand access, coordinate with private insurance, etc.) may use a streamlined application.<sup>11</sup>
- Other states, such as Utah, have used traditional §1115 waivers to expand a limited Medicaid benefit to some new eligibles while reducing the benefits offered to some current Medicaid beneficiaries.<sup>12</sup>
- The District, Maine, and Massachusetts have received approval of §1115 waivers to expand Medicaid to serve low-income people with HIV who would not otherwise qualify for Medicaid because they do not meet the SSI definition of disabled.<sup>13</sup>
- At least 13 states have also implemented Home and Community Based (§1915(c)) waivers that serve people with HIV or AIDS. These waivers allow people who would normally need to enter a nursing home to qualify for Medicaid to qualify while remaining in the community.<sup>14</sup>
- The District and Mississippi have both been awarded demonstration grants from CMS under §204 of the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIA) authorizing them to provide Medicaid benefits and services to up to 500 workers with HIV/AIDS that, without medical assistance, would likely result in disability.<sup>15</sup>

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<sup>11</sup>CMS Website, *Approved HIFA Demonstrations*. <http://www.cms.gov/hifa/hifaadem.asp>. Downloaded August 19, 2002.

<sup>12</sup>CMS Website, *State Waiver Programs and Demonstrations*. <http://www.cms.gov/medicaid/waivers/waivermap.asp>. Downloaded August 19, 2002.

<sup>13</sup>Ibid.

<sup>14</sup>CMS Website. *Home and Community-Based Services 1915(c) Waivers*. <http://www.cms.gov/medicaid/services/1915chcbw.asp>. Downloaded August 19, 2002. Note: This is the number of waivers that specify those with HIV or AIDS as the target population. Other states cover groups, such as all people with physical disabilities, that likely include people with HIV or AIDS.

<sup>15</sup>CMS Website. *Demonstration to Maintain Independence and Employment*. <http://www.cms.gov/twwia/independ.asp>, Downloaded August 19, 2002.

- States can, under two federal authorities, cover working people with disabilities (including those with HIV/AIDS) who, because of their earnings or resources, cannot qualify for Medicaid under other statutory provisions. These include:
  - Under §4733 of the Balanced Budget Act of 1997 (BBA), 11 states<sup>16</sup> have opted to cover all people with disabilities who have family incomes of 250 percent FPL or less.
  - Under TWIIA, 15 states<sup>17</sup> have opted to cover one or both of the following groups: (1) people age 16 through 64 who meet the SSI disability definition up to any income or resource limit established by the state for this population; and (2) employed individuals with a medically improved disability who lose Medicaid eligibility under the group described above because they no longer meet the SSI definition of disability.

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<sup>16</sup>National Association of State Medicaid Directors. *Medicaid Buy-in Update*. Downloaded August 19, 2002. <http://disabilities.aphsa.org/Resource%20Directory/MedicaidBuyIn.htm>.

<sup>17</sup>Ibid.

## METHODOLOGY

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Every two years NASHP conducts an extensive survey of the 50 states, plus the District of Columbia, on the scope and operations of Medicaid managed care programs. (The results of these surveys are analyzed in *Medicaid Managed Care: A Guide for States*.)<sup>18</sup>

In developing the 2000 survey, a group composed of state and federal officials, as well as other experts reviewed the 1998 survey and suggested revisions to capture topics of new interest. The revised draft was then piloted by four states in June 2000, and further refinements were made as a result of these pilots.

NASHP staff distributed the survey and made follow-up calls to collect accurate and complete data. All 50 states and the District of Columbia responded to the survey. States provided information on their programs as of June 30, 2000. This paper focuses on three major areas: enrollment, financing, and contract requirements:

- The enrollment section examines whether people with HIV/AIDS are enrolled voluntarily or mandatorily, and whether HIV/AIDS-specific programs/plans are available.
- The finance section looks at prospective risk-adjusting capitation rates, retrospective risk-sharing mechanisms, and drug carve-out policies.
- The contract requirement section discusses such issues as care management/care coordination, quality monitoring, keeping up with clinical standards, primary care physician HIV/AIDS experience and education, allowing specialists as primary care providers, and allowing standing referrals to specialists.

The data examined in this report are drawn from state responses to both:

1. Questions seeking information on policies specific to people with HIV/AIDS (Table 1);
2. Questions seeking information on policies developed for the general Medicaid population on issues that are particularly important to people living with HIV/AIDS (PLWH/A), such as care coordination requirements.

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<sup>18</sup>The most recent of the *Guides* is the Fifth Edition, authored by Neva Kaye, May 2001. For more information, contact the National Academy for State Health Policy at 207-874-6524 or [www.nashp.org](http://www.nashp.org).

**Table 1 HIV/AIDS related topics in 1996, 1998, and 2000 surveys of state Medicaid managed care policies<sup>19</sup>**

1996	1998	2000
Enrollment of people with HIV/AIDS into programs serving all Medicaid populations (either mandatory or voluntary)	Same	Same
Enrollment of people with HIV/AIDS into programs specifically targeted to this population (either mandatory or voluntary)	Same	Same
Contractual language about reimbursement mechanisms specific to HIV/AIDS	Same	Clarified 1996/98 question by inquiring about risk-sharing mechanisms instead of reimbursement mechanisms
Designing capitation rates specifically for HIV/AIDS	Divided 1996 question into: <ul style="list-style-type: none"> <li>• Rate category for HIV/AIDS within a comprehensive risk-adjustment system</li> <li>• Risk-adjusting rates for HIV/AIDS without a comprehensive system</li> <li>• Methods for identifying persons for whom the risk-adjusted rate applies</li> </ul>	Same
Special provisions within contracts regarding the care delivered to people with HIV/AIDS	Divided 1996 question into: <ul style="list-style-type: none"> <li>• Keeping up with changing clinical standards</li> <li>• following state-specified clinical protocols</li> <li>• Primary care provider HIV/AIDS-specific experience</li> <li>• Primary care provider HIV/AIDS-specific education</li> <li>• Case management/care coordination</li> <li>• Quality monitoring/quality indicators</li> </ul>	Same
Contractual language requiring health plans to provide AZT during pregnancy	Not included	Not included
	New in 1998: Carve-outs for HIV/AIDS drugs	Same
	New in 1998: Adjusting capitation rates for HIV/AIDS drugs	Same

<sup>19</sup> Please refer to the two previous editions of this report (published in 1997 and 1999) for specific responses to the survey questions posed in 1996 and 1998.

## Definitions

Several terms are used throughout this report and are defined here:

**Risk-based managed care** includes both comprehensive Managed Care Organizations (MCOs) and non-comprehensive Prepaid Health Plans (PHPs).

- A **comprehensive MCO** is a health plan that delivers a comprehensive range of Medicaid covered services and is often referred to as a Health Maintenance Organization (HMO).
- **PHPs** are health plans that deliver a limited set of services, such as only behavioral health or only dental services.

Some states operate Primary Care Case Management (**PCCM**) programs. These are non-risk managed care programs under which a physician or group of physicians agrees to manage the care provided to enrolled Medicaid beneficiaries but accepts no financial risk for the services provided. The PCCM providers are, however, often paid a small per enrollee per month care management fee (\$2 to \$3 usually). These programs are not examined in this report except as they relate to the enrollment options available to people living with HIV/AIDS.

There are also several pathways to Medicaid eligibility for people with HIV or AIDS.<sup>20</sup> Two of these are examined in this report.

- **SSI:** This population consists of low-income people who are elderly ("aged"), blind, or disabled.<sup>21</sup> SSI has been the traditional route to Medicaid eligibility for people with HIV/AIDS and the overwhelming majority of these beneficiaries have AIDS, although people with asymptomatic HIV infection may qualify for SSI because they have another disability. It is also important to note that in most states, SSI coverage is also the only route to Medicaid coverage that is open to single adults or childless couples.
- **Family Coverage:** This term refers to people who receive Medicaid because they are members of poor families. This group would include few people with AIDS, and they would be more likely to be in the earlier stages of the disease, either not yet qualifying for SSI because their condition is not yet severe enough or waiting for their SSI application to be approved.

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<sup>20</sup>Some states also include people living with HIV/AIDS in optional "expansion" populations. For example, in Tennessee, Medicaid also covers people with HIV/AIDS as part of an expansion population defined as "uninsured/uninsurable."

<sup>21</sup>States also have the option of including people who "spend down" in Medicaid eligible populations. These are people whose income is too high to be eligible for Medicaid unless their medical expenses are subtracted.

Two Medicaid populations have not been included in this report, due to the small numbers of people with HIV or AIDS within them: people over age 65 and children participating in SCHIP (State Children's Health Insurance Programs).

## ENROLLMENT

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As of June 30, 2000, 42 states (including the District of Columbia) reported enrolling people living with HIV or AIDS (PLWH/A) in their risk-based Medicaid managed care programs (Table 2; Figure 1). This is 100 percent of all states operating risk-based Medicaid managed care programs.<sup>22</sup> The proportion increased since 1998, when 98 percent of risk-based programs (in 44 of 45 states) reported their enrollment, and since 1996, when 92 percent (35 of 38 states) did so. Policymaker's questions about enrollment of PLWH/A, however, go beyond whether or not they are enrolled into Medicaid managed care. Policymakers are also interested in:

- the types of managed care programs that serve Medicaid beneficiaries with HIV/AIDS;
- the groups of Medicaid beneficiaries that can be enrolled in these plans (those eligible because they belong to poor families and/or those eligible due to disability); and
- the extent to which people with HIV/AIDS can choose their delivery system.<sup>23</sup>

Table 2 provides detailed information from the 2000 survey about these issues, while the remainder of this section analyzes the detailed data and identifies trends in program policy throughout the three surveys (1996, 1998, and 2000). The enrollment models identified in the table are defined as follows moving from least to most mandatory.

1. **Voluntary** programs are those in which a beneficiary will remain on fee-for-service unless he or she chooses risk-based managed care.
2. Programs that operate as a **voluntary alternative to PCCM** are those in which a beneficiary will be enrolled with a PCCM provider unless he or she chooses a comprehensive MCO.
3. Programs that operate as **mandatory with a PCCM option** are those in which a beneficiary will be enrolled with a comprehensive MCO and/or PCCM unless he or she chooses the PCCM.
4. **Mandatory** programs are those in which a beneficiary is required to enroll into risk-based managed care.

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<sup>22</sup>A total of 42 states operate risk-based managed care programs. Seven states (Arkansas, Georgia, Idaho, Louisiana, Mississippi, Montana, and Vermont) operate PCCM programs only. Two others (Alaska and Wyoming) do not have Medicaid managed care at all.

<sup>23</sup>Other issues of importance to beneficiaries with HIV or AIDS that are not addressed in this report include the factors considered when assigning beneficiaries to plans (in mandatory programs) and how often beneficiaries can change plans without cause.

The remainder of this analysis classifies models 1 and 2 as voluntary for risk-based managed care because a beneficiary is only enrolled into risk-based managed care if he or she chooses. Models 3 and 4 are classified as mandatory because a beneficiary may be enrolled in risk-based managed care without choosing that option.

**Table 2 HIV/AIDS enrollment in risk-based managed care as of June 30, 2000**

State	Specially Targeted Program	Comprehensive MCO Program Serving All Medicaid Populations Enrolls:		PHP Program Serving All Medicaid Populations Enrolls:	
		Family Coverage	SSI (non-elderly)	Family Coverage	SSI (non-elderly)
AL <sup>24</sup>				Mandatory	Mandatory
AZ <sup>25</sup>		Mandatory	Mandatory	Mandatory	Mandatory
CA <sup>26</sup>	Voluntary	Mandatory/Voluntary	Mandatory/Voluntary	Mandatory/Voluntary	Mandatory/Voluntary
CO <sup>27</sup>		Mandatory with PCCM option	Mandatory with PCCM option	Mandatory	Mandatory
CT		Mandatory	Mandatory/Voluntary <sup>28</sup>		
DE <sup>29</sup>		Mandatory	Mandatory	Mandatory	Mandatory
DC	Voluntary <sup>30</sup>	Mandatory			
FL		Mandatory with PCCM option	Mandatory with PCCM option	Mandatory	Mandatory

<sup>24</sup>Alabama operates a PHP program that delivers maternity care. All pregnant beneficiaries must enroll in this program regardless of eligibility category.

<sup>25</sup>Arizona has two PHP programs: (1) behavioral health and (2) long term care. People living with HIV/AIDS may be enrolled in either, depending on their needs.

<sup>26</sup>In California the mandatory/voluntary nature of the program varies based on county of residence. Also, California has two PHP programs: (1) behavioral health and (2) dental. People living with HIV/AIDS may be enrolled in either, depending on their needs. Finally, California has a specially targeted program in one county that serves only people living with HIV/AIDS.

<sup>27</sup>Colorado has a behavioral health PHP program.

<sup>28</sup>In Connecticut, enrollment is mandatory for SSI children until they become SSI adults who are not enrolled in managed care.

<sup>29</sup>In Delaware those who qualify for the AIDS waiver are excluded from managed care. Delaware operates a behavioral health PHP in which the contractor is another state agency.

<sup>30</sup>The District contracts with a comprehensive MCO to provide care to children with special needs (SSI children) on a voluntary basis.

State	Specially Targeted Program	Comprehensive MCO Program Serving All Medicaid Populations Enrolls:		PHP Program Serving All Medicaid Populations Enrolls:	
		Family Coverage	SSI (non-elderly)	Family Coverage	SSI (non-elderly)
HI <sup>31</sup>		Mandatory		Mandatory	
IA		Mandatory with PCCM option		Mandatory	Mandatory
IL		Voluntary			
IN <sup>32</sup>		Mandatory with PCCM option			
KS		Voluntary alternative to PCCM			
KY		Mandatory	Mandatory		
MA <sup>33</sup>	Voluntary	Mandatory	Voluntary alternative to PCCM	Mandatory (if select PCCM)	Mandatory (if select PCCM)
MD		Mandatory	Mandatory		
ME <sup>34</sup>		Voluntary			
MI		Mandatory	Mandatory	Mandatory	Mandatory
MN <sup>35</sup>		Mandatory			
MO		Mandatory <sup>36</sup>			

<sup>31</sup>Hawaii, in addition to its comprehensive MCO program, operates dental and behavioral health PHPs. Beneficiaries living with HIV/AIDS are mandatorily enrolled in all three programs.

<sup>32</sup>Indiana's specially targeted program for SSI beneficiaries ended in December 1999. In Indiana, Medicaid beneficiaries choose or are assigned to primary care providers (PCPs). If the beneficiary's PCP participates in a comprehensive MCO the beneficiary joins that plan. If, however, the PCP participates as a PCCM provider the beneficiary joins the PCCM program.

<sup>33</sup>In addition to its specialty program, Massachusetts operates a comprehensive MCO program, PCCM program, and a PHP program that delivers behavioral health care. Family coverage beneficiaries are mandatorily enrolled into comprehensive MCOs; they must choose an MCO or PCCM provider or be assigned to an HMO. SSI beneficiaries must choose an MCO or PCCM provider or be assigned to a PCCM provider; the comprehensive MCO program is a voluntary alternative to a mandatory MCO. All beneficiaries enrolled with PCCM providers must obtain behavioral health care from the behavioral health PHP. Finally, all family coverage and SSI beneficiaries that meet clinical criteria may choose the specialty HIV/AIDS program as an alternative to either the MCO or PCCM.

<sup>34</sup>Maine's comprehensive risk program was phased out in State Fiscal Year 2001.

<sup>35</sup>In Minnesota, people with AIDS who belong to the family coverage group are not enrolled in managed care, but people with HIV who belong to that same group are required to enroll.

<sup>36</sup>Missouri excludes people that join their AIDS waiver.

State	Specially Targeted Program	Comprehensive MCO Program Serving All Medicaid Populations Enrolls:		PHP Program Serving All Medicaid Populations Enrolls:	
		Family Coverage	SSI (non-elderly)	Family Coverage	SSI (non-elderly)
NC <sup>37</sup>		Mandatory/Mandatory with PCCM option	Mandatory/Mandatory with PCCM option		
ND		Voluntary alternative to PCCM			
NE <sup>38</sup>		Mandatory with PCCM option	Mandatory with PCCM option	Mandatory	Mandatory
NH		Voluntary			
NJ		Mandatory	Voluntary		
NM		Mandatory	Mandatory		
NV <sup>39</sup>		Mandatory/Voluntary			
NY		Voluntary	Voluntary		
OH		Mandatory			
OK <sup>40</sup>		Mandatory	Mandatory	Mandatory	Mandatory
OR <sup>41</sup>		Mandatory	Mandatory	Mandatory	Mandatory
PA <sup>42</sup>		Mandatory/Voluntary	Mandatory/Voluntary	Mandatory	Mandatory
RI		Mandatory			
SC		Voluntary	Voluntary		
SD <sup>43</sup>				Mandatory	Mandatory
TN		Mandatory	Mandatory		

<sup>37</sup>In North Carolina, beneficiaries with HIV/AIDS must choose an HMO or PCCM provider, except in Mecklenburg County where they must choose an HMO.

<sup>38</sup>Nebraska operates a behavioral health PHP in which all family coverage and SSI beneficiaries must enroll.

<sup>39</sup>In Nevada the program is mandatory or voluntary based on beneficiary residence.

<sup>40</sup> Oklahoma operates a PHP program that delivers only physician and laboratory services.

<sup>41</sup>Oregon operates both dental and behavioral health PHPs.

<sup>42</sup>Pennsylvania HealthChoices is mandatory. Beneficiaries must choose both a physical health plan (comprehensive MCO) and a behavioral health plan (PHP). It operates in most areas of the state, including Pittsburgh and Philadelphia. Voluntary managed care operates in other parts of the state and includes comprehensive MCOs and a PCCM program, but does not include a PHP.

<sup>43</sup>South Dakota operates a dental PHP.

State	Specially Targeted Program	Comprehensive MCO Program Serving All Medicaid Populations Enrolls:		PHP Program Serving All Medicaid Populations Enrolls:	
		Family Coverage	SSI (non-elderly)	Family Coverage	SSI (non-elderly)
TX <sup>44</sup>		Mandatory with PCCM option	Mandatory with PCCM option	Mandatory	Mandatory
UT <sup>45</sup>		Mandatory/Voluntary	Mandatory/Voluntary	Mandatory	Mandatory
VA <sup>46</sup>		Mandatory/Voluntary alternative To PCCM	Mandatory/Voluntary alternative To PCCM		
WA <sup>47</sup>		Mandatory		Mandatory	Mandatory
WI <sup>48</sup>		Voluntary	Voluntary		
WV		Mandatory <sup>49</sup>			
# states w/ program	Mandatory-0 Voluntary-3 Either-3 <sup>50</sup>	Mandatory-32 Voluntary-13 Either-40	Mandatory-19 Voluntary-10 Either-24	Mandatory-18 Voluntary-1 Either-18	Mandatory-17 Voluntary-1 Either-17

In general, there was little change in enrollment policies for PLWH/A between 1998 and 2000. The greatest change was not specific to PLWH/A: four states no longer enroll any Medicaid beneficiary into risk-based managed care. Also, this report once again found that most beneficiaries who are PLWH/A are enrolled into the same risk-based managed care plans into

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<sup>44</sup>Texas operates three managed care programs, none of which operate in all areas of the state. (1) STAR includes both comprehensive MCOs and a PCCM program and is mandatory for family coverage groups. These beneficiaries are assigned to a comprehensive MCO if they do not choose either an MCO or a PCCM provider. SSI groups may voluntarily join the program or remain on fee-for-service. Dual eligibles may not enroll in this program. (2) STAR+PLUS includes both a comprehensive MCO and a PCCM program. Aged and SSI beneficiaries must choose a comprehensive MCO; except, those SSI children and MR adults may choose a PCCM provider instead of an MCO. (3) NORTHSTAR is a behavioral health PHP that is mandatory for all beneficiaries where the program is available.

<sup>45</sup>In Utah, comprehensive MCOs are mandatory in urban areas and voluntary in rural areas. Also, Utah operates a mandatory behavioral health PHP program.

<sup>46</sup> In Virginia enrollment in a comprehensive MCO is mandatory in some parts of the state while in others, beneficiaries must select a comprehensive MCO or PCCM provider or be assigned to a PCCM provider. Also, beneficiaries who qualify for the state's AIDS waiver are disenrolled from managed care.

<sup>47</sup>Washington operates a behavioral health PHP.

<sup>48</sup>In Wisconsin, enrollment of all beneficiaries with HIV/AIDS is voluntary. Those who belong to family coverage groups are disenrolled upon request; those in SSI groups are enrolled upon request.

<sup>49</sup>West Virginia MCOs do not report any AIDS or HIV cases in enrolled populations.

<sup>50</sup>“Either” is the number of states that have (1) a voluntary program, (2) a mandatory program, or (3) both types of programs.

which other Medicaid beneficiaries are enrolled. This may relate to the relatively low percent of Medicaid beneficiaries who are PLWH/A (less than 1 percent).<sup>51</sup>

## **Trends in the Type of Program into Which Medicaid Beneficiaries with HIV/AIDS are Enrolled**

All 42 states that reported operating a risk-based managed care program for any group of Medicaid beneficiaries enrolled beneficiaries with HIV/AIDS into at least one of their risk-based programs. As in 1996 and 1998 all of these states offer the option of either mandatory or voluntary enrollment in health plans serving all Medicaid beneficiaries (not just people with HIV).

In addition, in 2000, three states reported programs targeted to those with HIV/AIDS or chronic illnesses/disabilities.<sup>52</sup> All three of these programs will enroll Medicaid beneficiaries with HIV/AIDS on a voluntary basis, and all three are among those states that had the highest number of people living with AIDS at the end of 1999. Specifically, California ranked second among all states in terms of the number of PLWA, Massachusetts was tenth, and the District was eleventh.<sup>53</sup>

- In California,<sup>54</sup> the AIDS Healthcare Foundation serves approximately 3,000 people, from those recently diagnosed with HIV to those with advanced cases of AIDS, through four outpatient clinics in Los Angeles, as well as hospice, skilled nursing, and transitional care programs. Each client chooses a primary care provider; a registered nurse case manager is assigned based on the client's choice of clinic.
- In Massachusetts, Community Medical Alliance serves people with active or advanced AIDS or other severe disabilities. Because the plan receives a special capitation rate from the state, all enrollees must meet certain health-related criteria. Clients often have complicated medical conditions in addition to AIDS. Each client chooses a primary care physician; a nurse practitioner case manager is assigned based on area of residence.

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<sup>51</sup>See Notes 4 and 6.

<sup>52</sup>It is important to note that some plans serving all types of Medicaid beneficiaries may have their own HIV-specific internal programs, providing such services as case management or specialized clinics/providers within the network.

<sup>53</sup>The Kaiser Family Foundation. State Health Facts On-Line. Accessed August 20, 2002. <http://www.statehealthfacts.kff.org>.

<sup>54</sup>Joanne Rawlings Sekunda and Neva Kaye. *Emerging Practices and Policy in Medicaid Managed Care for People with HIV/AIDS: Case Studies of Six Programs*. (National Academy for State Health Policy, Portland, ME: August 1998).

- The District contracts with an MCO to provide services to children with special health care needs, including those with HIV/AIDS. Children must meet medical criteria in order to qualify for the program.

The number of states with specially targeted programs declined from four to three between 1998 and 2000. Three states, however, changed their practices during this time.

- Indiana and Ohio dismantled their specialty programs; and
- The District reported enrolling children with HIV/AIDS into its specialty program in 2000 but did not do so in 1998.

For the first time, this report examines the type of program into which Medicaid beneficiaries with HIV/AIDS could be enrolled, as well as whether they were required to enroll into these programs. Among these 42 states:

- Forty states enroll people with HIV/AIDS into comprehensive MCOs. That is 95 percent of states that enroll people with HIV/AIDS into risk-based managed care and all states that contract with comprehensive MCOs to serve any Medicaid population.
- Eighteen states enroll people with HIV/AIDS into one or more PHPs<sup>55</sup> delivering a less than comprehensive package of services.<sup>56</sup> This amounts to 43 percent of all states with risk-based managed care and 82 percent of the 22 states that contract with PHPs to serve any Medicaid population. The specific types of service that beneficiaries with HIV/AIDS in the 18 states that enroll them into PHPs could obtain from the PHP are as follows:
  - S Alabama enrolls them into a PHP that delivers only maternity care.
  - S Arizona enrolls them into a program that delivers only long term care services.
  - S Oklahoma enrolls them into a PHP that delivers physicians' and laboratory services.
  - S Four states enroll them into a PHP that delivers only dental services (California, Hawaii, Oregon, and South Dakota).

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<sup>55</sup>Note: Four states (Arizona, California, Hawaii, and Oregon) enroll beneficiaries into more than one type of PHP. Arizona enrolls beneficiaries into both long term care and behavioral health PHPs. The other three states enroll beneficiaries into both dental and behavioral health PHPs.

<sup>56</sup>Note: Medicaid beneficiaries who are enrolled into PHPs continue to receive the complete Medicaid benefit package. Medicaid agencies usually pay providers directly (through their fee-for-service systems) for services that are not covered by the PHP. In some states, however, it is possible that someone could receive dental care from a dental PHP, behavioral health care from a behavioral health PHP, and all other Medicaid services from an MCO.

- S Fifteen states enroll them into a PHP that delivers only behavioral health services (Arizona, California, Colorado, Delaware, Florida, Hawaii, Iowa, Massachusetts, Michigan, Nebraska, Oregon, Pennsylvania, Texas, Utah, and Washington).

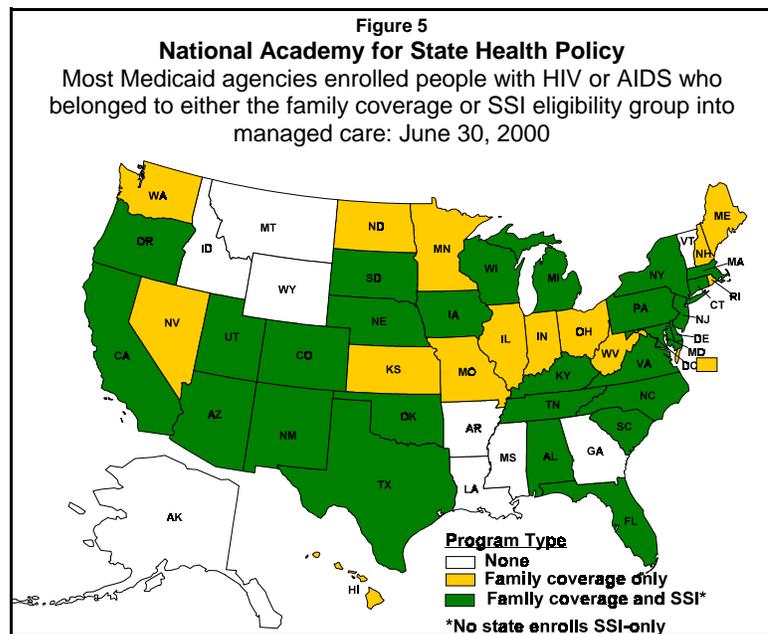
## Trends in the Groups of Medicaid Beneficiaries With HIV/AIDS Enrolled in Medicaid Managed Care and Degree of Choice in Enrollment

The number and percent of states enrolling family coverage only or also enrolling those who qualify for Medicaid due to disability (SSI) remained stable between 1998 and 2000.

- In 2000, all 42 states enrolling any PLWH/A into risk-based Medicaid managed care enrolled those with HIV/AIDS who qualified for Medicaid under family coverage. The situation in 1998 was the same; all 44 states enrolling any beneficiary with HIV/AIDS into risk-based Medicaid managed care enrolled those who qualified for Medicaid under family coverage.
- In 2000, 25 of the 42 states (60 percent) enrolling any beneficiary with HIV/AIDS into risk-based Medicaid managed care enrolled those who qualified for Medicaid due to disability (SSI), while in 1998, 28 of 44 states (64 percent) did so.

Many of the changes that occurred between 1998 and 2000 resulted from the eight states that implemented or ended a risk-based managed care program entirely.

- Four states (Georgia, Mississippi, Montana, and Vermont) reported that they did not enroll any beneficiary with HIV/AIDS into general risk based managed care in 2000 although they reported doing so in 1998.
- North Dakota and South Dakota reported that they enrolled people with HIV/AIDS into risk-based managed care in 2000, but did not report doing so in 1998.
- Indiana and Ohio reported voluntary programs for





**Table 3 States that continued to operate risk-based managed care programs in 2000 but changed enrollment policies between 1998 and 2000.**

State	Description of Change in Policy
<b>Beneficiaries more likely to be enrolled into risk-based managed care without choosing that option</b>	
NC	<ul style="list-style-type: none"> <li>• North Carolina operates both a PCCM program and risk-based managed care in some parts of the state.               <ul style="list-style-type: none"> <li>S In 1998, those beneficiaries who did not choose a managed care option were assigned to a PCCM provider.</li> <li>S In 2000, those beneficiaries who did not choose a managed care option were enrolled into risk-based managed care.</li> </ul> </li> <li>• North Carolina operates only a risk-based managed care program in some parts of the state. In both 1998 and 2000 beneficiaries in those parts of the state were required to enroll into risk-based managed care.</li> </ul>
NV	<p>Nevada operates a risk-based managed care program that serves only beneficiaries who belong to the family coverage group.</p> <ul style="list-style-type: none"> <li>• In 1998, Nevada did not require any PLWH/A to enroll into risk-based managed care.</li> <li>• In 2000, this state required PLWH/A who lived in some parts of the state and belonged to the family coverage group to enroll into risk-based managed care, while those who lived in other parts of the state were only enrolled in risk-based managed care when they chose that option.</li> </ul>
OK	<ul style="list-style-type: none"> <li>• In 1998, Oklahoma required PLWH/A who belonged to the family coverage group to enroll into risk-based managed care, but no SSI beneficiary was enrolled in managed care.</li> <li>• In 2000, Oklahoma continues to require PLWH/A who belonged to the family coverage group to enroll in risk-based managed care <i>and</i> also required those who belonged to the SSI group to enroll.</li> </ul>
<b>Beneficiaries less likely to be enrolled into risk-based managed care without choosing that option</b>	
CT	<ul style="list-style-type: none"> <li>• In 1998, Connecticut required both PLWH/A who belonged to the family coverage group or were children who qualified for Medicaid through SSI to enroll into risk-based managed care.</li> <li>• In 2000, this state continues to require PLWH/A who belong to the family coverage group to enroll, but only enrolls some children with HIV/AIDS who qualify for Medicaid through SSI into risk-based managed care when they choose that option.</li> </ul>
NE	<p>Nebraska operates a PCCM program and also a risk-based managed care program that operates only in urban areas.</p> <ul style="list-style-type: none"> <li>• In 1998, this state's PCCM program did not operate in urban areas and PLWH/A who lived in urban areas and belonged to either the family coverage or SSI groups were required to enroll into risk-based managed care.</li> <li>• By 2000 this state had expanded the PCCM program to include urban areas and PLWH/A who belonged to either group could choose the PCCM program, but were assigned to a comprehensive MCO if they did not choose a managed care option.</li> </ul>
NY	<ul style="list-style-type: none"> <li>• In 1998, PLWH/A in some parts of New York who belonged to the family coverage group were required to enroll into risk-based managed care, while those in other parts of the state, as well as all PLWH/A who belonged to the SSI group were only enrolled into risk-based managed care when they chose that option.</li> <li>• In 2000, no PLWH/A were enrolled into risk-based managed care unless they chose that option.</li> </ul>
TX	<ul style="list-style-type: none"> <li>• In 1998, Texas required PLWH/A who belonged to either the family coverage or SSI groups to enroll in risk-based managed care.</li> <li>• By 2000, Texas had established a PCCM program and allowed PLWH/A who belonged to either the family coverage or SSI group to choose that option. However, those who did not choose a managed care option were assigned to an MCO.</li> </ul>

## FINANCE

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Medicaid beneficiaries with HIV/AIDS typically require more services and are, therefore, more costly to care for than most other Medicaid beneficiaries.<sup>57</sup> In addition, those with HIV/AIDS who are eligible for Medicaid due to disability (SSI beneficiaries) are more likely than those who are eligible because they belong to poor families (family coverage groups) to have infections that have progressed to AIDS.

States typically adjust their capitation payments using demographic factors (age, sex, eligibility, and/or geography). Unfortunately these factors predict little of the costs of populations with complex needs, such as PLWH/A.<sup>58</sup> Inadequate payment to plans to serve PLWH/A could encourage a plan to structure coverage policies to discourage PLWH/A from selecting the plan, because any plan which enrolls a significant number of PLWH/A runs the risk of losing money. For example, since physicians with HIV-experience are often a small, easily-identified group, plans that do not contract with them may meet general access requirements, while avoiding the enrollment of PLWH/A.

State approaches to accommodating the higher than average cost of serving PLWH/A and the potential of selection bias fall into two major categories: risk-adjusting payments and sharing financial risk. Some states adjust payments made to the plan for individual enrollee health status or to accommodate a particular service (such as the cost of HIV drugs). These states are said to risk adjust payments. States may also use one of a number of models to provide extra funding to plans to make up all or some of the difference between the prospective payments the state makes to the plan and the actual cost of serving enrollees. These states are said to risk-share. Some states both risk-adjust payment and risk share. In 2000, 35 (83 percent) of the 42 Medicaid agencies that enroll PLWH/A into risk-based managed care either risk adjust plan payments or share financial risk with health plans. Among these 35 states:

- fourteen (40 percent) risk-adjust plan payments (Table 4, page 25);
- five (14 percent) have HIV-specific risk sharing arrangements (page 30);
- thirty-one (88 percent) have generic risk-sharing mechanisms in place that would accommodate the cost of serving PLWH/A in addition to other groups of beneficiaries with higher than average costs (Table 7, page 32); and
- seven (20 percent) do not hold plans responsible for paying for HIV drugs and instead the Medicaid agency pays providers directly for the drugs (Table 8, page 34).

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<sup>57</sup>GAO, *HIV/AIDS Drugs: Funding implications of new combination therapies for federal and state programs*, GAO/HEHS-99-2, 1998.

<sup>58</sup>U.S. Bureau of Census, *Profile of General Demographic Characteristics*, 2000.

**Table 4 HIV/AIDS-related payment mechanisms: June 30, 2000<sup>59</sup>**

State	Comprehensive risk adjustment system: rate category for HIV/AIDS	Comprehensive risk adjustment system: NO separate HIV/AIDS category	Risk adjust capitation for HIV/AIDS: NO comprehensive risk adjustment system	Capitation rate adjustment for HIV drugs	PLWH/A enrolled into comprehensive MCOs that also serve others who qualify for Medicaid through:	
					Family coverage	SSI (non-elderly)
AZ				*	M <sup>60</sup>	M
CA	*				M/V	M/V
CO		*			M	M
DE		*			M	M
KY				*	M	M
MA			*	*	M	V
MD	*				M	M
MI		* <sup>61</sup>			M	M
MN		*		*	M	
NM	*				M	M
NY				*	V	V
OR		* <sup>62</sup>			M	M
PA			*	*	M/V	M/V
UT		* <sup>63</sup>	*(AIDS only)		M/V	M/V
Total	3 (21% of 14)	6 (42%)	3 (21%)	6 (42%)		

<sup>59</sup>As of October 1, 2001 (after the survey date of June 30, 2000), New Jersey began risk-adjusting all beneficiaries who belonged to the aged, blind and disabled (ABD) population who do not have Medicare coverage. Two specific conditions risk-adjusted are AIDS and HIV. For all other Medicaid beneficiaries there are several AIDS-specific capitation rates, depending on eligibility category.

<sup>60</sup>In this table “M” means mandatory enrollment and “V” means voluntary enrollment.

<sup>61</sup>Michigan uses a comprehensive risk adjustment system in its program that serves only children with special needs.

<sup>62</sup>Oregon uses a comprehensive risk adjustment system for the SSI and aged populations only.

<sup>63</sup>Utah uses a comprehensive risk adjustment system only for SSI populations.

## Adjusting Payments<sup>64</sup>

One way to ensure that plans receive appropriate payment for serving people with disabilities or chronic illnesses is to vary the rates paid by diagnosis or health status. Medicaid programs that adjust this way believe that the method encourages plans to enroll more people with complex needs and enables them to better serve these members. Health status based risk-adjustment by Medicaid programs generally falls into three major categories:

- Some states have comprehensive risk adjustment systems that assign beneficiaries to groups reflecting health status and service utilization, then develop risk-adjusted rates for each cost group.
- Others adjust for certain diagnoses, rather than developing a comprehensive system.
- To avoid the issues of identifying people with certain diagnoses in claims processing systems, a third group of states adjust payments for HIV/AIDS drugs, such as protease inhibitors.

When a Medicaid agency decides to risk-adjust by health status or diagnosis, it must first identify eligible beneficiaries within its claims processing system. This can be difficult, as no marker exists on a Medicaid eligibility file identifying those who are HIV positive and many claims do not list a diagnosis code for HIV. Therefore, in addition to claims data, these programs reported several other identification sources including notification from the plans, needs assessments/discussions with enrollment brokers, discussions with state staff during Medicaid-eligibility determination, or in some states, information from HIV and AIDS registries (with appropriate state laws and protocols to ensure the continued confidentiality and security of the information in the registry).

In 2000, 14 (33 percent) of the 42 Medicaid agencies that enroll PLWH/A into risk-based managed care adjusted plan payments for individual enrollee health status. Among these 14 agencies:

- Nine states use a comprehensive risk adjustment system.
  - S three (California, Maryland, and New Mexico) of these nine use a rate category for HIV/AIDS within a comprehensive risk adjustment system; and
  - S six (Colorado, Delaware, Michigan, Minnesota, Oregon, and Utah) include people with HIV/AIDS in risk adjustment "cells" composed of people with similar health services cost and utilization patterns;

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<sup>64</sup>The 1996 and 1998 surveys asked states to report any HIV-specific reimbursement strategies. Since all mechanisms reported in response to that question were risk-sharing arrangements the question was clarified to address only risk-sharing arrangements in 2000 and responses to that question are now reported in the risk-sharing section. The 1996 and 1998 numbers presented here have been adjusted accordingly.

- Three states (Massachusetts, Pennsylvania, and Utah<sup>65</sup>) also reported that they adjust the capitation rate for HIV/AIDS, but not as part of a comprehensive system.
- Six states (Arizona, Kentucky, Massachusetts, Minnesota, New York, and Pennsylvania) adjust capitation rates for HIV drugs.

## Trends over time

Using the survey data to examine trends in state use of risk adjustment in plan payment reveals little change in state policies between 1998 and 2000, but significant increases in state use of payment adjustment between 1996 and 1998 (Table 5). This trend may relate to advances in treatment of the disease. Between 1996 and 1998 new, more effective treatments for HIV/AIDS, such as combination therapy, were first introduced and became common.<sup>66</sup> Although medical advances continue, no similar breakthrough occurred between 1998 and 2000, and no major changes in state policies occurred during that time either.

**Table 5 Number of states with HIV-related payment mechanisms: 1996-2000**

	1996		1998		2000	
Comprehensive risk-adjustment system: NO specific HIV/AIDS category	NR		4	9%	6	14%
Comprehensive risk-adjustment system: specific HIV/AIDS category	4	100%	3	7%	3	7%
Risk adjust capitation rates for HIV/AIDS: NO comprehensive risk-adjustment system			3	7%	3	7%
Capitation rate adjustment for HIV drugs	NR		7	16%	6	14%
Total states that adjust payments	4	11%	15	34%	14	33%
Total states w/program	35	100%	44	100%	42	100%

In 2000, 14 (33 percent) of the states enrolling PLWH/A into risk-based managed care adjusted payments to accommodate the higher than average cost of serving PLWH/A. This is almost unchanged from 1998 when 15 states (34 percent) did so. Although the number of states

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<sup>65</sup>Utah uses a comprehensive risk adjustment system for SSI populations that does not have a separate category specifically for enrollees with HIV/AIDS. The state does, however, adjust the capitation rate (but not as part of the comprehensive system) for all enrollees with AIDS.

<sup>66</sup>For example, the first protease inhibitor (Invirase) was approved by the FDA in November 1995.

adjusting payments fell by one between the two years, five states actually stopped or started adjusting payments.

- Delaware and Michigan both instituted a comprehensive risk adjustment system that does not have a specific category for PLWH/A. Michigan, however, limits the use of the comprehensive system to plans participating in its specialized program for children with special health care needs.
- Indiana, New Jersey, and Ohio all stopped adjusting payments.

S In 1998, Indiana and Ohio both reported that they used a comprehensive risk adjustment system in their specialized programs for those with chronic illness (Ohio) or all SSI beneficiaries (Indiana). Both states dismantled these specialized programs between 1998 and 2000 and, therefore, did not report using a comprehensive system in 2000.

S In 1998, New Jersey reported that it adjusted capitation rates for HIV drugs but did not report doing so on June 30, 2000. (Note: As of October 1, 2001, New Jersey began risk-adjusting all beneficiaries who belonged to the aged, blind and disabled (ABD) population who do not have Medicare coverage. Two specific conditions risk-adjusted are AIDS and HIV. For all other Medicaid beneficiaries several AIDS-specific capitation rates exist, depending on eligibility category.)<sup>67</sup>

The greatest change between 1998 and 2000 was the change in the number of states that used a comprehensive system to adjust plan payment for enrollee health status. Between 1998 and 2000 this number increased from seven to nine. In particular, the number of states using a comprehensive adjustment system that includes PLWH/A in rate categories with populations of similar cost increased from four to six states.<sup>68</sup>

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<sup>67</sup>Personal communication with Sander Kelman, Chief, Bureau of Statistical Analysis & Managed Care, New Jersey Medicaid Program, August 2, 2002.

<sup>68</sup>The nine states that used a comprehensive risk adjustment system in 2000 are California, Colorado, Delaware, Maryland, Michigan, Minnesota, New Mexico, Oregon, and Utah. Of these, California, Maryland, and New Mexico have an HIV/AIDS-specific rate category and the remaining six include people with HIV/AIDS in groups with similar costs.

## Trends across populations

Most Medicaid beneficiaries who have HIV/AIDS qualify for Medicaid due to receipt of SSI. Also, those who belong to the SSI group are more likely to have an advanced form of the illness than those who qualify for Medicaid as family coverage beneficiaries. The data show that states that enroll SSI, in addition to family coverage groups, are more likely to have payment mechanisms to adjust for the higher than average cost of serving SSI populations (Table 6). In addition, those that require SSI beneficiaries to enroll in health plans are also more likely to adjust payment to accommodate their cost.

**Table 6 Selected payment mechanisms for family coverage and SSI (non-elderly) based on mandatory and/or voluntary enrollment: 2000**

	Enrolls family coverage group only		Enrolls SSI and family coverage groups		Requires SSI beneficiaries with HIV/AIDS to enroll	
Comprehensive risk-adjustment system: NO specific HIV/AIDS category	6	14%	5	18%	5	22%
Comprehensive risk-adjustment system: specific HIV/AIDS category	3	7%	3	11%	3	13%
Risk adjusted capitation rates for HIV/AIDS: NO comprehensive risk-adjustment system	3	7%	3	11%	2	9%
Capitation rate adjustment for HIV drugs	6	14%	5	18%	3	13%
Total states w/payment mechanisms in the group	14	33%	13	46%	11	48%
Total states w/program	42	100%	28	100%	23	100%

All but one<sup>69</sup> of the states that use a comprehensive risk adjustment system (with or without an HIV/AIDS specific category) enroll SSI beneficiaries and will assign SSI beneficiaries with HIV/AIDS to a comprehensive MCO. Enrolling the SSI population, particularly on a mandatory basis, increases the importance of adjusting payment because plans that serve the SSI population are more likely to serve people with HIV/AIDS. Also, PLWH/A who qualify for Medicaid due to disability (SSI beneficiaries) are more likely than those that qualify for Medicaid as family coverage enrollees to have an advanced form of the disease. If plans are more likely to serve

<sup>69</sup>Minnesota enrolls the family coverage and aged groups into risk-based managed care and uses a comprehensive risk adjustment system in its specialized program for the aged population.

more costly enrollees, states have a greater need to make sure that compensation follows enrollment. Almost half (48 percent) of states that mandate enrollment of SSI beneficiaries with HIV/AIDS risk adjust payments to accommodate the higher than average cost of serving PLWH/A.

## Risk Sharing

Retrospective reimbursement, or risk sharing, is another way to increase the likelihood that plans receive appropriate payment for serving people with HIV/AIDS. Common risk limitation strategies include:

- *Stop loss/reinsurance*, in which the plan is financially responsible for an individual enrollee's care until total costs exceed a predetermined amount. After that point the entity sponsoring the stop loss pays a predetermined percent of those costs that exceed the threshold. Plans may purchase stop loss from commercial firms or from some Medicaid agencies.
- *Risk corridors*, in which the state covers a portion of a plan's total loss if it exceeds a predetermined amount, and receives a portion of a plan's total profits if these exceed a predetermined amount.
- *Risk pools* may be budgeted by legislative appropriation or funded with small deductions from capitation payments. The funds in these pools are divided among plans in proportion to the incidence of certain events.
- *Recalculating the upper payment limit*. In 2000 the most that could be paid to plans under federal law was the fee-for-service cost of serving a group of Medicaid beneficiaries who were actuarially equivalent to those enrolled in managed care. Because capitation payments are prospective, the 2000 limit had to be calculated well before January 1, 2000, using cost and utilization data that may be more than a year old. Some states, therefore, recalculated that limit when they had more recent (2000) information and adjusted the payments to the plans accordingly.

Any of these methods can be targeted for serving certain groups of high-cost beneficiaries such as people living with HIV/AIDS, or they can be used for the entire Medicaid population. In 2000, five states (12 percent) of the 42 states that enrolled people with HIV/AIDS into risk-based managed care reported using an HIV-specific risk-sharing mechanism.

- Hawaii reimburses plans for the actual cost of protease inhibitors. (This is similar to an HIV drug carve-out where the cost of the drugs is removed from plan payment and the state reimburses providers for them through fee-for-service.)

- Massachusetts offers risk corridors to the contracted plan that has a specialized program for people with severe AIDS.
- New York provides an enhanced payment to plans with higher than anticipated AIDS enrollment.
- Pennsylvania reimburses the plan the fee-for-service cost of serving people with HIV/AIDS if it exceeds the prevalence rate and has risk pools for certain HIV/AIDS costs.
- Wisconsin reimburses plans for 100 percent of their cost for serving beneficiaries with HIV and/or AIDS.

The five states using an HIV-specific risk-sharing mechanism is one fewer than in 1998 when six (14 percent) of the 44 states enrolling people with HIV/AIDS into risk-based managed care reported this arrangement. However, it is a significant increase over 1996 when three (8 percent) of the thirty-five states enrolling PLWH/A did so. Again, this may relate to the progress in disease treatment during these years; in 1996 the treatments that are accepted standards today were new and not reflected in the previous fee-for-service costs on which most states base plan payments. By 1998, however, most of the treatments were more widely accepted and as a result states:

- were better able to project the cost of serving PLWH/A because they had cost and utilization histories that better reflected the accepted standard of care on which to base their projections; and
- had worked out reimbursement arrangements with plans that were acceptable to both the plan and the Medicaid agency.

States are far more likely to use risk sharing mechanisms that are not diagnosis specific. In 2000, 31 (74 percent) of the HIV-enrolling states reported such generic mechanisms (Table 7). Among these states some use more than one mechanism; some limit the use of specific mechanisms to certain contracts or regions. Use of these arrangements by states changed little between 1998 and 2000; in 1998, 33 (77 percent) of the HIV-enrolling states used them. (Generic risk-sharing arrangements were not examined in the 1996 version of this report.)

**Table 7 Risk sharing mechanisms in states enrolling people with HIV/AIDS into risk-based managed care as of June 30, 2000**

State	Stop loss: state sponsored	Stop loss: commercial	Risk corridors	Risk pools	Condition specific risk arrangement	Recalculate upper payment limit	PLWH/A enrolled into MCOs that also serve others who qualify for Medicaid through	
							Family coverage	SSI (non-elderly)
AZ	Required						M	M
CA	Optional	Optional	*	*			M/V	M/V
CT	Optional	Optional					M	M/V
DE		Required					M	M
DC <sup>70</sup>		Required	*				M	
HI	Required		*				M	M
IA <sup>71</sup>	Optional	Optional					M	
IN		Required					M	
KS		Required					V	
MA <sup>72</sup>	Optional		*		*	*	M	V
MD	Required						M	M
MN	Optional						M	
MO	Required	Required					M	
NC		Required					M	M
ND		Required					V	
NE		Optional					M	M
NH						*	V	
NJ		Required					M	V
NM		Required					M	M
NV	Required						M/V	
NY	Required/Optional		*				V	V
OH		Required					M	
OK		Required	*		*		M	M

<sup>70</sup>The District requires plans that participate in the program that serves only family coverage groups to buy commercial stop loss reinsurance. It also offers risk corridors to its speciality contractor that serves only SSI children.

<sup>71</sup>Iowa offers stop loss reinsurance in its program that serves only the family coverage group.

<sup>72</sup> Massachusetts offers stop loss and risk corridors to plans for SSI enrollees; it offers a condition specific arrangement and will recalculate the upper payment limit for plans serving all groups of enrollees.

State	Stop loss: state sponsored	Stop loss: commercial	Risk corridors	Risk pools	Condition specific risk arrangement	Recalculate upper payment limit	PLWH/A enrolled into MCOs that also serve others who qualify for Medicaid through	
							Family coverage	SSI (non-elderly)
OR		Required					M	M
PA <sup>73</sup>	Required	Optional			*		M/V	M/V
RI		Required			*	*	M	
SC		Required					V	V
TN				*			M	M
UT		Required			*		M/V	M/V
VA		Required					M/V	M/V
WI <sup>74</sup>	Optional	Optional	*	*	*	*	V	V
<b>Total</b>	Req: 7 (23% of 31) Opt: 7 (23%)	Req: 16 (52%) Opt: 6 (19%)	7 (23%)	3 (9%)	6 (19%)	4 (13%)		

## Drug Carve-Outs

States base capitation payments on the historic costs of serving beneficiaries through the fee-for-service system, by analyzing service utilization. In 1996, the use of protease inhibitors and combination therapy was new, and states had little information to determine how costly these treatments would be. Even in 1998, projections of HIV/AIDS drug costs were uncertain. Since that time the cost of the Medicaid pharmacy benefit as a whole has rapidly increased and some data “indicate that Medicaid spending on antiretrovirals represents a small but significant portion of overall Medicaid prescription drug spending and expenditures have risen rapidly over the last decade.”<sup>75</sup>

Due to the difficulty of predicting the cost of HIV/AIDS drugs and their high cost, some states have carved these drugs out of the plan benefit package. The Medicaid agency adjusts the

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<sup>73</sup>Pennsylvania allows plans that participate in its voluntary managed care program to purchase commercial stop loss but requires plans in the HealthChoices program to participate in state-sponsored stop loss.

<sup>74</sup>Wisconsin offers state-sponsored stop loss to comprehensive MCOs that serve family coverage groups. Wisconsin also allows all plans to purchase optional commercial stop loss and offers risk corridors to those plans that serve SSI. Finally, Wisconsin has a condition-specific risk arrangement for all plans.

<sup>75</sup>Richard Sorian, et al. *Policy Brief: Critical Challenges in the Third Decade of the HIV/AIDS Epidemic*. (Henry J. Kaiser Family Foundation, Menlo Park, CA: January 2002).

capitation payments made to the plans to exclude the cost of these drugs and then directly reimburses providers for the cost of the drugs. Others, for various policy reasons carve all drugs (including those used to treat HIV) out of the plan benefit package. In 2000, a total of 18 states either carved out HIV/AIDS drugs or all drugs, the same number as did so in 1998. Specifically, in 2000:

- Seven of the states enrolling people with HIV/AIDS into comprehensive MCOs have HIV/AIDS drug carve outs in place (Table 8).
- Eleven of the states enrolling people with HIV/AIDS into comprehensive MCOs carve out all prescription drugs.

**Table 8 States that carve drugs out of the comprehensive plan benefit package: June 30, 2000<sup>76</sup>**

HIV/AIDS drugs: 7 states	All drugs: 11 states
California (some counties) Hawaii Maryland Missouri Nevada Pennsylvania Washington	Delaware Iowa Maine Nebraska North Carolina North Dakota New Hampshire New York Texas Utah West Virginia

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<sup>76</sup>Alabama and South Dakota do not contract for comprehensive services and are, therefore, excluded from this list.

## HIV-RELATED CONTRACT REQUIREMENTS

Concerns have been raised that risk-based managed care programs, designed to serve relatively healthy people, may not meet the needs of people with HIV/AIDS. To minimize this possibility, 11 states (26 percent of those enrolling PLWH/A into risk-based managed care) created contract provisions regarding the care delivered to people with HIV/AIDS in their health plans (Table 9).<sup>77</sup> This is the same number that reported doing so in 1998 and five more than the six states that did so in 1996.

**Table 9 HIV-specific plan contract requirements: June 30, 2000**

State	Keep up with changing clinical standard	Follow state-specified clinical protocol	PCP w/ HIV/AIDS treatment experience	PCP w/ HIV/AIDS-specific education	Case mgt or care coordination	Quality monitoring or indicators	PLWH/A enrolled into MCOs that also serve others who qualify for Medicaid through		State ranking: persons living w/ AIDS at the end of 1999 <sup>78</sup>
							Family coverage	SSI	
DC	*				*		M		11 <sup>th</sup>
HI	*					*	M		35 <sup>th</sup>
MA	*		*	*	*	*	M	V	10 <sup>th</sup>
MD					*	*	M	M	9 <sup>th</sup>
NE			*				M	M	43 <sup>rd</sup>
NH				*	*		V		41 <sup>st</sup>
NJ		*				*	M	V	5 <sup>th</sup>
NY	*	*	*	*	*	*	V	V	1 <sup>st</sup>
PA	*				*	*	M/V	M/V	6 <sup>th</sup>
SC					*	*	V	V	17 <sup>th</sup>
UT			*(HIV-only)		*	*	M/V	M/V	38 <sup>th</sup>
Total	5 (45% of 11)	2 (18%)	4 (36%)	3 (27%)	8 (73%)	8 (73%)			

<sup>77</sup>Note: Sample purchasing specifications for HIV infection, AIDS, and HIV-related conditions which were developed by George Washington University and reviewed by consumers, health care providers, policy makers, managed care officials, and state Medicaid agencies are available at [www.gwu.edu/~chsrp/sps/HIV/aug99/intro.html](http://www.gwu.edu/~chsrp/sps/HIV/aug99/intro.html).

<sup>78</sup>The Kaiser Family Foundation. State Health Facts On-Line. Accessed August 20, 2002. <http://www.statehealthfacts.kff.org>

Incidence of the disease may be a factor in which states establish HIV or AIDS-specific contract language. Seven of the eleven states that do so were in the top third of states in the nation in terms of the number of people who were living with AIDS at the end of 1999. The eligibility groups enrolled and whether PLWH/A are required to enroll in risk-based managed care also appear to be factors. Among the eleven states with HIV or AIDS-specific contract requirements, eight (73 percent) enroll PLWH/A who are SSI beneficiaries into risk-based managed care. (For comparison, 59 percent of the states that enroll PLWH/A into risk-based managed care enroll SSI beneficiaries who are PLWH/A.)

An example from Massachusetts' contract illustrates the type of HIV or AIDS-specific contract requirements states may implement. Among other things, Massachusetts requires that any contractor that wishes to receive an enhanced capitation rate for serving PLWH/A who meet certain clinical criteria have:<sup>79</sup>

- experienced PCPs who specialize in the treatment of people with active/advanced AIDS,
- specialists with experience working in multi-disciplinary teams to provide case management to people with active/advanced AIDS,
- a well developed operational case management program specializing, at a minimum, in the care of people with active/advanced AIDS, and
- relationships with researchers who conduct clinical trials in which people with active/advanced AIDS may participate.

Bear in mind when considering the information in this section that states may encourage plans—or even require through regulation—that they maintain certain HIV-related standards, without ever using contract language. For example, in Tennessee a group of representatives from health plans, the pharmacy benefits manager, the provider community, advocates, consumers, and the Department of Health developed AIDS Centers of Excellence across the state (with HIV-experienced physicians and staff) that all Medicaid contracted plans may subcontract with to provide primary and specialty services. The physicians in this group are also making across-the-board recommendations on formularies and clinical protocols. Plans participate voluntarily, both in subcontracting to the Centers and in following treatment recommendations. The Medicaid agency participates as invited. As another example, New Jersey encourages plans to establish links with AIDS clinical education programs in order to remain current on treatment standards.<sup>80</sup>

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<sup>79</sup>All Massachusetts contract information taken from State of Massachusetts, *Managed Care Organization Contract*, July 1, 1998.

<sup>80</sup>Joanne Rawlings Sekunda and Neva Kaye. *Emerging Practices and Policy in Medicaid Managed Care for People with HIV/AIDS: Case Studies of Six Programs*. (National Academy for State Health Policy, Portland, ME: August 1998).

Finally, in their contracts most states require or encourage plans to deliver care in certain ways to all people with chronic illnesses or disabilities, including those with HIV/AIDS. For example, New York includes the following requirements (among others) that, while not specifically aimed at PLWH/A, address how care will be provided to them.

- “...for enrollees that require ongoing care from a specialist, the MCO must have a procedure for implementing a standing referral for that enrollee with an appropriate specialist.”
- “For enrollees diagnosed with a life threatening condition or disease, or a degenerative and disabling condition or disease, either of which requires specialized medical care over a prolonged period of time, MCOs must have a procedure in place that allows for a referral to a specialist with appropriate expertise who will be responsible for both the primary and specialty care of the enrollee.”
- “MCOs will be responsible for reimbursement of care provided outside the network if there is no network provider with appropriate training and expertise to meet Partnership Plan enrollees’ needs.”
- Specifically regarding adults with chronic illnesses and physical or developmental disabilities: “MCOs must have in place all of the following to meet the needs of their adult members with chronic illnesses and physical or developmental disabilities:
  - S Satisfactory methods for ensuring their providers are in compliance with Title II of the Americans with Disabilities Act. The Americans with Disabilities Act accessibility checklist is included in the Technical Assistance library.
  - S Satisfactory methods/guidelines for identifying persons at risk of, or having, chronic diseases and disabilities and determining their specific needs in terms of specialist physician referrals, durable medical equipment, medical supplies, home health services, etc.
  - S Satisfactory case management systems to ensure all required services are furnished on a timely basis.
  - S Satisfactory systems for coordinating service delivery with out-of-network providers, including behavioral health providers in the case of SSI physical health only members.
  - S Policies and procedures to allow for the continuation of existing relationships with out-of-network providers, when considered to be in the best medical interest of the member.”<sup>81</sup>

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<sup>81</sup>New York State Department of Health. *MCO Organization Qualification Guidelines, Chapter 2: MCO Participation Standards*. (The Department: June 7, 1999).  
[http://www.health.state.ny.us/nysdoh/manicare/mco/mco\\_main.htm#schedules](http://www.health.state.ny.us/nysdoh/manicare/mco/mco_main.htm#schedules)

## Case Management/Care Coordination<sup>82</sup>

One of the promises of managed care is increased care coordination, an avoidance of the fragmentation that may occur in traditional fee-for-service systems and among the multiple systems that may serve beneficiaries. When done properly, coordination can facilitate better care by addressing a full range of needs across care delivery systems and can keep costs down by avoiding duplicative services. As the populations affected by the virus change—particularly to include more people who are dually or triply diagnosed with substance abuse or mental illness—coordination of both medical and non-medical services becomes more necessary to sustain health. Research appears to back the usefulness of case management in serving PLWH/A. One of the preliminary findings from eight HRSA-sponsored studies on the effect ancillary services had on HIV/AIDS care is that case management had a strong relationship to the likelihood of entering medical care and making regular medical visits.<sup>83</sup>

The case manager/care coordinator ensures that a comprehensive plan is developed and followed. Such a plan would typically include short- and long-term treatment goals, action/intervention plans and target dates, contingencies in case of complications, and cost-effectiveness. The case manager works with the enrollee, his or her family members and/or caregivers, primary care physician, and other providers in developing and implementing the plan. Specific responsibilities can include:

- Assessing needs,
- Ordering and authorizing in-plan services,
- Educating clients on how to navigate the health care system,
- Educating clients on ways to increase treatment adherence,<sup>84</sup>
- Referring or otherwise helping beneficiaries access out-of-plan services,<sup>85</sup> and
- Monitoring services to ensure the care plan is implemented.

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<sup>82</sup>Although the terms “case management” and “care coordination” are often used interchangeably, there are differences between the two types of activities. Case management tends to focus more on medical care provided to people with high cost conditions, while care coordination often also includes coordination of social services (including services that are not covered by the health plan) to support medical care and is provided to high-risk enrollees. The focus of case management is often to contain costs, while that of care coordination is to facilitate access to appropriate care.

<sup>83</sup>Martha McKinney. *Delivering HIV Services to Vulnerable Populations: What have we learned?* Report #6 in the HIV/AIDS Evaluation Monograph Series. (HRSA: October 2000).

<sup>84</sup>Combination therapies are not effective unless individuals strictly adhere to complicated treatment regimens that involve taking many pills over the course of a day. Some states have found that ongoing, one-on-one education provided by case managers is an effective way to increase adherence.

<sup>85</sup>Many case managers work at building informal relationships with local AIDS service organizations/community based organizations to facilitate access to non-medical services.

Eight states or 19 percent of those that enroll PLWH/A into risk-based managed care reported having contract provisions for case management/care coordination specifically for plan enrollees with HIV/AIDS: The District, Maryland, Massachusetts, New Hampshire, New York, Pennsylvania, South Carolina, and Utah (Table 9). This is the same number of states that reported having such provisions in 1998. In Maryland, for example, “MCOs must offer HIV/AIDS case management services at any time after HIV/AIDS diagnosis. An individual who refuses these services can request case management from the MCO at any time. MCOs must ensure that individuals with HIV/AIDS receive case management services that link the enrollee with the full range of available benefits, as well as any needed support services.”<sup>86</sup>

Many states have contract provisions for case management/care coordination that are not specific to plan enrollees with HIV/AIDS. In fact, many more states use generic requirements, perhaps due to the relatively small number of PLWH/A in relation to the total number of Medicaid beneficiaries and the wide range of chronic or disabling conditions that Medicaid-contracted plans may be called upon to care for.

In 2000, 24 of the 42 states (57 percent) enrolling people with HIV/AIDS into risk-based managed care require plans to provide care coordination that is not HIV-specific (Table 10). This is a slight increase over 1998 when 22 of 44 states (50 percent) did so.

**Table 10 Twenty-four states require plans to provide care coordination to groups that are likely to include people with HIV or AIDS: June 30, 2000<sup>87</sup>**

Alabama	Kentucky	Oregon (SSI)
California	Massachusetts	Pennsylvania
Connecticut	Maine	Rhode Island
The District (SSI children only)	Michigan	South Carolina
Florida	Minnesota (aged only)	Texas (SSI and aged only)
Hawaii	New York	Utah
Illinois	Ohio	Washington (high-risk only)
Indiana (pregnant women only)	Oklahoma	Wisconsin (SSI)

It is important to remember when using this information that several models of care coordination exist and that the survey did not distinguish among them. Two examples illustrate the range of possible activities that these more generic provisions may require.

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<sup>86</sup>Maryland Department of Health and Mental Hygiene. *HealthChoice Program Overview*. (The Department: 1998). <http://www.dhmf.state.md.us/healthchoice/index.htm>.

<sup>87</sup>Maryland and New Hampshire are not included in this list. Maryland is not included because its case management requirements, cited earlier in this section, are specific to enrollees with HIV/AIDS, and New Hampshire’s care coordination requirements are voluntary.

1. Oregon requires comprehensive MCOs to hire Exceptional Needs Care Coordinators (ENCCs). ENCCs assist members who have complex medical and/or special needs by helping to coordinate health care services for persons age 65 or older or persons with disabilities. ENCC services must be available at the request of the enrollee, his or her representative, a physician, or other medical personnel serving the enrollee.<sup>88</sup>
2. Ohio requires plans to submit a written description of their case management program to the Medicaid agency for approval. Among other requirements the case management program description must: (a) establish the criteria the plan will use to identify which enrollees require specialized case management due to catastrophic, acute, chronic, or complex illness or injury; (b) establish service coordination mechanisms between the PCP and specialists; (c) describe under what circumstances and how care plans are developed and implemented; and (d) establish a policy regarding the enrollees' responsibility for and participation in their care.<sup>89</sup>

In addition to care coordination, some states address Targeted Case Management (TCM) in their managed care contracts. TCM is an optional Medicaid service that states can choose to provide to a number of target groups including people with “AIDS or HIV related disorders.” CMS further defines TCM services as “services which assist individuals eligible under the [Medicaid state] plan in gaining access to needed medical, social, educational, and other services.”<sup>90</sup> In 2000, 13 HIV-enrolling states have managed care contract provisions regarding TCM (Table 11). This is the same number as did so in 1998.

**Table 11 Thirteen states require plans to provide targeted case management: June 30, 2000<sup>91</sup>**

Arizona	Iowa (SSI adults only)	Pennsylvania
Colorado	Kentucky	Tennessee (children and uninsured/uninsurable)
The District (SSI children only)	Massachusetts*	Wisconsin (SSI only)*
Florida	Nevada	
Indiana*	Oklahoma	

<sup>88</sup>Oregon Department of Human Services. *Client Handbook for the Oregon Health Plan*. (The Department: July 2000).

<sup>89</sup>Ohio Bureau of Managed Health Care. *Medicaid Managed Care Request for Proposals*. (The Bureau: January 2000). Appendix E. [http://www.state.oh.us/odjfs/ohp/bmhc100599\\_rfp/](http://www.state.oh.us/odjfs/ohp/bmhc100599_rfp/)

<sup>90</sup>CMS. §4302 State Medicaid Manual.

<sup>91</sup>A “\*” denotes a state with a targeted case management program specifically designed for beneficiaries with HIV or AIDS. The other states would provide targeted case management to beneficiaries with HIV or AIDS if they also belonged to the group for which the service was designed (e.g., pregnant women, beneficiaries with hemophilia, beneficiaries with chronic mental illness, etc.)

Finally, the 2000 survey, for the first time, asked states about HIV/STD prevention. While not strictly care coordination, it is an important aspect of care delivery to those with or at-risk for HIV. In response, eight of the states enrolling PLWH/A into risk-based managed care (19 percent) reported requiring plans to educate enrollees about HIV/STD prevention: California, Connecticut, the District, Florida, Massachusetts, New York, Utah, and Washington.

## Quality Monitoring

Monitoring the quality of care provided specifically to people with HIV/AIDS is difficult because of their small numbers within the overall Medicaid managed care population. Plans may find burdensome requirements that are aimed at measuring items related to small subsets of the Medicaid enrolled population. Moreover, the small numbers make it difficult to obtain statistically valid information.

In 2000, eight states (19 percent) reported including contract provisions regarding HIV-specific quality monitoring/quality indicators: Hawaii, Maryland, Massachusetts, New Jersey, New York, Pennsylvania, South Carolina, and Utah. This is the same number that reported having HIV-specific quality monitoring and indicators in 1998.

As an example of quality monitoring, health plan network providers in Massachusetts are strongly urged to follow the Medicaid agency's protease inhibitor guidelines, developed by a panel of physicians and reviewed by a larger group of physicians and advocates. Providers identified as deviating from the guidelines receive a letter requesting clarification from the State Medical Director. State officials noted that thus far the largest problem uncovered is treatment adherence, and that many doctors do not follow up to see if patients are following prescribed regimens. These officials are trying to develop ways to increase physician follow-up in this area.<sup>92</sup> (Of course, physicians are not solely responsible for ensuring treatment adherence. Others, such as case managers, also have a role to play.)

In another example, New Jersey requires plans to report quarterly data that allows the Medicaid agency to assess pregnant women's access to HIV testing and AZT therapy. Specifically, each plan must report: (1) the number of pregnant women; (2) the number of pregnant women receiving HIV testing within the HMO; (3) the number of pregnant women testing positive for HIV; (4) the number of pregnant women treated with AZT; (5) the number of births involving AZT treatment in utero; and (6) the number of newborns receiving full AZT treatments.<sup>93</sup>

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<sup>92</sup>Joanne Rawlings Sekunda and Neva Kaye. *Emerging Practices and Policy in Medicaid Managed Care for People with HIV/AIDS: Case Studies of Six Programs*. (National Academy for State Health Policy, Portland, ME: August 1998).

<sup>93</sup>New Jersey Department of Human Services. 2002 Managed Care Contract. (The Department: 2001). <http://www.state.nj.us/humanservices/dmahs/managedcare.html>.

Finally, all states that enroll PLWH/A into risk-based managed care also engage in other quality monitoring activities that are pertinent to PLWH/A. For example, a study of the quality of prenatal care is likely to examine HIV testing for pregnant women. Or state quality monitoring efforts to ensure delivery of primary and preventive services could result in improved delivery of these services to PLWH/A. Some states also focus some quality activities specifically on people with disabilities, including those with HIV/AIDS.<sup>94</sup> Colorado's Medicaid program, for example, partners with disability advocates, contracted plans, and providers to conduct quality improvement studies. Disability advocates help select the study topic, design the study, and conduct the study. Plans and providers also help design the study. State staff reported that partnering not only improves the studies but also fosters communication and understanding between the advocates and providers.<sup>95</sup>

## Keeping up with Clinical Standards/State Clinical Protocols

States can require plans to keep up with accepted clinical standards<sup>96</sup> or develop their own protocols.<sup>97</sup>

- The District of Columbia, Hawaii, Massachusetts, and Pennsylvania require plans to keep up with changing clinical standards;
- New Jersey requires plans to follow state-specified protocols; and
- New York requires both.

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<sup>94</sup>For a detailed discussion of measuring plan performance in the delivery of care to people with disabilities, please refer to: Shoshanna Sofaer, et al. *Meeting the Challenge of Serving People With Disabilities: A Resource Guide for Assessing the Performance of Managed Care Organizations*. (ASPE: July 1998). <http://aspe.os.dhhs.gov/daltcp/reports/resource.htm>.

<sup>95</sup>Laurel B. Karabatsos, Partnering for Quality. Presented at AHRQ User Liaison Program Workshop, Philadelphia PA, October 17-19, 2001.

<sup>96</sup>The Agency for Healthcare Research and Quality maintains the National Guideline Clearinghouse (NGC), a comprehensive database of evidence-based clinical practice guidelines and related documents addressing a variety of subjects including HIV/AIDS at [www.guideline.gov](http://www.guideline.gov).

<sup>97</sup>42 CFR 438.236 requires states to “ensure through their contracts” that each MCO develops (or adopts), disseminates and applies practice guidelines.

For example, New York requires health plans to “adopt practice guidelines consistent with current standards of care, taking into consideration recommendations of professional specialty groups such as...the AIDS Institute Clinical Standards for Adult and Pediatric Care.”<sup>98</sup>

## **Primary Care Physician HIV/AIDS Experience and Education<sup>99</sup>**

The evolving state of treatment and the many unknowns of treating HIV/AIDS<sup>100</sup> have led to controversies over whether all primary care physicians (PCPs) treating people with HIV/AIDS should have HIV-specific experience. Proponents argue that treatment possibilities have become so complex that only physicians with a significant number of HIV-infected patients will keep up with current knowledge. Others argue that barriers such as geography make this standard unrealistic.

Provider experience is key to keeping up with changing standards. A nationwide survey of physicians found that initial HIV therapy is inconsistent with DHHS guidelines in one-quarter of all patients; suboptimal treatment is more frequently provided by physicians with little HIV experience.<sup>101</sup> A more recent study also found that greater physician experience in the care of persons with HIV infection is associated with earlier adoption of new antiretroviral treatment.<sup>102</sup> Physicians need support and easy access to information (e.g., Internet, telemedicine); an isolated seminar or workshop will not change a physician's practice style.

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<sup>98</sup>Sara Rosenbaum, et al., *Negotiating the New Health System: A Nationwide Study of Medicaid Managed Care Contracts, 3<sup>rd</sup> Edition, Chapter 5, Quality Assurance, Data and Reporting*. (George Washington University: June 1999).

<sup>99</sup>Section 112 of the sample purchasing specifications for HIV infection, AIDS, and HIV-related conditions developed by George Washington University addresses this issue. These specifications are available at [www.gwu.edu/~chsrp/sps/HIV/aug99/intro.html](http://www.gwu.edu/~chsrp/sps/HIV/aug99/intro.html). An October 1999 CMS letter to state Medicaid agencies also stated, “We urge you to ensure access to experienced providers by Medicaid beneficiaries living with HIV/AIDS.”

<sup>100</sup> Knowing what to prescribe is a critical and complicated issue; the wrong combination can lead to treatment failure and the emergence of drug-resistant viral strains. Adding to the complexity are critical issues of when to begin treatment and how to facilitate long-term adherence.

<sup>101</sup>Deborah L. Shelton. "HIV Patients Not Getting Recommended Treatment" (reporting on the National HIV/AIDS Treatment Survey, conducted by the University of California, San Francisco; Johns Hopkins University; and Louis Harris & Assoc.), *American Medical News*. Volume 41, No. 27, July 20, 1998.

<sup>102</sup>Mari Kitahata, et al., “Physician experience in the care of HIV-infected persons is associated with earlier adoption of new antiretroviral therapy”, *J Acquir Immune Defic Syndr*, Volume 24, No. 2, June 1, 2000.

In 2000, Massachusetts, Nebraska, New York, and Utah report including provisions in their contracts requiring plans to include primary care providers with HIV/AIDS experience. This is an increase from 1998 when only Massachusetts and New York reported doing so.

Massachusetts, for example, requires each plan to have in its network “a sufficient number of experienced PCPs who specialize in the treatment of persons with end-state AIDS.” The names of these physicians are to be provided to the Medicaid agency and to enrollees upon request.<sup>103</sup>

Also, in 2000, 15 states required plans to provide enrollees who have special needs (including PLWH/A) with access to providers with experience in caring for their condition (Table 12).

Once again, states may prefer the more generic requirement because of the relatively small number of Medicaid beneficiaries who have HIV/AIDS and the broad range of conditions that may require access to experienced providers.

**Table 12 Fifteen states require plans to provide enrollees who have special needs with access to experienced providers: June 30, 2000**

Delaware	Missouri	Texas
Kansas	Nebraska	Utah
Kentucky	Nevada	Virginia
Massachusetts	North Carolina	Washington (specialized
Michigan (Specialized program for children w/special needs)	Oklahoma (SSI)	mental health program)
	Oregon	

Finally, in 2000, Massachusetts, New Hampshire, and New York report requiring plans to provide education on new AIDS treatment and technologies. In 1998 only Massachusetts and New York reported doing so. Other states may encourage this without including it in contracts; Tennessee's AIDS Centers of Excellence criteria include the provision that any provider offering care have at least 20 CME/CEU credits per year in AIDS-related care.<sup>104</sup> This program also requires participating physicians to have managed at least 50 HIV/AIDS patients.

## Allowing Specialists as Primary Care Providers

A more common practice is to include language requiring or allowing plans to use specialists as primary care providers for all Medicaid beneficiaries (not just people with HIV/AIDS). This

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<sup>103</sup>Joanne Rawlings Sekunda and Neva Kaye. *Emerging Practices and Policy in Medicaid Managed Care for People with HIV/AIDS: Case Studies of Six Programs*. (National Academy for State Health Policy, Portland, ME: August 1998).

<sup>104</sup>TennCare launches voluntary managed care program for HIV/AIDS patients with Centers of Excellence," *State Health Watch*. May 1998.

avoids the potential political issues of singling out a specific disease. However, it does not ensure that primary care physicians with HIV-experience will be included in plan networks.

Sixteen states (38 percent of those enrolling people with HIV/AIDS) require plans to allow specialists as PCPs (Table 13). Another 15 (36 percent) report that at least one of their contracted plans allows specialist PCPs without being required to do so. This is a slight reduction from 1998 when 18 states (41 percent of the 44 states that enrolled PLWH/A in 1998) required plans to allow specialists as PCPs and another 18 reported that at least one contracted plan did so without a specific mandate.

**Table 13 Allowing specialists as PCPs: June 30, 2000**

16 states require plans to allow		In 15 states at least one plan allows without state requirement	
Delaware	New York	Arizona	Nebraska
Florida (OB/GYN)	Ohio	California	New Jersey
Iowa (Comprehensive MCO only)	Oklahoma	Colorado	North Carolina
Kentucky	Pennsylvania (certain instances)	The District	Oregon
Massachusetts (OB/GYN)	Tennessee	Hawaii	Rhode Island
Michigan (General program)	Texas	Michigan (Specialized program for Children with Special Needs)	South Carolina
Missouri	Utah	Minnesota	Washington
New Mexico	Virginia		Wisconsin

### Allowing Standing Referrals to Specialists

Specialists are frequently paid fee-for-service, which may result in plans discouraging their use. Standing referrals, however, allow Medicaid beneficiaries with complex needs (such as people with HIV/AIDS) to access these physicians more easily. After the initial referral is approved, there is no need to go through plan authorization processes each time.

Eleven states (27 percent of those with enrollees with HIV/AIDS) report requiring plans to allow standing referrals to specialists (Table 14, next page). Another 22 states (52 percent) report that at least one of their contracted plans allows but does not require these standing referrals. The number of states reporting each situation is unchanged from 1998.

**Table 14 Allowing standing referrals to specialists: June 30, 2000**

11 states require plans to allow		In 22 states at least one plan allows without state requirement	
Connecticut	New York	Arizona	Nebraska
Delaware	Oklahoma	California	New Jersey
Florida (special needs populations only)	Tennessee	The District	New Mexico (family coverage only)
Kansas	Washington (Title V children only)	Hawaii	Nevada
Missouri	Wisconsin (Family coverage)	Illinois	Ohio
New Mexico (SSI)		Iowa (comprehensive MCO only)	Oregon
		Kentucky	Pennsylvania
		Massachusetts	Rhode Island
		Maine	Texas
		Minnesota	Virginia
		North Dakota	Wisconsin (SSI)

Finally, Maryland also protects access to care by requiring MCOs to pay for one self referred evaluation a year outside the plan's network for certain beneficiaries (including those with HIV or AIDS).

## SUMMARY

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Between 1998 and 2000, although some individual states changed their policies, there was little overall change in the policies governing:

- the enrollment of Medicaid beneficiaries with HIV/AIDS into risk-based managed care,
- the financial arrangements between plans and states for the cost of serving people with HIV/AIDS; or
- contractual requirements regarding how care will be delivered to people with HIV/AIDS who are enrolled in Medicaid managed care.

Although little change occurred between 1998 and 2000 in any of the three areas examined in this report, the greatest change occurred in enrollment practices. The number of states enrolling people with HIV/AIDS into risk-based managed care fell by two during this time (from 44 in 1998 to 42 in 2000). Seven other states changed enrollment policies specific to those with HIV: three states became more mandatory and four became more voluntary. This 1998/2000 trend counters that observed between 1996 and 1998 when the number of HIV-enrolling states increased from 35 to 44; 13 states became more mandatory; and no state became more voluntary.

The reductions in enrollment (and mandatory enrollment) of people with HIV/AIDS observed between 1998 and 2000 may, however, relate to changes in the larger Medicaid managed care market. For example, between 1998 and 2000, four states stopped contracting with health plans entirely and no longer enroll any Medicaid beneficiary into Medicaid managed care. The lack of change in financial arrangements and contract requirements reinforces this conclusion; few states that continued to enroll PLWH/A into Medicaid managed care changed their policies regarding payment and service delivery to this population. For example, the greatest change observed in financing the care delivered to beneficiaries with HIV/AIDS who were enrolled into health plans was the increased use of comprehensive systems to adjust capitation payments for individual enrollee health status (seven in 1998; nine in 2000).

The magnitude of change in state policies between 1996 and 1998 was greater than that observed between 1998 and 2000. In addition to the trends in enrollment policies:

- Between 1996 and 1998, the number of states adjusting the capitation rate for HIV/AIDS (either as part of a comprehensive risk adjustment system or more targeted methods) increased from four states (11 percent of 35 HIV-enrolling states) in 1996 to fifteen states (34 percent of 44) in 1998, then fell to 14 states (33 percent of 42) in 2000.
- Between 1996 and 1998, the number of states with HIV-specific contract requirements regarding the delivery of care increased from six states (17 percent of 35 HIV-enrolling

states) to 11 states (31 percent of 35), then held steady between 1998 and 2000 when 11 states (26 percent of 42) also reported HIV-specific service delivery contract provisions.

These observed trends may relate to the progress in treatment of the disease. In 1995/96 revolutionary new treatments were introduced which became widespread by 1998 (and are now the practice standard). In other words, the greatest changes in Medicaid policies governing enrollment, payment, and treatment for PLWH/A correspond with the time of greatest change in treatment (and treatment cost).

Although the magnitude of change in state policies was greatest between 1996 and 1998, the 2000 data continue to indicate that states generally treat the relatively small numbers of Medicaid beneficiaries (less than one percent of all Medicaid beneficiaries) much as they treat the larger Medicaid population or other groups with chronic illness. For example, the biggest increase in state use of comprehensive risk adjustment systems was in the number of states that use a system that includes people with HIV/AIDS among other beneficiaries with similar cost or utilization (four in 1998; six in 2000). When states do develop specific policies, they are more likely to develop HIV-specific financial arrangements (14 of 42 HIV-enrolling states in 2000) than they are to develop HIV-specific contractual requirements for delivery of service (11 states in 2000).

Finally, when the focus of the analysis is broadened to include policies developed for people with chronic illness or for the Medicaid population as a whole but that also address issues of particular importance to people with HIV/AIDS (such as care coordination requirements), it finds that most states have policies in place to address payment and delivery of care. For example, in 2000:

- Five states had HIV-specific risk-sharing arrangements with plans; 31 had generic risk-sharing arrangements designed to address the higher than expected costs of serving broader groups of Medicaid beneficiaries.
- Eight states had HIV-specific care coordination or case management requirements; 24 had such requirements for the general Medicaid population.
- Four states required plans to provide enrolled Medicaid beneficiaries with HIV/AIDS with access to primary care providers experienced in the treatment of the condition; 15 required plans to provide enrollees with special needs (including those with HIV/AIDS) with access to experienced providers.

Appendix A  
**Key Concepts in Medicaid Managed Care**

## KEY CONCEPTS IN MEDICAID MANAGED CARE

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This appendix provides basic information about two aspects of managed care.

1. The types of managed care programs and contractors Medicaid agencies use.
2. The methods Medicaid agencies can use to mandate enrollment into Medicaid managed care programs.

### Types of Medicaid Managed Care Programs

In 2000, Medicaid agencies contracted with three types of managed care providers (MCO, PHP, and PCCM provider) that the NASHP survey classified into two types of managed care programs (risk and PCCM).

1. In a *risk program*, a Medicaid agency contracts with an entity or individual (the contractor) to provide or arrange for the provision of an agreed upon set of services in exchange for a set fee per person enrolled per month; the prepaid fee does not vary month-to-month based on services used by the individual enrollee. In other words, in risk-based managed care, the contractor assumes some level of financial risk for providing care to enrollees. There are two types of contractors that participate in risk programs:
  - A. **Managed Care Organizations (MCOs)** are entities that contract to provide a comprehensive set of benefits. Comprehensive is defined as inpatient hospitalization and at least one of the following services: (1) outpatient hospital and rural health clinic; (2) other laboratory and x-ray; (3) skilled nursing facility; (4) physician; or (5) home health. Contracts that exclude inpatient hospitalization but include three or more of the five groups of services are also considered comprehensive.<sup>105</sup>
  - B. **Prepaid Health Plans (PHPs)** are risk contractors that cover a less than comprehensive set of services, such as only behavioral health services.
2. A *PCCM* program assigns responsibility for the care of a Medicaid beneficiary to a specific primary care provider who receives payment on a fee-for-service basis and who (typically) receives a small additional fee per enrollee per month to compensate for case management functions. This primary care provider is often referred to as a PCCM provider. PCCM providers do not generally assume any financial risk for providing care other than services within their scope of practice that they deliver directly to enrollees.

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<sup>105</sup> 42 Code of Federal Regulations 434.21(b)

## Changes to managed care provider types stemming from the BBA<sup>106</sup>

The Balanced Budget Act of 1997 (BBA) and the Final Medicaid Managed Care rule changed these classifications. The majority of these changes were not in place when the 2000 survey was issued and are not used in this document. They are, however, discussed here to ensure that readers are aware of the current definitions.

- The term ***risk contract*** has now been formally defined to mean a contract under which the contractor assumes risk for the cost of the services covered under the contract and incurs loss if the cost of providing services exceeds the payments from the Medicaid agency to the contractor.
- The term ***MCO***, continues to refer to any entity that contracts for comprehensive risk, and the definition of comprehensive risk remains unchanged.
- There are now two types of PHPs and different rules will apply to each type.
  - S A ***Prepaid ambulatory health plan (PAHP)*** is a PHP that is not responsible for the provision of any inpatient hospital or institutional services.
  - S A ***Prepaid inpatient health plan (PIHP)*** is a PHP that is responsible for the provision of any inpatient hospital or institutional services.
- ***Primary care case management*** means a system under which a primary care case manager contracts with the State to furnish case management services (which include the location, coordination, and monitoring of primary health care services) to Medicaid recipients.

It is important to note that the definition of a primary care case management program does not preclude capitation. As a result, the definitions of PAHP and PCCM are not mutually exclusive. The same provider can be classified as both a PAHP and PCCM provider, depending on the reimbursement arrangements (capitation v. fee-for-service).

## Options for Mandating Enrollment Into Medicaid Managed Care

There are now three federal authorities under which Medicaid agencies can require beneficiaries to enroll into managed care: as a 1932(a) state plan option, a 1915(b) waiver, or 1115 waiver. Agencies have used waivers to mandate enrollment since the 1980s, but the state plan option was created by the BBA.

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<sup>106</sup> Much of the remainder of this Appendix is drawn from: CMS, *Notice of Proposed Rulemaking: Medicaid Managed Care; 42 CFR Part 400, et.al.* (Washington, DC: CMS, 2001). <http://www.hcfa.gov/medicaid/cms2104p.pdf>

**Table A Comparison of the three federal authorities that Medicaid agencies can use to mandate enrollment into managed care**

	<b>§1932(a) State Option</b>	<b>§1915(b) Waiver</b>	<b>§1115 Waiver</b>
<b>Beneficiary choice of managed care provider</b>	State must offer a choice between at least two managed care providers (MCOs, PIHPs, PAHPs, and/or PCCMs). Except in rural areas where the state may offer a single choice if the beneficiary can choose between at least two physicians or case managers within the entity.	Same as 1932(a); except the requirement to offer a choice of at least two PAHPs/PIHPs may be waived under this authority.	Choice may be waived and state may be allowed to offer beneficiaries a single managed care option in all circumstances.
<b>Groups excluded from mandatory enrollment under the authority</b>	Special needs children, <sup>107</sup> Medicare beneficiaries, and, in most circumstances, Indians who are members of Federally-recognized Tribes <sup>108</sup> may not be required to enroll.	None	None
<b>Relationship to requirements in BBA and proposed Medicaid managed care rule, when implemented</b>	Program and contractors must meet all of the requirements in the BBA (and the Medicaid managed care rule, when implemented). These include requirements for the enrollment process, quality assurance, grievance rights, and coverage of emergency services, among others.	Same as 1932(a)	Same as 1932(a) unless requirement is specifically waived by the Secretary under the waiver.
<b>Approval Process</b>	<ul style="list-style-type: none"> <li>Reviewed by CMS Regional Offices, with consultation from the Central Office at the request of the Region;</li> <li>Once submitted CMS has 90 days to approve, deny, or request more information.</li> </ul>	<ul style="list-style-type: none"> <li>Reviewed by both the Regional and Central Offices;</li> <li>States may use a streamlined waiver application;</li> <li>Once submitted CMS has 90 days to approve, deny, or request more information.</li> </ul>	<ul style="list-style-type: none"> <li>Reviewed by CMS and other Federal agencies;</li> <li>No time limit for response;</li> <li>An evaluation must be part of the waiver.</li> </ul>
<b>Renewal requirements</b>	Once approved no renewal is ever needed.	<ul style="list-style-type: none"> <li>Must be renewed every two years;</li> <li>Requires an independent assessment of the waiver.</li> </ul>	Generally every five years.

<sup>107</sup> Special needs children are children under age 19 who are: eligible for SSI; described in §1902(e)(3) of the Act; in foster-care or other out-of-home placement; receiving foster care or adoption assistance; or receiving services through a family-centered, community-based, coordinated care system receiving grant funds under Title V.

<sup>108</sup> Indians may only be required to enroll if the plan or PCCM is the Indian Health Service or Indian Health Program operated by a Tribe under a contract/compact with the Indian Health Service.

Appendix B  
**2000 Survey Data**

National Academy for State Health Policy  
**HIV/AIDS Related Data in the Survey of State Medicaid Managed Care Policies - 2000**

			AL	AZ	CA	CO	CT	DE	DC	FL	HI	IA	IL	IN	KS	KY	MA	ME	MD	MI	MN	MO
<b>A. ENROLLMENT</b>																						
People with HIV/AIDS participate in risk based managed care on:																						
Mandatory basis in a program serving beneficiaries from any Medicaid population	HIV	34	•	•	•	•	•	•		•	•	•		•	•	•			•	•	•	•
	AIDS	32	•	•	•	•	•			•	•	•		•	•	•			•	•		•
Mandatory basis in a program specifically targeted to people with HIV/AIDS or other chronic illnesses	HIV	0																				
	AIDS	0																				
Voluntary basis in a program serving beneficiaries from any Medicaid population	HIV	13			•				•			•	•				•	•				
	AIDS	13			•				•			•	•				•	•				
Voluntary basis in a program specifically targeted to people with HIV/AIDS or other chronic illness	HIV	3			•												•					
	AIDS	3			•												•					
Mandatory or Voluntary into ANY Program	HIV or AIDS	42	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
<b>B. RISK ADJUST RATES</b>																						
Do you use a comprehensive risk adjustment system with a rate category for people with HIV/AIDS?	Yes	3			•														•			
	No	39	•	•		•	•	•	•	•	•	•	•	•	•	•	•	•		•	•	•
Do you use a comprehensive risk adjustment system that does not have a separate category for HIV/AIDS?	Yes	6				•		•												•	•	
	No	36	•	•	•		•		•	•	•	•	•	•	•	•	•	•	•			•
If you do not use a comprehensive risk adjustment system, do you risk adjust the capitation rate for people with HIV/AIDS?	HIV	2															•					
	AIDS	3															•					
	No	39	•	•	•	•	•	•	•	•	•	•	•	•	•	•		•	•	•	•	•
How do you identify person to whom risk adjusted rates apply?		6			Physician/plan certification	Disability Payment System											At enrollment		HMO identifies			

National Academy for State Health Policy  
**HIV/AIDS Related Data in the Survey of State Medicaid Managed Care Policies - 2000**

			NC	ND	NE	NH	NJ	NM	NV	NY	OH	OK	OR	PA	RI	SC	SD	TN	TX	UT	VA	WA	WI	WV	
<b>A. ENROLLMENT</b>																									
People with HIV/AIDS participate in risk based managed care on:																									
Mandatory basis in a program serving beneficiaries from any Medicaid population	HIV	34	•	•	•		•	•	•		•	•	•	•	•		•	•	•	•	•	•			• (a)
	AIDS	32	•	•	•		•	•	•		•	•	•	•	•		•	•	•	•	•	•			•
Mandatory basis in a program specifically targeted to people with HIV/AIDS or other chronic illnesses	HIV	0																							
	AIDS	0																							
Voluntary basis in a program serving beneficiaries from any Medicaid population	HIV	13				•	•		•	•				•		•							•		
	AIDS	13				•	•		•	•				•		•							•		
Voluntary basis in a program specifically targeted to people with HIV/AIDS or other chronic illness	HIV	3																			•				
	AIDS	3																			•				
Mandatory or Voluntary into ANY Program	HIV or AIDS	42	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
<b>B. RISK ADJUST RATES</b>																									
Do you use a comprehensive risk adjustment system with a rate category for people with HIV/AIDS?	Yes	3						•																	
	No	39	•	•	•	•	•		•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Do you use a comprehensive risk adjustment system that does not have a separate category for HIV/AIDS?	Yes	6											•							•					
	No	36	•	•	•	•	•	•	•	•	•	•		•	•	•	•	•	•	•	•	•	•	•	•
If you do not use a comprehensive risk adjustment system, do you risk adjust the capitation rate for people with HIV/AIDS?	HIV	2												•											
	AIDS	3												•						•					
	No	39	•	•	•	•	•	•	•	•	•	•	•		•	•	•	•	•	•	•	•	•	•	•
How do you identify person to whom risk adjusted rates apply?		6												Drug use & NDC9 Coding in claims data						MCO reports to Medicaid					

**HIV/AIDS Related Data in the Survey of State Medicaid Managed Care Policies - 2000**

			AL	AZ	CA	CO	CT	DE	DC	FL	HI	IA	IL	IN	KS	KY	MA	ME	MD	MI	MN	MO
<b>C. OTHER REIMBURSEMENT MECHANISMS</b>																						
Does your state's Medicaid managed care contract include any reimbursement mechanisms designed specifically for people with HIV/AIDS?	HIV	5									.						.					
	AIDS	5									.						.					
	No	37	.	.	.	.	.	.	.	.		.	.	.	.	.		.	.	.	.	.
If yes, to HIV or AIDS reimbursement mechanisms, what type		6									Reimbursement for actual cost of protease inhibitors.											
<b>D. CONTRACT REQUIREMENTS</b>																						
Keeping up with changing clinical standards	HIV	5							.		.						.					
	AIDS	5							.		.						.					
	No	37	.	.	.	.	.	.	.	.		.	.	.	.	.		.	.	.	.	.
Following state-specific clinical protocols	HIV	2																				
	AIDS	2																				
	No	40	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.
Primary care provider disease-specific experience	HIV	3															.					
	AIDS	3															.					
	No	39	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.
Primary care provider disease-specific education	HIV	4															.					
	AIDS	3															.					
	No	38	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.
Case management/care coordination	HIV	8							.								.		.			
	AIDS	8							.								.		.			
	No	34	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.
Quality monitoring/quality indicators	HIV	8									.						.		.			
	AIDS	8									.						.		.			
	No	34	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.
<b>E. DRUG CARVE OUTS</b>																						
Does your state have a carve-out for HIV Drugs	Yes	7			.						. (b)								.			.
	All drugs FFS	13	.	. (c)				.				.						.				
	No	22		.		.	.	.	.	.		.	.	.	.	.	.	.	.	.	.	.
Did your state adjust capitation rates for HIV drugs?	Yes	6		. (d)												.	.	.	.	.	.	.
	No	36	.		.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.

**HIV/AIDS Related Data in the Survey of State Medicaid Managed Care Policies - 2000**

			NC	ND	NE	NH	NJ	NM	NV	NY	OH	OK	OR	PA	RI	SC	SD	TN	TX	UT	VA	WA	WI	WV		
<b>C. OTHER REIMBURSEMENT MECHANISMS</b>																										
Does your state's Medicaid managed care contract include any reimbursement mechanisms designed specifically for people with HIV/AIDS?	HIV	5								.				.										.		
	AIDS	5								.				.										.		
	No	37	.	.	.	.	.	.	.		.	.	.		.	.	.	.	.	.	.	.	.	.	.	
If yes, to HIV or AIDS reimbursement mechanisms, what type		6								Planned				Not specified												Reimburse 100% of HMO cost for HIV/AIDS.
<b>D. CONTRACT REQUIREMENTS</b>																										
Keeping up with changing clinical standards	HIV	5								.				.												
	AIDS	5								.				.												
	No	37	.	.	.	.	.	.	.		.	.	.		.	.	.	.	.	.	.	.	.	.	.	
Following state-specific clinical protocols	HIV	2								.				.												
	AIDS	2								.				.												
	No	40	.	.	.	.	.	.	.		.	.	.		.	.	.	.	.	.	.	.	.	.	.	
Primary care provider disease-specific experience	HIV	3								.				.												
	AIDS	3								.				.												
	No	39	.	.	.	.	.	.	.		.	.	.		.	.	.	.	.	.	.	.	.	.	.	
Primary care provider disease-specific education	HIV	4								.				.												
	AIDS	3								.				.												
	No	38	.	.	.	.	.	.	.		.	.	.		.	.	.	.	.	.	.	.	.	.	.	
Case management/care coordination	HIV	8								.				.												
	AIDS	8								.				.												
	No	34	.	.	.	.	.	.	.		.	.	.		.	.	.	.	.	.	.	.	.	.	.	
Quality monitoring/quality indicators	HIV	8								.				.												
	AIDS	8								.				.												
	No	34	.	.	.	.	.	.	.		.	.	.		.	.	.	.	.	.	.	.	.	.	.	
<b>E. DRUG CARVE OUTS</b>																										
Does your state have a carve-out for HIV Drugs	Yes	7								.				.												
	All drugs FFS	13	.	.	.	.	.	.	.		.			.											.	
	No	22								.	.	.	.		.	.							.	.	.	
Did your state adjust capitation rates for HIV drugs?	Yes	6								.				.												
	No	36	.	.	.	.	.	.	.		.	.	.		.	.	.	.	.	.	.	.	.	.	.	

National Academy for State Health Policy  
**HIV/AIDS Related Data in the Survey of State Medicaid Managed Care  
Policies - 2000**

Letter	Notes
a	Plans do not report any AIDS or HIV cases in enrolled populations
b	Plans reimbursed for protease inhibitors
c	Alabama and South Dakota do not contract with any comprehensive MCOs, but do contract with PHPs.
d	Additional payments for members using Protease inhibitors.