



Experiences of HIV-Infected Beneficiaries in the Move to Mandatory Medicaid Managed Care in Three States

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Executive Summary

The Center for Health Services Research and Policy (CHSRP) at the George Washington University School of Public Health and Health Services conducted a study over the winter and spring of 1998 of the Medicaid managed care arrangements in nine states.¹ An extension of this study was conducted later involving a closer look at enrollment issues and satisfaction with mandatory Medicaid managed care (MMMC) relevant to HIV-infected beneficiaries. This evaluation, funded by the Health Resources and Services Administration, was done in three of the nine states previously examined, and focused on the experiences of HIV-infected Medicaid beneficiaries in enrolling in managed care and accessing specialized services.

According to the Health Care Financing Administration,² Medicaid serves over 50 percent of all HIV-infected persons living with AIDS and is the largest single payer of direct medical services for HIV-infected persons living with AIDS. As states are moving increasing numbers of Medicaid beneficiaries including the disabled populations into managed care, it is useful to consider the issues of enrollment and MMMC through careful examination of the experiences of beneficiaries with chronic illness. Because the patient/provider relationship is often critical to the care of patients with special conditions, the concern for maintaining these relationships through the transition to MMMC is heightened. This is especially true for HIV-infected persons whose health care must be consistently maintained by experienced providers. Also, information about specialists and benefits is very important for HIV-infected beneficiaries and many others with chronic illness to ensure that they receive access to the appropriate range of specialized services and quality care.

Study Objectives and Approach

The objective of this study was to explore the experiences of HIV-infected beneficiaries in mandatory Medicaid managed care through beneficiary focus groups, and key informant interviews with state officials working in Medicaid or in AIDS administration, providers of HIV/AIDS care to Medicaid beneficiaries, and community advocates for HIV/AIDS. We conducted site visits in three states: Missouri, Oregon and Maryland. These three states represented a range of characteristics in terms of region of the country, the level of experience with MMMC, and the size and make-up of the HIV-infected population.

By collecting and synthesizing information from several different perspectives, we sought to achieve a comprehensive understanding of the experience of HIV-infected beneficiaries in MMMC. We focused on these issues: the experiences and satisfaction of HIV-infected beneficiaries with MMMC, the characteristics of the enrollment process that particularly address the needs of HIV-infected beneficiaries, and reactions of HIV/AIDS community and providers to the transition to MMMC.

¹ Maloy K.A., Rosenbaum S. et al. *Results of a Multi-Site Study of Mandatory Medicaid Managed Care Enrollment Systems: Implications for Policy and Practice*. The George Washington University Center for Health Services Research and Policy, March 1999.

² Information drawn from *Medicaid and Acquired Immune Deficiency Syndrome (AIDS) and Human Immunodeficiency Virus (HIV) Infection* of the HCFA website. Accessed 10/15/98 on Internet: <http://www.hcfa.gov/medicaid/obs11.htm>.

Findings

Involvement of HIV/AIDS Community in Planning for Implementation of Mandatory Medicaid Managed Care Contributes to Improved Enrollment Process

The foresight and preparedness of each state and the HIV/AIDS community for the enrollment of HIV-infected populations into Medicaid managed care appeared to be a contributing factor to the successful implementation of MMMC for HIV-infected beneficiaries.

Substantial preparation took place in Oregon and Maryland, however, the enrollment of HIV-infected beneficiaries in the MMMC program in Missouri was a surprise to many HIV/AIDS providers and advocates. This lack of preparation may have caused barriers to care and gaps in treatment for HIV-infected beneficiaries.

In Oregon, state officials coordinated efforts with community advocates to restructure the list of prioritized services in order to place more services for special populations, including HIV-infected beneficiaries, above the cut-off line for coverage. Also, traditional providers and case managers to the Medicaid and uninsured populations teamed up to ensure that the care of HIV-infected beneficiaries continued through the transition to MMMC with as little disruption as possible.

The planning and development of Medicaid managed care in Maryland included formal involvement of community advocates and providers. The state convened advisory groups involving providers, advocates and patients that gave input on the contents of the MMMC waiver and led to special provisions for HIV-infected beneficiaries. In addition, unique managed care arrangements were made in Maryland that allowed for a smooth transition for traditional providers to continue serving their patients.

HIV-Infected Beneficiaries Successfully Enroll in Managed Care and Maintain Relationships with Previous Providers with Assistance from Case Managers

HIV-infected beneficiaries in Missouri, Oregon, and Maryland received virtually the same minimal to nonexistent information about providers and plans as received by all Medicaid beneficiaries. In each of the states, beneficiaries participating in the focus groups reported having little difficulty enrolling with their previous providers because they were assisted by case managers at the care facility or affiliated with the provider.

State informants and case managers in Oregon and Missouri reported that there were technical problems with the enrollment process initially that worked themselves out over time. However, widespread enrollment problems in Maryland, such as incorrect provider lists and computer errors resulting in incorrect placements, impaired the transition to MMMC and distracted case managers from providing their full range of services. Because beneficiaries were successfully enrolled in their previous providers' plans with the aid of their case managers, most beneficiaries—especially in Missouri and Maryland, were not very knowledgeable about their other choices under the new system or about managed care in general because the transition was handled for them.

Case Management is Integral to the Navigation of Managed Care for HIV-Infected Beneficiaries

We found the most significant element in the success of HIV-infected beneficiaries under MMMC in Missouri, Oregon, and Maryland, was case management. Beneficiaries in each focus group commented about their use of—and in many instances, reliance on their case managers. This service was reportedly built into the managed care systems to some degree in all three states (although one clinic in Missouri and one agency in Oregon provided case management independently from the MMMC program). Case managers in each state navigated the MMMC system for their clients and freed HIV-infected beneficiaries from many hassles pertaining to the rules, bureaucracy, and paperwork that complicate the Medicaid managed care systems.

Comparison of our findings for HIV-infected beneficiaries to the findings from the focus groups conducted during the main enrollment study reveals that HIV-infected beneficiaries expressed higher satisfaction with their health care. The disparity between the experience and satisfaction of HIV-infected beneficiaries and that of the general beneficiaries may be attributed to case management. HIV-infected beneficiaries in Missouri, Oregon, and Maryland, had access to case management services through their providers who assisted them through enrollment and in coordinating their health care. Case management is not provided to the larger MMMC population. Also, HIV-infected beneficiaries were well-connected in a network of community support that promoted their interests and concerns related to health care and other issues such as housing, transportation, and child care. The general Medicaid beneficiaries were required to be more responsible for their enrollment and management of their health care, and do not have this type of organized intermediary whom they know and trust to voice their concerns and coordinate their health care services.

HIV-Infected Beneficiaries Report High Level of Satisfaction with Health Care under Mandatory Medicaid Managed Care

Focus group participants were very satisfied with their medical care under MMMC, but had some complaints concerning complexity of the new system. However, as stated above, case managers in each state navigated the MMMC system for their clients and freed HIV-infected beneficiaries from many hassles pertaining to the rules, bureaucracy, and paperwork that complicate the Medicaid managed care systems. Participants in all three states were satisfied with their relationships with their providers and with prescription benefits, and did not report feeling discriminated against for their Medicaid status or HIV status.

Reimbursement Issues Associated with HIV-Infected Beneficiaries Under Mandatory Medicaid Managed Care May Affect Access to Care

While beyond the scope of the study, some informants did discuss the issue of reimbursement for HIV/AIDS-related services under MMMC. Reimbursement was not identified as an issue in Missouri and Maryland primarily because disabled beneficiaries are not covered by MMMC in Missouri, Maryland established risk-adjusted rates, and prescription drug costs were carved out of the MMMC programs in both Missouri and Maryland. In Oregon,

while risk-adjusted rates are used for beneficiaries with conditions with high medical costs, one informant felt that these rates do not cover enough of the HIV-infected Medicaid population and are not set high enough to account for the costs of treatment. The informant warned that a lack of comprehensive risk adjustment could translate to a lack of access to high quality treatment for beneficiaries as plans and providers are discouraged from offering services to high risk populations such as HIV-infected people.

Conclusion

The experience of HIV-infected beneficiaries under the MMMC programs of Missouri, Oregon, and Maryland, can provide valuable lessons for implementation in other states, and enrollment of other special populations. The support of providers, case managers, and community advocates plays an important role in the navigation of MMMC for HIV-infected beneficiaries. Other important factors include thorough pre-planning of the implementation of MMMC and preparation of providers and community advocates for the transition, as well as careful consideration of reimbursement rates and risk adjustment for costly services as those associated with HIV/AIDS care.

Recommendations

Our findings suggest that the high level of satisfaction of the HIV-infected beneficiaries participating in our focus groups reflected the involvement of case managers. Ongoing education about managed care that involves participation of all stakeholders, and increased financial support for case management services is necessary to ensure that HIV-infected beneficiaries can successfully navigate managed care. We recommend specific strategies to improve the enrollment and experience of HIV-infected beneficiaries in mandatory Medicaid managed care:

- Continue to increase the role of, contracts with, resources allocated to, and oversight of, providers and community-based organizations providing case management services and ongoing education and support for HIV-infected beneficiaries to navigate managed care.
- Enhance efforts for advanced preparation during mandatory enrollment periods with comprehensive information and education available to all stakeholders, especially community-based organizations and experienced providers in the HIV/AIDS community.
- Increase the amount and quality of community-based education for HIV-infected beneficiaries about enrollment and how MMMC enrollment might affect access to traditional sources of specialized HIV/AIDS services.
- Ensure that comprehensive and accurate information about provider networks and experienced providers of HIV/AIDS care is available before enrollment begins so that HIV-infected beneficiaries can maintain continuity of care with their previous providers.

EXPERIENCES OF HIV-INFECTED BENEFICIARIES IN THE MOVE TO MANDATORY MEDICAID MANAGED CARE IN THREE STATES

Introduction

The Center for Health Services Research and Policy (CHSRP) at the George Washington University School of Public Health and Health Services conducted a study over the winter and spring of 1998 of the Medicaid managed care arrangements in nine states.³ This study focused on the enrollment practices in each state with the goal of developing a better understanding of the various states' mandatory Medicaid managed care (MMC) enrollment policies and practices, and the enrollment-related experiences of safety-net providers and beneficiaries. An extension of this study was conducted later involving a closer look at enrollment issues and satisfaction with MMC relevant to HIV-infected beneficiaries. This evaluation was done in three of the nine states previously examined, and focused on the experiences of HIV-infected Medicaid beneficiaries in enrolling in managed care and accessing specialized services.

Enrollment Policies and Practices under Mandatory Medicaid Managed Care: Summary of Findings

For the main enrollment project, case studies were performed in each of the nine sites involving key informant interviews with state Medicaid officials, managed care plan officials, community health center directors and senior staff, and representatives of community-based organizations (CBOs). Also, focus groups were conducted with Medicaid beneficiaries enrolled in managed care plans to achieve an in-depth examination of their experiences in and opinions of

³ Study was conducted in California (Santa Clara and Los Angeles Counties), Connecticut, Florida, Maryland, Michigan, Missouri, New Mexico, Oklahoma, and Oregon.

the new managed care arrangements. The findings of this study are discussed briefly below but are reported in detail in the final report.⁴

It became evident upon analysis of the findings about enrollment policies and practices across the nine states that the overall enrollment process plays two pivotal roles: 1) ensuring that covered individuals actually enter a plan, and 2) giving states the necessary leverage to create a market among managed care plans through the availability of large blocs of covered lives. It was also evident that these two roles are potentially in conflict as many of the desirable characteristics of an enrollment process designed to achieve a high rate of voluntary enrollment could impede rapid establishment of a stable market. The provision of, for example, lengthy choice windows, extensive information about plans and provider networks, and face-to-face choice counseling for enrolling beneficiaries could conflict with the goal for states to enroll large blocs of covered lives quickly with few administrative burdens on participating plans. While states were generally aware of the potential for mandatory enrollment to have a negative effect on access and quality of care, the study found that the procedures for introducing Medicaid beneficiaries to the new managed care system were frequently compromised by a conversion process characterized by too rapid change, inadequate support systems, poorly prepared participants, and an unwillingness by states to slow the process and make substantial corrections.

Perhaps the most compelling finding of the enrollment project concerned beneficiaries' ability to choose their primary care provider (PCP) during enrollment. It was found that enrollees were uniformly more concerned about choosing their PCP than their plan and that the most common reason for plan switching was the inability to find one's previous provider in the plan. Yet, in most states, information regarding plan networks was either inaccurate or

⁴ Maloy K.A., Rosenbaum S. et al. *Results of a Multi-Site Study of Mandatory Medicaid Managed Care Enrollment Systems:*

unavailable to the enrollees. State officials almost universally acknowledged the problems caused by the lack of provider information.

Serious deficiencies in state data and management information systems contributed significantly to the lack of provider information. The lack of information so critical to choice raises a thought-provoking enrollment issue: what constitutes voluntary enrollment under mandatory managed care? In each of the study sites, the information most crucial to voluntary and informed enrollment in mandatory Medicaid managed care—an accurate, timely, and understandable explanation of which providers belong to what plan networks – either was not available during the enrollment process or was available in an incomplete, inaccurate, and potentially misleading format.

Despite the complex and conflicting demands associated with enrollment, and notwithstanding the reality that shorter-than-desirable enrollment periods will probably take precedence over a more gradual transformation through enrollment, there are manageable ways to improve enrollment. These strategies include: 1) enhancing efforts at advance preparation for mandatory enrollment periods with comprehensive information and education available to all stakeholders; 2) imposing more responsibilities on, as well as providing more resources to, brokers to make enrollment more accessible; 3) ensuring that comprehensive provider information is available before mandatory enrollment begins; 4) ensuring that thorough explanations of provider networks are developed and available including how to access certain traditional providers and specialty care; 5) increasing the incidence and quality of community-based education efforts that include a focus on implications of managed care enrollment on access to regular source of care; 6) allowing a greater role for providers in educating patients

about managed care that balances provider abuse concerns with patient needs; and 7) continuing to increase the role of, as well as resources allocated to and oversight of, community-based organizations involved in the enrollment and education process.

Our findings strongly suggest that simply achieving high rates of voluntary enrollment is not a sufficient measure of the adequacy of the enrollment process and whether beneficiaries have gained about knowledge about managed care beyond enrollment. Ongoing and accessible education about managed care, that involves the participation of all stakeholders, is necessary.

Expectations About Experience of HIV-Infected Beneficiaries in Mandatory Medicaid Managed Care

As states are moving increasing numbers of Medicaid beneficiaries—including the disabled populations, into managed care, it is useful to consider the issues of enrollment and MMMC through careful examination of the experiences of beneficiaries with chronic illness. According to the Health Care Financing Administration,⁵ Medicaid serves over 50 percent of all HIV-infected persons living with AIDS and is the largest single payer of direct medical services for HIV-infected persons living with AIDS. Although in many states Medicaid populations such as the disabled or elderly are excluded from MMMC, many beneficiaries with special conditions—in particular many HIV-infected patients, qualify for Medicaid under other categories that were moved into mandatory managed care. For example, a young HIV-infected mother who is not disabled but is eligible for Medicaid as part of the AFDC/TANF-related populations would be moved into managed care.

The discovery in the enrollment project that beneficiaries were not well-informed about the Medicaid managed care enrollment process or provider networks led to speculation that the

1999.

ability of beneficiaries with chronic illness to navigate the MMMC system might be seriously compromised. Because the patient/provider relationship is often critical to the care of patients with special conditions, the concern for maintaining these relationships through the transition to MMMC is heightened. This is especially true for HIV-infected persons whose health care must be consistently maintained by experienced providers. Continuity of care of HIV-infected persons is vital as drug treatments follow strict regimens. Therefore, a smooth transition to MMMC is essential to the successful care of these beneficiaries. Also, information about specialists and benefits is very important for HIV-infected beneficiaries and many others with chronic illness to ensure that they receive access to the appropriate range of specialized services and quality care.

Study Objectives and Questions

The objective of this sub-study was to explore the experiences of HIV-infected beneficiaries in mandatory Medicaid managed care through beneficiary focus groups, and through key informant interviews with state officials working in Medicaid or in AIDS administration, providers of HIV/AIDS care to Medicaid beneficiaries, and community advocates for HIV/AIDS issues. By collecting and synthesizing information from several different perspectives, we sought to achieve a comprehensive understanding of the experience of HIV-infected beneficiaries in MMMC. We focused on these issues: the experiences and satisfaction of HIV-infected beneficiaries with MMMC, the characteristics of the enrollment process that particularly address the needs of HIV-infected beneficiaries, and reactions of HIV/AIDS community and providers to the transition to MMMC.

⁵ Information drawn from *Medicaid and Acquired Immune Deficiency Syndrome (AIDS) and Human Immunodeficiency Virus (HIV) Infection* of the HCFA website. Accessed 10/15/98 on Internet: <http://www.hcfa.gov/medicaid/obs11.htm>.
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Scope and Approach

We chose three of the nine states from the main enrollment study for this sub-study: Missouri, Oregon, and Maryland. The study focused on the largest metropolitan areas in each state: Saint Louis, Missouri; Portland, Oregon; and Baltimore, Maryland. The three states represented a range of characteristics in terms of region of the country, the level of experience with MMMC, and the size and make-up of the HIV-infected population (See Tables 1 and 2 on page 42). MMMC had existed in Missouri since 1995, but the prevalence of AIDS is lower in Missouri than in most other states. The HIV-infected population is even smaller in Oregon, however, Oregon's MMMC system has been in place the longest of any other state and is known as a unique and successful program. In contrast, MMMC was fairly new in Maryland at the time of this study, but the prevalence of AIDS there is much higher than the national average.

Site visits for each state included interviews with key informants and focus groups with HIV-infected Medicaid beneficiaries who had been enrolled in mandatory managed care. This method of evaluation allowed us to examine and compare the perceptions of state officials, providers of HIV/AIDS care, advocates for HIV-infected populations and HIV/AIDS issues, and beneficiaries within and among each state. We did not examine state managed care waivers or contract purchasing specifications, but rather based our report on the various experiences and accounts of people involved in the move to MMMC for HIV-infected beneficiaries. While the informant interviews represent the informants' particular experiences with and perspectives on issues associated with MMMC and HIV-infected beneficiaries, these data provide the basis for identifying common concerns and assessing policies and practices in these three states. The informant interviews also highlight issues that could be informative for other states.

Contact lists of the key informants were developed and state officials, Ryan White CARE Act grantees,⁶ providers, and advocates were selected to be interviewed either by phone, or in person during the site visits. Interview protocols were tailored for each type of informant and interviews lasted approximately forty minutes. Informants were asked to describe their background as it related to the issues of HIV-infected beneficiaries and MMMC, and were then asked series of questions pertaining to the enrollment process and about the effects and experiences with the transition to MMMC of stakeholders involved with HIV/AIDS issues. Informants also assisted with the development of the beneficiary focus groups. In Missouri we interviewed three state officials, one community advocate, two providers, and staff at one Ryan White CARE Act grantee site. Interviews in Oregon were conducted with two state officials, two community advocates, and four providers. In Maryland, two state officials were interviewed as well as one community advocate, and one provider.

The focus groups were coordinated with local HIV/AIDS community-based organizations and health centers providing HIV/AIDS services in each state. Case managers at each of the centers recruited eight to twelve clients or patients for the groups and organized locations for the focus groups to take place. Participation and assistance of the local centers was integral to the success of the focus groups in each state. Involvement of the local centers also helped create a comfortable atmosphere in the groups as focus group participants were in a familiar setting and had been encouraged to come to the meeting by their case manager or other center staff.

⁶The Ryan White CARE act was enacted in 1990 to “provide emergency assistance to localities that are disproportionately affected by the [HIV] epidemic and to make financial assistance available to States and other public or private nonprofit entities to provide for the development, organization, coordination, and operation of more effective and cost efficient systems for the delivery of essential services to individuals and families with HIV disease.” From *The Ryan White Comprehensive AIDS Resources Emergency Act of 1990*, on the HRSA website. Accessed 11/20/98 on the Internet: <http://www.hrsa.gov/hab/dhs/leg.htm>.

While focus groups involve a small sample of individuals and are not meant to be representative of a larger population, they provide detailed descriptions of a situation and allow for issues to be explored in-depth. In addition, we found that participants appreciated hearing the comments of the other people in the focus groups and were able to discuss their perspectives openly because of what they shared in common.

All focus group participants were HIV-infected Medicaid beneficiaries. Eight female African American participants comprised the focus group conducted at a clinic in Saint Louis, Missouri. Most participants were young mothers. There were twelve participants in the focus group in Portland, Oregon conducted at an HIV/AIDS advocacy center. Two of the group's twelve participants were patched in by phone from rural areas in Oregon. Three of the participants were female, and the remaining ten participants were male. The group included a mix of race and a mix of ages ranging from early 20's to mid 50's. Backgrounds related to sexuality and IV drug use were also varied. The Maryland focus group was held at an HIV/AIDS clinic in Baltimore. There were eleven participants, and their backgrounds differed as did those of the participants in Oregon. There were six female participants who were all African American, and five male participants, four of whom were African American and one of whom was white.

Background and Description of Sites

Missouri

Missouri's per capita income is slightly less than the U.S. average with the overall poverty rate being about one-quarter less than the average (See Table 1). While the poverty rate for adults is about average, the poverty rates for children and the elderly are somewhat lower than average, and the poverty rate for African Americans is substantially higher than average. A smaller percentage of Missouri residents are enrolled in Medicaid or are uninsured, and Missouri spends a somewhat greater percentage of its budget on health than the national average. Table 2 shows that slightly more children and considerably fewer adults are enrolled in Medicaid than the U.S. average. Medicaid spending for children and adults is much less in Missouri, and spending for the disabled and elderly is somewhat less than the U.S. average. On the other hand, growth in number of beneficiaries and spending levels is somewhat greater than the national average and Missouri spends a slightly greater percentage of its budget on Medicaid.

Missouri has employed managed care arrangements under Medicaid for many years.⁷ The iteration of the Missouri managed care system currently in place grew out of a §1915(b) waiver that was approved in 1995, and was expanded through a §1115 waiver in 1998. The program, known as Managed Care Plus (MC+), uses fully capitated managed care arrangements. Implementation began in 1995 and expanded in 1996. Enrollment in MC+ is mandatory for AFDC/TANF-related groups, poverty-level pregnant women and children, and children in foster care arrangements. SSI-related Medicaid beneficiaries receive fee-for-service Medicaid and are

⁷ Information drawn from *Missouri State Profile*. Health Policy Tracking Service. Washington, DC. 1997, 163-166.
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not required to enroll in MC+. Thus, any HIV-infected adult who meets the disability requirements of SSI (and all HIV-infected children) are excluded from MC+.

Important to note is the home and community based waiver that Missouri obtained under the traditional fee-for-service Medicaid program. The waiver was designed to ensure that all HIV-infected Medicaid beneficiaries (as well as elderly, mentally retarded and/or developmentally disabled beneficiaries) “who would otherwise require institutionalization in a nursing facility, hospital, or intermediary care facility,” could receive coverage for home and community based services.⁸

In 1997, 7,827 AIDS cases were reported in Missouri representing 1.14 percent of the national total of 641,086.⁹ Missouri reported 577 new cases for an annual rate of 10.7 cases per 100,000 population compared to the national rate of 22.3. The metropolitan area of Saint Louis alone accounted for 3,979 or 55 percent of the reported cases in Missouri and 315 of the new cases at a rate of 12.3 per 100,000.

Oregon

Table 1 shows that Oregon’s population is largely white with a per capita income that is slightly smaller than the U.S. average and an overall poverty rate that is much lower than the average. While substantially fewer people are uninsured or enrolled in Medicaid, Oregon spends a slightly smaller percentage of its budget on health. Table 2 shows that substantially fewer children are enrolled in Medicaid although the rate of growth in beneficiaries is almost double

⁸ Information about the home and community-based waiver was drawn from informant interviews. The waiver is described briefly on the website of the Division of Medical Services, Missouri Department of Social Services. Accessed 11/20/98 on the Internet: <http://www.dss.state.mo.us/dms/pages/programs.html#mcplus>.

⁹ Statistics are reported from the *HIV/AIDS Surveillance Report* of the National Center for HIV, STD, and TB Prevention of the Centers for Disease Control and Prevention. Atlanta, GA. 1997. Vol. 9, No. 2. Accessed 10/17/98 on the Internet: www.cdc.gov/nchstp/hiv_aids/stats/hasrlink.htm. Data reported here only applies to AIDS cases and does not reflect the prevalence or incidence of HIV infection.

the national average. Oregon spends slightly more Medicaid dollars on children, considerably more on the blind and disabled, and considerably less on adults and the elderly. Overall, Oregon spends almost one-third less than the national average on Medicaid as measured by percent of its budget spent on Medicaid.

In 1989, Oregon lawmakers enacted legislation to establish universal health coverage for all residents through a combination of Medicaid restructuring, employer coverage mandates, and increased state investment.¹⁰ A centerpiece of the overall plan was the state's Medicaid reform plan which simultaneously expanded coverage to all low income residents, and established a nearly universal managed care system. The Medicaid reform plan also instituted a health care rationing scheme which eliminated traditional Medicaid coverage requirements in favor of a prioritized condition/treatment coverage approach developed through technical studies and community consultations. Oregon's §1115 Medicaid managed care demonstration proposal was approved with modifications in early 1993, and was the first such demonstration to be approved.

The §1115 demonstration waiver established the Oregon Health Plan (OHP), which is overseen by the Office of Medical Assistance Programs (OMAP) within the Department of Human Resources. Enrollment in OHP was designed to be implemented over two phases targeted at two different coverage groups. Phase I began in 1994, covering AFDC-related families, pregnant women, and children up to age 6 with family incomes up to 133 percent of the federal poverty level. Phase I also expanded coverage to individuals and families earning up to 100 percent of the federal poverty level. Phase II mandated enrollment for children in foster care and out-of-home placements as well as SSI recipients. In addition, Phase II included the

¹⁰ Background information on the implementation of OHP is drawn from Marsha Gold et al., *Managed Care and Low-Income Populations: A Case Study of Managed Care in Oregon*, July 1995 and January 1997 (update).
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integration of prioritized mental health and substance abuse treatment services into the managed care benefit package.

The Oregon Health Plan has managed care contracts with several commercial plans, and also includes several provider-sponsored plans which are made up mostly of providers in rural areas. One provider-sponsored plan, CareOregon, is a partnership of the traditional safety-net providers in the Portland area. It is comprised of the county clinics, Oregon Health Sciences University academic health center, local health departments, and community and migrant health centers.

Oregon reported 4,163 cases of AIDS in 1997 equaling only .65 percent of the national total. 305 of the AIDS cases were newly reported in 1997 corresponding to an annual rate of 9.4 cases per 100,000 population—considerably lower than the national rate of 22.3. Portland reported 81.5 percent of the AIDS cases in Oregon were reported and accounted for 243 or 79.7 percent of the 305 new cases at a rate of 13.6 cases per 100,000 population.

Maryland

The percentage of Maryland's state budget spent on health is the same as the U.S. average, however, the amount spent by Maryland per beneficiary is more generous than the national average (See Tables 1 and 2). The percentage of African Americans residing in the state of Maryland is more than twice the national average. In addition, the poverty rate for the state is lower than the national average which may be correlated to the lower percentage of Maryland residents who are on Medicaid or uninsured as compared to the U.S. average. Also, as shown in Table 2, 19 percent of all children and five percent of all adults in the state of Maryland are covered by Medicaid; these figures are lower than the U.S. average.

In 1996, in an effort to contain costs and improve quality of health care services, the Maryland Department of Health and Mental Hygiene contracted with the University of Maryland at Baltimore County Center for Health Program Development and Management to develop an §1115 waiver application for the state of Maryland. Approval was granted in 1996, and Maryland became the 14th state to implement a Section §1115 managed care demonstration.

Principles guiding the application focused on cost containment (e.g., \$56 million in savings was projected for 1997), the provision of high quality services, achieving improved health status through prevention, and public accountability. No eligibility expansion was sought in the initial trial, although in 1998, the state expanded coverage for pregnant women and children as part of its implementation of the State Children's Health Insurance Program.

The Maryland MMMC program, HealthChoice, contains certain innovations: case management for most costly Medicaid beneficiaries; mandatory inclusion of historic providers in plan networks; the institution of risk adjusted rate payments to plans in accordance with ambulatory care groups; delivery of mental health services through a separate managed behavioral health carve-out agreement; and delivery of substance abuse services provided by the managed care organizations. An innovation of HealthChoice specific to HIV-infected beneficiaries is the diagnostic evaluation service that allows a beneficiary to receive a complete clinical and psychosocial assessment from a provider other than the beneficiary's PCP, even outside the plan's provider network.

The Maryland MMMC demonstration called for enrollment of approximately 80 percent of Medicaid beneficiaries into HealthChoice. Individuals who were dually-eligible for both Medicare and Medicaid, short-term medically-needy eligible persons in spend-down status,

institutionalized persons, and beneficiaries receiving care through other waiver programs were initially excluded from the demonstration.

AIDS is more prevalent in Maryland than in most other states, and the annual rate for 1997 was one of the highest in the nation at 36.8 per 100,000 population. Maryland reported 17,138 AIDS cases in 1997 which equaled 2.67 percent of the national total. The Baltimore metropolitan area accounts for 11,394 or 66.5 percent of these patients and cases there are reported at a rate of 51.6 per 100,000 population—well above the national rate of 22.3.

Findings

The findings below are drawn from information from informant interviews and beneficiary focus groups across all three sites. The sections discussing preparation and involvement of the HIV/AIDS community in the transition to MMMC, and reimbursement issues associated with HIV-infected beneficiaries under MMMC, are based mainly on reports from state officials and community providers and advocates. Discussion of the enrollment process and case management includes contributions from both informant interviews and focus group participants, while the section pertaining to beneficiary satisfaction in MMMC is based solely on reports from focus group participants.

Involvement of HIV/AIDS Community in Planning for Implementation of Mandatory Medicaid Managed Care

The level of preparedness for the transition to MMMC for the HIV-infected population varied greatly among Missouri, Oregon, and Maryland. We examined the actions taken by the states, if any, to address issues related to enrolling HIV-infected beneficiaries, as well as the knowledge and opinions of community advocates and providers about the transition.

Missouri: The population of HIV-infected Medicaid beneficiaries mandatorily enrolled in MC+ in Missouri is comprised mostly of young women who are in the AFDC/TANF-related groups. One care facility in particular, the Helena Hatch Special Care Center for Women (HHSCC) shouldered the burden of serving most of the HIV-infected MC+ beneficiaries in and around Saint Louis. Other providers, health plans, and community leaders refer patients to this facility.

The enrollment of HIV-infected beneficiaries in MMMC (MC+) in Missouri was a surprise to many HIV/AIDS providers and advocates, including the Helena Hatch clinic. The

case management coordinator at HHSCC explained that she and her colleagues had understood that beneficiaries with terminal illnesses were to be carved out of the mandatory enrollment process, however, they learned after enrollment began that this did not apply to HIV-infected beneficiaries (unless patients were qualified for the home and community-based care waiver exemption). Because HIV-infected AFDC/TANF-related beneficiaries were required to enroll in health plans, providers had to scramble to learn about the new MMMC system, and inform their patients about the plans with which they had become affiliated.

Providers such as HHSCC and other community advocates were not fully informed about MC+ enrollment, had little input into the process, and were not properly prepared for the transition. There was also confusion about whether doctors at HHSCC could be identified as primary care providers or as specialists. The case management coordinator stated that her clinic and similar care facilities in the Kansas City area had only recently learned that patients are allowed to choose physicians at these clinics as their PCP if the specialty care is their greatest need. The informant said this fact was “hidden in the fine print” since the implementation of MC+ in 1995.

More confusion about the onset of MMMC in Missouri centered around questions about exactly which groups of HIV-infected beneficiaries were to be mandatorily enrolled. Many community advocates had the impression that male beneficiaries were categorically left out of the move to MMMC, while female beneficiaries had to enroll. This dynamic is a consequence of conditions for Medicaid eligibility. The AFDC/TANF-related Medicaid eligibility requires a family with a child, and, as such, these beneficiaries are usually women. Otherwise, individuals have to be blind, aged, or disabled to qualify. HIV-infected male beneficiaries will usually fall into the disabled category—which was not moved into MMMC in Missouri. The confusion over

why some, primarily male HIV-infected beneficiaries in Missouri are not enrolled in MMMC illustrates a lack of information in general about the MC+ program. This confusion may have caused barriers to care and gaps in treatment for HIV-infected beneficiaries.

Oregon: The HIV-infected population enrolled in the Oregon Health Plan is very diverse and includes beneficiaries from all eligibility categories. Enrollment of HIV-infected beneficiaries in OHP was not a surprise for providers or advocates. The director of OMAP explained that although specific work groups or panel discussions about moving HIV-infected beneficiaries into OHP were not used prior to the implementation of MMMC, OHP did work closely with elderly and disabled population advocates. As a result of the coordination between state officials and advocates, the list of prioritized services was restructured to place more services for special populations—including HIV-infected beneficiaries, above the cut-off line for coverage.

The CareOregon safety-net provider-sponsored plan was established in direct preparation for MMMC. Representatives reported that safety-net providers formed CareOregon as a way for them “to control their own destiny” and the destiny of their patients, many of whom were HIV-infected. There were concerns that beneficiaries would lose access to longtime providers if affiliations with commercial plans were made and the network of safety-net hospitals, clinics, providers, and specialists did not solidify. Of equal concern was access to health care services of uninsured patients that were already being served by the safety-net providers, and would now potentially be eligible for Medicaid under the changed system. CareOregon’s medical director explained that because the safety-net providers had traditionally done the “lion’s share” of caring for the Medicaid and uninsured populations in Oregon, the partnership “came together by design” in order to continue doing so with as little disruption as possible.

Several Portland area HIV/AIDS case management agencies joined forces in a manner similar to the safety-net providers. The agencies had formed an informal consortium in order to work together in serving HIV-infected people in the Portland area. This consortium later received all Title I funding for the state of Oregon from the Ryan White CARE Act and became a formal alliance named the Partnership Project (PP). PP is affiliated with several managed care plans under OHP, but is funded by the support from the Ryan White CARE Act and by its own operating budget. The director of PP explained that after the alliance of case management agencies was formed, working with Medicaid beneficiaries was not complicated much by the transition to managed care because they had time to prepare and orient themselves to the policies of the plan.

Maryland: As in Oregon, the HIV-infected Medicaid population in Maryland is very diverse. Advocacy groups are visible and active. Providers and advocates were well-prepared for enrollment of HIV-infected beneficiaries into MMMC in Maryland, however, glitches in the enrollment system plagued the process.

The planning and development of HealthChoice included formal involvement of community advocates and providers, and some initial issues concerning HIV-infected beneficiaries had already been addressed. The director of the Maryland AIDS Administration stated that before the transition to HealthChoice, the AIDS Administration was working on implementing a program of voluntary managed care for HIV/AIDS beneficiaries. This included work on developing capitation rates, and a special rate for AIDS patients was already in place at that time to account for the high costs of treating HIV/AIDS. The work accomplished by the AIDS Administration during this process laid much of the groundwork for the planning for the §1115 which moved the entire Medicaid population into HealthChoice.

The AIDS Administration director explained that before the implementation of the §1115 waiver, state officials convened two large groups of roughly 200 people each from across the state to meet over a period of three months to prepare for the transition. One group comprised representatives from external organizations, and consumer groups including HIV/AIDS providers, advocates and patients. The other group was more of a technical advisory panel comprised mostly of state officials. The external group “helped guide the direction of what eventually got put into the §1115.” For HIV-infected beneficiaries specifically, this meant special provisions concerning capitation rates, the carving out of protease inhibitors and other HIV-related drugs, and the carving out of all pediatric AIDS patients including symptomatic as well as “indeterminate” patients. The director stated that these were issues that the technical advisors were mostly “attuned to anyway” but the input of the external group was very helpful in nailing down issues and concerns.

As mentioned above, unique managed care arrangements were made in Maryland that allowed for traditional providers to continue serving their patients. One state official explained that new entities and networks were formed in order that each plan contracting under HealthChoice could provide care to HIV-infected beneficiaries. The state official explained that “any willing provider” could participate in Medicaid managed care and the network of providers was not strictly limited by health plan. Physicians who had a history of seeing Medicaid patients were identified as “historical providers” and included in a HealthChoice plan. In addition, it was planned that beneficiaries who did not participate in the enrollment process were to be autoenrolled in the plan with which their previous provider was affiliated.

Enrollment Process

HIV-infected beneficiaries in Missouri and Oregon did not receive any particular accommodations or special treatment (e.g., enrollees with special needs being given a longer period to choose) during the enrollment process. In Maryland, beneficiaries did receive enrollment information that included a booklet describing particular resources and services available to beneficiaries with certain chronic conditions such as HIV/AIDS. Otherwise, these HIV-infected beneficiaries received the same minimal to nonexistent information about providers and plans as received by all Medicaid beneficiaries. In all three states, however, beneficiaries participating in the focus groups reported having little difficulty enrolling with their previous providers largely because they were assisted in the process by their case managers.¹¹

Similar to most Medicaid beneficiaries facing enrollment in MMMC, the HIV-infected beneficiaries in Missouri and Maryland were not very knowledgeable about their plan and provider choices or about the new managed care system. Unlike most Medicaid beneficiaries, however, these HIV-infected beneficiaries were not concerned about this lack of knowledge because their priority in the enrollment process was to stay with their existing providers. Moreover, the availability of case managers to handle the transition to MMMC and ensure that these beneficiaries remained with their providers and were enrolled in the appropriate plan meant that the lack of information did not create enrollment problems for HIV-infected beneficiaries.

State informants and case managers in Oregon and Missouri reported that there were technical problems with the enrollment process initially that were worked out over time. These problems did not adversely affect the HIV-infected beneficiaries. In Maryland, however, serious problems with the enrollment process, such as incorrect provider lists and computer errors

resulting in incorrect placements, had a substantial negative effect on the overall transition to MMMC and adversely affected the ability of HIV-infected beneficiaries to access care.

Missouri: In Missouri, focus group participants noted that the enrollment process was easy. They received letters in the mail about the changes, as well as information about which plans included their doctors in the network of providers. As stated above, these participants were mainly concerned with keeping their previous providers and were not concerned with the lack of information comparing plans or the managed care system in general. Each participant reported calling into the Medicaid office and choosing a plan over the phone. Only one participant was autoenrolled, but because her provider at the Helena Hatch clinic was affiliated in the plan she was autoenrolled in, she did not experience any problems accessing health care services from the clinic.

In contrast to the enrollment experiences of the focus group participants, the case management coordinator at the Helena Hatch clinic stated that when MMMC was first implemented, many beneficiaries were autoenrolled to plans and autoassigned to doctors. Case managers at HHSCC worked to straighten out the enrollment problems and stated that switching plans was not difficult for the case managers to perform, but was a task that required a considerable amount of time and paperwork. Patients would come to the clinic for care, only to realize they were not enrolled in the right plan. The case coordinator explained that for HIV/AIDS patients especially, being able to keep their previous provider is essential because of issues of trust and confidentiality. She explained that HHSCC patients either refused to see new providers, or would not disclose their HIV status. She said, “If we can’t see them, they don’t get care.”

¹¹ The work of case managers is described below under *Case Management and the Roles of Medical Care*

Oregon: Most focus group participants in Oregon reported that they utilized the case management resources from local providers and advocacy agencies for assistance in managing their care and in finding support. The switch to managed care was virtually seamless for this group, as those who were previously on Medicaid stayed with their previous providers and noticed few changes. Those participants newly-enrolled into the Oregon Health Plan reported receiving a lot of information about the choices in plans and providers, and did not report having any difficulty with enrollment.

Focus group participants in Oregon reported few complaints about the enrollment process, and they seemed knowledgeable about their options. One participant was in the process of switching plans in order to return to a previous provider. He did not realize initially that the plan he chose was not affiliated with the small clinic he preferred to go to, so he waited the mandatory six month period before switching plans. He made it clear that he was satisfied with the care he received under the new plan, but wanted to return to the smaller clinic. Others commented that they preferred the larger care facilities and this led the group to agree that there were several good options to choose from for HIV-infected OHP beneficiaries.

One participant was given an “open card” from OHP because he had not yet found a doctor that he wanted as his PCP. The open card allows beneficiaries who are having trouble choosing a PCP to go to any provider over a six month period to search for the right doctor. This participant was searching for a provider practicing “non-Western medicine” and reported that OHP understood his needs and was supportive in trying to help him find a new provider. Other participants were familiar with the Open Card option as well but had not needed to use it.

Maryland: We learned during the main enrollment study that confusion and state data deficiencies gravely impaired the transition to MMMC in Maryland.¹² The state hired an enrollment broker to handle the process and set an aggressive enrollment goal of 60,000 beneficiaries per month. While the broker was prepared to receive this number of phone calls from beneficiaries enrolling or asking questions, circumstances around enrollment created a deluge of calls. In addition to receiving calls from the 60,000 beneficiaries who received enrollment packets each month, the broker also received calls from numerous people who were encouraged by providers and advocates to enroll immediately and not wait until they received an enrollment packet. During initial start-up, there were as many as 3,000 to 4,000 calls a day. Many informants believe that the initial backlog on the phones resulted in many beneficiaries being autoenrolled because they were not able to get through to the enrollment broker to enroll voluntarily. The broker acknowledged being overwhelmed by the tremendous volume of calls during the first few weeks of implementation.

Many of the difficulties encountered with the initial enrollment process resulted from problems with state data. For example, the state used a Medicaid provider master file to create the provider directory used by beneficiaries to select a PCP. This same file was also used by the broker to locate beneficiaries' choice of provider. Unfortunately, the database of 48,000 names was not updated and according to numerous informants was full of inaccuracies. As a result, the broker frequently could not locate a beneficiary's choice for a PCP in the directory. The inaccuracies in the provider directory created so many problems that the majority of the informants, including the state officials, concurred in declaring that the enrollment process

¹² See main report for detailed discussion of MMMC implementation problems in Maryland, (referenced in Footnote 2, page 2).

would have been much easier if the correct data had been available from the state. Informants reported that efforts to correct the provider database problems were still ongoing.

The second major data problem involved incorrect beneficiary contact information provided by the state. This database provided the basis for generating the names and addresses of the 60,000 beneficiaries targeted for enrollment each month. Estimates from informants indicated that 15 percent of the beneficiary database was incorrect. Hundreds of enrollment packets sent to beneficiaries came back unopened because they went to the wrong address. The dual problems with the provider database and the beneficiary database problems created barriers to the broker's efforts to match beneficiaries with selected providers and plans, and probably exacerbated the incidence of autoenrollment.

The director of the AIDS Administration explained that all beneficiaries who did not voluntarily enroll were supposed to be placed with their previous provider as the "default provider," however this system has "been somewhat problematic." Errors can result not only from incorrect provider and beneficiary lists, but also because of other factors including physician affiliation with more than one plan, or the inability of a managed care organization to identify a beneficiary's previous provider once they had been assigned to that plan. One state official commented that this problem with default providers not being correctly selected continues to be "one of the most problematic issues of enrollment."

The director of an HIV clinic in Baltimore also noted that in regards to MMMC, "the biggest hassle we had was during the enrollment process." He cited the problem with default assignment and stated that over the first four to six months HealthChoice was implemented, many of their patients were enrolled in other plans, and also many other were wrongly assigned to the clinic.

Some focus group participants in Maryland had trouble enrolling in HealthChoice. Participants reported receiving notification from the state about the change to managed care, but only one participant received information about all the health plans. Three participants voluntarily enrolled in the health plan before the implementation of HealthChoice upon the advice of their case managers or providers at their clinic. While all participants reported filling out paperwork and sending it to the state to enroll in the plan affiliated with their clinic, or to continue seeing specific providers there, two participants were not enrolled in the right plan and experienced mishaps with the enrollment process. One of these participants reported, “every time I went [to a care facility] I was under a different doctor.” He stated that names listed in the books he was given were often incorrect or had wrong phone numbers, and that he struggled to finally get his paperwork straight at the clinic with the help of a case manager. The other of these participants was autoenrolled into another plan that was far from her home. She found out about the switch when her card arrived with a different provider listed on it, and she called for information. This participant had to wait seven months to switch back to the original plan.

Maryland focus group participants were not knowledgeable about the enrollment process or about their health plan benefits. Although participants were getting the care they needed from their providers once they accessed them, they had little information about their coverage options, and were troubled with complications of the enrollment process and navigation of the managed care system. Case managers and doctors advised their clients to join the plans with which they were affiliated so that the beneficiaries could continue to access the services at the clinic, but most participants were not informed about the benefits covered outside the clinic. Some were surprised to learn they could not use the same hospital or dentist they had used before. Most participants had little knowledge of benefits such as transportation to and from appointments. In

fact, group members exchanged addresses in order to share information about the health plan and benefits. A few of the participants reported receiving information in the mail about their health plan services, but most reported having no information.

Case Management and the Roles of Medical Care Providers

Coordination of services through case management proved to be an essential element in the successful navigation of MMMC for HIV-infected beneficiaries in Missouri, Oregon, and Maryland. Case management includes assistance with enrollment, help with procedures such as referrals, and access to specialized services such as substance abuse treatment. Beneficiaries in each focus group commented about their use of—and in many instances, reliance on their case managers.

Missouri: Case management was reportedly built into the managed care systems in all three states, but was provided in Missouri by staff at the Helena Hatch Special Care Center for Women independently from MC+. The clinic is supported by Ryan White CARE Act funds, and does not receive reimbursement for case management services from MC+. ¹³

HHSCC “runs interference” with the health plans for its patients. To facilitate their patients’ appointments, the case managers acquire referrals for each patient for each appointment, and communicate with other providers and with the health plan to coordinate all aspects of their patients’ care. The case management staff also considers carefully for each client whether they will be best served by the clinic in a primary or a specialty care capacity.

Patients not only rely on the care from their physicians at HHSCC, but also on the help and support from their case managers. Case managers found ways to circumvent some aspects

¹³ This issues is discussed in more detail below under *Reimbursement Issues Associated with HIV-Infected Beneficiaries Under Mandatory Medicaid Managed Care*, page 33.
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The George Washington University School of Public Health and Health Services

of the MMMC system to more easily serve their patients. For example, the clinic established relationships with several PCPs across the three plans with which its providers are affiliated. The PCPs gave beneficiaries a year's worth of referrals to HHSCC to allow the beneficiaries to more easily continue accessing treatment and care at the Helena Hatch clinic with less hassle. Normally a patient would have to return to their PCP periodically in order to acquire more referrals for specialist care, however, these providers allowed for patients to go directly to HHSCC and saw their patients only once a year.

The case management coordinator at HHSCC felt their services were encouraging case management practices in the health plans. She explained that often plans call the clinic for information about patients, knowing that the clinic stays on top of every patient's status. She stated that case management determines the success of any HIV/AIDS patient, and she felt that the health plans were beginning to recognize this through the efforts of HHSCC.

Oregon: In Oregon, case management is a service provided through the Partnership Project service and by staff at care facilities. At PP, the director explained that clients are usually referred by physicians and sometimes by community organizations. Case management in Oregon addresses issues for patients beyond navigation of the managed care system. Case managers perform a case history of each patient, and then design care plans that address a full range of issues such as developing basic life skills, overcoming poverty, and improving communication between patients and their care providers.

PP's services are provided through an "interdisciplinary model/ team approach" so that patients are in contact with a group of three to five professionals including their physician, physician assistants, field nurses, social workers, and counselors. PP's director explained that OHP reimburses plans for case management services provided by field nurses to HIV-infected

beneficiaries, but they do not currently reimburse plans for any other case management services that PP provides.

Many OHP beneficiaries rely on the case management services and support from community advocacy agencies. Several participants explained how the network of AIDS specialists and advocacy groups serving HIV-infected OHP beneficiaries in the Portland area was very tight-knit. As one participant noted, “The resources here are incredible.” One woman described how ill she had been before enrollment in OHP. She was referred to OHP from a drug abuse treatment center and has since recovered from drug addiction and is successfully managing her AIDS condition. She attributes her current health to the treatment she receives from the health plan and the support from two local advocacy agencies.

Maryland: The director of the AIDS Administration in Maryland explained that the managed care organizations are required to offer case management services for HIV-infected beneficiaries. She reported that case management was a required practice for pediatric AIDS patients in fee-for-service Medicaid up to age 17, but for adults it depended on the needs and preferences of the patient. She stated that for patients with “more disorganized lives,” case management was more of a necessity in navigating the managed care system, and she commented that in some cases beneficiaries actually avoid switching providers or plans in order to maintain the case management they have.

One case manager at an HIV clinic explained that their job is to “eliminate or minimize any barriers to care” including dealing with mitigating circumstances in their clients’ lives such as housing, nutrition, mental health, or substance abuse. He went on to explain that for their Medicaid clients, however, enrollment problems associated with HealthChoice now represent the primary barrier to care and that some of the other traditional case management duties are often

overlooked due to the focus on enrollment problems. Erroneous autoenrollment or disenrollment were the main problems discussed by case managers at one clinic. When asked if clients could navigate the system of Medicaid managed care without case management, one case manager commented that in most cases, no. He cited one example of a woman he recently helped to enroll during a confusing episode of her being disenrolled and then wrongly re-assigned—he stated, “ She could never have done this on her own.” As one case manager concluded about the complications of the Medicaid managed care enrollment system: “It negatively impacts patient care.”

Focus group participants reported that they benefited from the case management services at their health care facility. One participant was a patient at an HIV clinic and at a methadone clinic before having to enroll in HealthChoice. The two facilities were not affiliated under HealthChoice, but the participant was able to enroll with his primary clinic’s plan and maintain a relationship with the methadone clinic through coverage of Ryan White CARE Act funds. He reported that his case manager at the primary clinic helped him to coordinate this arrangement “long before” the mandatory changes took place so that he could avoid complications in the enrollment process. Two other participants explained that before being enrolled in Medicaid managed care with the help of clinic case managers they “had nothing” and were very grateful for the assistance.

Interestingly, participants in the Maryland focus group reported that their case managers were too caught up in the managed care system to assist them properly. These beneficiaries reported a lack of attention from their case managers, and problems getting specialized services such as dental care or chiropractic care. They did not fault the health plan for their dissatisfaction, but more the staff at their clinic for not better coordinating their care and

advocating for their needs. One participant reported, “case managers focus on getting you enrolled in HealthChoice and assigned to the clinic, but not on getting your care.” After enrollment was completed, participants felt they were left to manage their care on their own. One woman reported that since her case manager had helped her to be properly enrolled in HealthChoice, she has told her that she has too many people to deal with and this beneficiary should “back off” from trying to get help with other problems. The beneficiary said that now that she is going to the clinic and is properly enrolled, “I’m on my own.”

Beneficiary Satisfaction with Health Care under Mandatory Medicaid Managed Care

Focus group participants were very satisfied with their medical care under MMMC, but had some complaints concerning complexity of the new system. Participants in all three states were satisfied with their relationships with their providers and with prescription benefits, and did not report feeling discriminated against for their Medicaid status or HIV status.

Confidentiality was not a concern for most beneficiaries in terms of disclosure of their HIV status. Two beneficiaries across the three sites reported having specific problems with confidentiality related to individuals whom they felt acted unprofessionally, but they did not attribute these problems to Medicaid or to the managed care system.

Missouri: Focus group participants in Missouri were very satisfied with their care at the Helena Hatch clinic. They reported that they had good relationships with their providers and that waiting time was never a problem. Even when patients did not have appointments, the participants reported that the nursing staff would supply medications for the patients until appointments could be made.

Although participants did not like the managed care system, they were happy at HHSCC because case managers handled much of the paperwork and bureaucracy involved with the health

plans. These participants did complain about the MMMC system being complicated, about having to get approval for emergency care, about only having access to certain hospitals, and about the lack of free transportation or the hassle involved in obtaining any transportation.

The satisfaction of Missouri focus group participants seemed contingent on the work of their case managers at HHSCC. Loopholes in the system such as extended referrals and provision of medications to fill gaps between appointments are making it possible for the clinic to adequately serve their patients under MMMC. Unfortunately, the clinic faces termination of its Ryan White CARE Act funding and may have to close. The continued access of HIV-infected beneficiaries to quality specialized services is left uncertain. At the time of the study, no one addressed the fate of HHSCC's Medicaid patients if the clinic were to close, but the clinic's case management coordinator predicted that other clinics would be overwhelmed with the added patients, and would not be prepared to navigate the MMMC system since HHSCC had endured this burden almost single-handedly.

Oregon: Focus group participants in Oregon reported being very satisfied with their health care and with the Oregon Health Plan. Participants reported easy access to valued resources within the health plans and within the community. Being in a health plan provided stability for several participants who, in the past, did not have insurance coverage or established care plans to manage their condition. One woman described how she had formerly experienced discrimination from doctors who did not want to treat her or were not knowledgeable about HIV. She stated that her current physician checks on her regularly and helps her to avoid “behavior that is going to get me sick” such as missing medications or abusing drugs. One man explained that he had trouble managing his condition consistently in the past, but now “I’ve had the greatest treatment.” At one time he stopped taking medications and became ill, but has

maintained his health with the support and guidance within OHP and in the community. At least two participants reported that their physicians call to check on them or visit them at their homes.

One exception to the satisfaction of the focus group participants in Oregon was one beneficiary participating from home via telephone. He reported having a lot of trouble accessing good care in his area, and explained that he had no choice of plans because there was only one available in his area. This participant struggled to find a physician who was both knowledgeable about HIV/AIDS treatment, and was a member of the plan's network of providers. He reported that his previous provider was "willing to work with me" and the OHP insurance after he had tried other providers and was either turned down or dissatisfied. The other rural caller was very satisfied with his care, but the two agreed that resources for HIV-infected patients were scarce outside urban areas of Oregon.

Maryland: As discussed above, focus group participants in Maryland were satisfied with their medical care at their clinic, but were disappointed in the case management services they received, and felt this negatively affected their ability to access the medical care at the clinic. Participants also discussed the lack of special consideration by the health plan for their needs as HIV-infected patients. Although Maryland state officials worked to anticipate the special needs of populations such as HIV-infected beneficiaries, focus group participants felt the limitations under HealthChoice were too strict and the support from their case managers was not adequate to navigate the system. Participants commented that issues such as access to doctors, specialists, and hospitals, were unfair considering the amount of care and treatment HIV-infected patients require and the importance of strong relationships with providers. One woman commented, "I feel like when you have a sickness or condition like we have, you should be able to go to any hospital they you need and get the services you need." Participants discussed examples of how

exceptions could be made to help them as patients with chronic illness, such as delivering prescriptions when patients are not well enough to come and pick them up. One woman stated that under normal circumstances this would not be necessary, but as HIV-infected persons, “we have special needs.”

Reimbursement Issues Associated with HIV-Infected Beneficiaries Under Mandatory Medicaid Managed Care

It was beyond the scope of this project to examine the complex reimbursement issues related to payment for services delivered to HIV-infected beneficiaries under MMMC programs. However, informants did address their concerns about reimbursement for HIV/AIDS-related services under a fully capitated system and we briefly report these concerns to illustrate important reimbursement issues.

Missouri: Reimbursement for covered HIV-related services under MMMC was not identified as a problem in Missouri for three reasons: 1) the SSI (disabled) population is not required to enroll in MC+ and thus the majority of the most expensive HIV-infected and disabled Medicaid beneficiaries remain in fee-for-service Medicaid, 2) drug formularies were adjusted to carve out HIV-related prescriptions and 3) HIV-infected beneficiaries enrolled in MC+ are apparently evenly distributed across the three managed care plans.

However, as noted earlier, unlike in Oregon and Maryland, the case management services provided by the Helena Hatch Special Care Center for Women in Missouri are not covered under MC+. Consequently, this agency must cover these services under its HIV/AIDS revenue streams. This situation raises the question of whether agencies such as HHSCC should have to cover these services when they represent such a benefit to the Medicaid beneficiaries and ensure that the implementation of MC+ goes more smoothly.

Oregon: In Oregon, one informant expressed concerns about reimbursement because of the disproportionate amount of HIV-infected Medicaid beneficiaries served by CareOregon, which is the safety-net provider-sponsored plan. While, risk-adjusted rates were phased-in as of June of 1998 for the disabled, state general assistance, and expansion (adults with no children) populations, the medical director of CareOregon stated that the risk-adjusted rates did not go far enough in accounting for the high expense of treating HIV-infected patients. He noted that “it is not risk adjustment for the entire OHP membership.” The informant reported that the risk adjustment only applied to 25 percent of the entire OHP population, excluding many HIV-infected beneficiaries who are treated by CareOregon.

CareOregon serves approximately 10 percent of the Medicaid population; however they care for approximately 35 percent of all OHP beneficiaries with AIDS. This statistic does not include the percentage of HIV-infected beneficiaries. CareOregon’s medical director reported that the average amount of beneficiaries with AIDS in the 14 commercial plans is 2.9 per 1,000 whereas the proportion for CareOregon is 7.7 per 1,000. The high proportion of AIDS patients in CareOregon is attributed to the plan’s visibility as a conglomerate of safety-net providers; many beneficiaries choose CareOregon primarily because the two largest HIV clinics are traditional safety-net providers and are affiliated in the CareOregon partnership. Also, the CareOregon facilities, by tradition, attract the uninsured, homeless people, and many IV drug users who are at high risk for HIV infection.

Care Oregon’s medical director also stated that not only is there a lack of incentive for plans to serve HIV-infected patients, but there is a clear disincentive for doing so. He explained that the effective annual capitation rate for OHP is approximately \$2,000 per patient, and that the adjusted capitation rate for HIV-infected beneficiaries is approximately \$3,000. However, he

estimated that the actual annual cost of treatment for HIV-infected beneficiaries, including drugs, can amount to an average of \$10,000 per patient. Therefore, CareOregon's medical director stated that there is a need for further risk adjustment under OHP. He commented that "the state officials realize this is an issue, but they're moving cautiously" because plans with fewer patients in the higher risk groups would be negatively affected by risk adjustment. However, the informant warned, a lack of comprehensive risk adjustment could translate to a lack of access to high quality treatment for beneficiaries as plans and providers are discouraged from offering services to high risk populations such as HIV-infected people.

Maryland: Reimbursement for covered HIV-related services under MMMC was not identified as a problem in Maryland for three reasons: 1) risk-adjusted capitation rates are used based on ambulatory care groups for high-cost patients such as HIV-infected beneficiaries, 2) costs for HIV-related prescriptions are carved out of the managed care agreements, and 3) there is an even distribution of HIV-infected beneficiaries among the HealthChoice plans.

Discussion

Experiences and Satisfaction of HIV-Infected Beneficiaries Under Mandatory Medicaid Managed Care

The HIV-infected Medicaid beneficiaries in Missouri, Oregon, and Maryland interviewed for this sub-study reported being very satisfied in general with their medical care, although there were some important differences by site. We found the most significant element in the success of HIV-infected beneficiaries in dealing with MMMC and accessing care was case management. Case managers in each state navigated the MMMC system for their clients and freed HIV-infected beneficiaries from many hassles pertaining to the rules, bureaucracy, and paperwork that complicate managed care systems. The foresight and preparation during the initial development of MMMC for treating HIV-infected populations under managed care arrangements appeared to be another contributing factor to the successful implementation of MMMC for HIV-infected beneficiaries in Oregon and Maryland.

In Missouri, the state did not make special arrangements for HIV-infected beneficiaries at the implementation of MMMC in terms of preserving relationships with providers or continuity of care. However, providers as well as community advocates with other sources of funding were able to informally ensure that these patients had access to what was considered the best specialized care available in the Saint Louis area, at the Helena Hatch clinic. Case managers at HHSCC act as liaisons between patients and their health plans to shield patients from the hassles and complications of MMMC. While beneficiaries in the focus group reported having no trouble enrolling in MC+ and were satisfied with their health care, the lack of special provisions under MC+ to maintain access to quality care and treatment for HIV-infected beneficiaries leaves the continued good care of these beneficiaries dependent on funding of the community

organizations. This instability becomes more apparent as Ryan White CARE Act funding for HHSCC is in jeopardy and was scheduled to be cut shortly after this study was conducted.

Based on focus group participant reports and informant interviews, we found that HIV-infected patients are very satisfied with their health care in Oregon, and have access to a wealth of resources within the Oregon Health Plan and in the community to help them acquire the best treatment and support. Case management in Oregon provided in clinics and by the Partnership Project is an excellent example of how good coordination of patient services is central to successful treatment of HIV-infected beneficiaries. While beneficiaries report that they are satisfied, the issue of adequate payment rates for plans and providers under MMMC is becoming increasingly controversial in Oregon.

Planning on the part of the state of Maryland in designing HealthChoice, and input from community advocates and providers facilitated the shift to MMMC for HIV-infected beneficiaries. However, lack of appropriate planning for the enrollment process impaired the initial transition and continues to affect new beneficiaries and beneficiaries experiencing changes in their eligibility status. We found that HIV-infected beneficiaries are satisfied with their medical care, but have trouble accessing all the treatment they need because of the lack of good case management. While case management is recognized as an important service for HIV-infected beneficiaries under HealthChoice, case managers are often overwhelmed with enrollment problems for their clients, and therefore cannot adequately serve their needs for coordination of care. Glitches in the HealthChoice enrollment process and adjustment to the changes endured by their providers and case managers seemed to be the most difficult aspects of the transition for these beneficiaries.

Comparison of Experiences in Mandatory Medicaid Managed Care of HIV-infected Beneficiaries and Other Beneficiaries

HIV-infected beneficiaries reported fewer problems about the transition to managed care than other beneficiaries. Comparison of our findings for HIV-infected beneficiaries to the findings from the focus groups conducted during the main enrollment study reveals that HIV-infected beneficiaries expressed higher satisfaction with their health care. HIV-infected beneficiaries voiced many fewer complaints about: lack of information about coverage and providers the need for referrals, access to preferred hospitals, prescription coverage, the availability of mental health and substance abuse treatment, or appointment scheduling and long waits. Also, other Medicaid beneficiaries were generally more concerned about information needs and provider lists than the HIV-infected beneficiaries. In addition, autoenrollment was practically a non-issue for HIV-infected beneficiaries because their case managers helped them to enroll with the same provider. Only one HIV-infected beneficiary in the focus groups was autoenrolled, whereas several of the focus group participants in the main study were autoenrolled.

The disparity between the experiences and level of satisfaction of HIV-infected beneficiaries and those of the beneficiaries overall may be attributable to case management. HIV-infected beneficiaries in Missouri, Oregon, and Maryland had access to case management services through their providers or community organizations who assisted them through enrollment and in coordinating their health care. Case management is not provided to the general Medicaid population enrolling in MMMC. Also, HIV-infected beneficiaries were well-connected in a network of community support that promoted their interests and concerns related to health care and other issues such as housing, transportation, and child care.

Another sub-study completed during the main enrollment study echoes these findings from the study of HIV-infected beneficiaries. We conducted focus groups with minority MMMC beneficiaries in four sites.¹⁴ These groups were interviewed separately about their experiences with enrollment and managed care and included Hispanics, both English-speaking and not; Asians, some non English-speaking; and African Americans. We found during this sub-study that there was virtually no difference in experience between English-speaking minorities and other beneficiaries, however there were differences in the experiences of the foreign language sample.

Surprisingly, the non-English speakers had an easier time with MMMC enrollment than other beneficiaries. Although non-English speakers lacked knowledge of how the process worked, they had providers who acted as intermediaries and ensured proper enrollment. The participants reported that the physician or a staff person at a clinic who spoke the beneficiary's language would give the beneficiary clear directions and assistance with enrollment, often filling out the enrollment forms. These beneficiaries have strong bonds with their providers and reported being unaware of any change in their care. Of course, they are also unaware of their choices, although, in many cases the provider is the only physician in the area who speaks the language or dialect of the beneficiary.

By contrast, the general beneficiaries were required to handle enrollment in MMMC and management of their health care without assistance. The HIV-infected beneficiaries, and the non-English speaking beneficiaries were able to utilize services from their providers through case management or intermediary assistance, or advocate support. The general Medicaid

¹⁴ Two focus group of Hispanic beneficiaries were conducted in Albuquerque, New Mexico, and two were conducted in Miami, Florida. One of the groups in Miami consisted of Spanish-only speakers. One focus group of African American beneficiaries was conducted in Detroit, Michigan. Two focus groups of Asian American beneficiaries were conducted in Los Angeles, California, with a mix of English-speaking and non-English speaking participants in each group.

beneficiaries do not have this type of organized intermediary whom they know and trust to voice their concerns and coordinate their health care services.

Recommendations

The experience of HIV-infected beneficiaries under the mandatory Medicaid managed care programs of Missouri, Oregon, and Maryland can provide valuable lessons for implementation in other states, and MMMC enrollment of other special populations. In each state, the support of providers, case managers, and community advocates played an important role in the navigation of MMMC for HIV-infected beneficiaries. Other important factors include thorough pre-planning of the implementation of MMMC and preparation of providers and community advocates for the transition, as well as consideration of reimbursement rates and risk adjustment for costly services as those associated with HIV/AIDS care.

In Missouri, because of the lack of pre-planning, it may become necessary to enact special provisions under MC+ to provide case management, preserve patient/ provider relationships, and ensure continuity of care. Also, more funding under MC+ to traditional providers such as the Helena Hatch Special Care Center for Women could ensure that HIV-infected beneficiaries are getting the care and treatment they need.

Although advance preparations were made in Maryland for the implementation of MMMC, inaccuracies of information and technical problems in the enrollment process hindered the transition for HIV-infected beneficiaries. Improvements in the databases and procedures can allow providers and case managers to focus on preserving continuity and coordination of care for these beneficiaries.

The experience of HIV-infected beneficiaries in Oregon illustrates how careful pre-planning and effective case management can combine to prevent negative effects of enrollment

in mandatory Medicaid managed care. The well-implemented enrollment system and support from case managers and CBOs appeared to have positive impacts on the experience of HIV-infected beneficiaries in MMMC, and may have allowed for their increased knowledge about managed care and their options within the system.

Our findings suggest that the high level of satisfaction of the HIV-infected beneficiaries participating in our focus groups reflected the involvement of case managers. Ongoing education about managed care that involves participation of all stakeholders, and increased financial support for case management services is necessary to ensure that HIV-infected beneficiaries can successfully navigate managed care. We recommend specific strategies to improve the enrollment process and overall experience of HIV-infected beneficiaries in mandatory Medicaid managed care:

- Continue to increase the role of, contracts with, resources allocated to, and oversight of, providers and community-based organizations providing specialized HIV/AIDS care, case management services, and ongoing education and support for HIV-infected beneficiaries to navigate managed care.

- Enhance efforts for advanced preparation during mandatory enrollment periods with comprehensive information and education available to all stakeholders, especially community-based organizations and experienced providers in the HIV/AIDS community.

- Increase the amount and quality of community-based education for HIV-infected beneficiaries about enrollment and how MMMC enrollment might affect access to traditional sources of specialized HIV/AIDS services.

- Ensure that comprehensive and accurate information about provider networks and experienced providers of HIV/AIDS care is available in benefits packages before enrollment begins so that HIV-infected beneficiaries can maintain continuity of care with their previous providers.

Table 1: State Characteristics

	Maryland	Missouri	Oregon	U.S. Average
Total Population 1996¹	5,094,289	5,402,058	3,243,487	267,636,061 (total)
AIDS Cases 1997²	17,138	7,827	4,163	641,086
Rate of AIDS Cases in 1997 per 100,000 population	36.8	10.7	9.4	22.3
Racial/Ethnic Distribution 1996¹				
White	68.9%	87.4%	93.8%	82.8%
African American	27.1%	11.2%	1.8%	12.6%
Hispanic (counted twice)	3.4%	1.4%	5.5%	10.7%
Asians	3.7%	1.0%	3.0%	3.7%
Native American	0.3%	0.4%	1.4%	0.9%
Poverty Rate 1996¹	10.4%	11.5%	11.6%	14.0%
Children³	19.8%	20.3%	19.6%	22.9%
Adults	8.4%	11.7%	10.5%	11.8%
Elderly	17.4%	11.3%	10.5%	15.7%
Poverty Rate 1996⁴				
African American	20.1%	38.1%	no data	31.8%
Hispanic	16.7%	no data	23.9%	29.0%
Insurance Coverage 1994-1995³				
Medicaid	9.3%	10.7%	10.4%	12.2%
Uninsured	14.4%	13.4%	13.7%	15.5%
% Uninsured < 100% FPL	21.8%	24.9%	16.3%	22.9%
% Uninsured 100-200% FPL	27.4%	21.1%	23.2%	27.4%
Economic Indicators 1995¹				
Per Capita Income	\$27,618	\$23,022	\$23,074	\$24,426
Unemployment Rate	5.1%	4.2%	5.8%	4.9%
% Budget Spent on Health	12.2%	13.4%	11.6%	12.1%

Table 2: Characteristics of State Medicaid and Mandatory Medicaid Managed Care Programs

	Maryland	Missouri	Oregon	U.S. Average
Medicaid Enrollment 1995³				
Total	413,000	695,000	452,000	35,214,000 (total)
% Children	50.2%	50.1%	35.1%	49.6%
% Adults	17.8%	22.5%	46.3%	22.6%
% Blind & Disabled	20.8%	14.0%	10.2%	16.6%
% Elderly	11.3%	13.4%	8.4%	11.0%
Spending 1995³ (per beneficiary)				
Children	\$2,635	\$986	\$1,644	\$1,451
Adults	\$3,280	\$1,162	\$1,717	\$2,080
Blind & Disabled	\$11,026	\$7,169	\$10,154	\$8,784
Elderly	\$12,330	\$8,715	\$8,484	\$10,308
% Growth in Beneficiaries 1995³	4.7%	9.2%	14.7%	7.9%
% Budget Spent on Medicaid 1995³	17.9%	21.7%	14.4%	20.4%
MMMC Initiative	Health-Choice	MC+	Oregon Health Plan	
Program Type	Full Risk	Full Risk	Full Risk	
Year Began⁵ §1915(b) §1115	1991 1996	1995 1996	1994	
Medicaid MC Penetration Rate	80%	42%	90%	
Populations Required to Enroll in MMMC	AFDC/ TANF SSI	AFDC/ TANF	AFDC/ TANF	
Total MMMC Enrollment Spring 1998	330,000	248,000	337,800	

¹ O'Leary Morgan K., Morgan S., eds. *State Rankings 1998: A Statistical View of the 50 United States*. Morgan Quinto Press, 9th edition, 1998.

² National Center for HIV, STD, and TB Prevention of the Centers for Disease Control and Prevention. *HIV/AIDS Surveillance Report*. Vol. 9, No. 2, 1997.

³ Long P., Liska D., eds. *State Facts: Health Needs and Medicaid Financing*. Kaiser Commission on Medicaid, February 1998.

⁴ Three-year average of U.S. Census Bureau Current Population Survey (1993-1995) <http://www.newfederalism.urbsn.org>. Accessed 7/7/98.

⁵ Horvath J. and Kaye N., eds. *Medicaid Managed Care A Guide for States*. National Academy for State Health Policy, 3rd edition, 1997.