

Access to and Quality of HIV/AIDS Care in Medicaid Managed Care Programs: A Summary of the HIV/AIDS Bureau's Research Program, 1996–2000

A. Introduction

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act provides health and supportive services for people living with HIV/AIDS (PLWH) who lack adequate insurance. The CARE Act is administered by the HIV/AIDS Bureau (HAB), within the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services. State Medicaid programs form a critically important part of the context for the implementation of the CARE Act. Medicaid eligibility, benefits, and reimbursement vary widely from State to State; these variations affect the levels of both patient demand for CARE Act-funded services and provider willingness to serve Medicaid clients.

The growth of managed care in Medicaid programs during the 1990s has further compounded the challenges that face Medicaid providers. With the adoption of managed care, Medicaid programs began instituting capitation rates that prepay managed care organizations (MCOs) for the care of their Medicaid enrollees. Generally the rates have been based on enrollees' eligibility categories (AFDC—Aid to Families with Dependent Children, now Temporary Aid to Needy Families or TANF), disabled, or medically needy), with adjustments for gender, age, and geographic region of the State.

Many PLWH are aware of research showing that patients of experienced HIV providers have better health outcomes than patients who have less experienced providers. Hence, it is to be expected that Medicaid enrollees living with HIV will seek out MCOs that offer experienced HIV providers. However, the standard capitation rates that State Medicaid programs pay to MCOs for all categorical eligibility categories typically fall far short of the costs that MCOs incur in providing HIV and AIDS care. Thus, the MCOs that draw disproportionate shares of enrollees living with HIV/AIDS may experience revenue shortfalls, threatening their financial viability. In consequence, MCOs may be reluctant to contract with experienced HIV providers, and such providers may find it difficult to receive fair reimbursement for their services.

In 1996, HRSA's HIV/AIDS Bureau began a program of research to document whether and where such revenue shortfalls might exist, how great they might be, and what their consequences are for access to and quality of HIV care. Clearly, such research requires information about not only Medicaid programs but also the cost of HIV and AIDS care.

This document describes the research program that the HIV/AIDS Bureau has undertaken on Medicaid managed care access and quality for HIV and AIDS, especially as they relate

to costs and reimbursement levels. It also describes other HAB-funded studies that concern the relationship of Medicaid to CARE Act programs.

B. Studies on Medicaid Managed Care Reimbursement

1. R. Conviser, D. Kerrigan, and S. Thompson. The adequacy of reimbursement for HIV under section 1115 Medicaid waivers. *AIDS & Public Policy Journal* 12, 3 (Fall 1997): 112-127.

HAB's first study in this area, undertaken in 1996, investigated Medicaid capitation rates in the first nine States to institute managed care Statewide for their Medicaid programs under Section 1115 waivers to the Social Security Act. The study did not examine States that had received Section 1915(b) waivers, which provide managed care only for certain Medicaid services—for example, mental health only—or cover only certain regions of a State. The nine States studied were Arizona, Delaware, Hawaii, Minnesota, Ohio, Oklahoma, Oregon, Rhode Island, and Tennessee.

The study documented that the 1996 Medicaid capitation rates in these States, varying both within and between States according to categorical eligibility categories, ranged from \$36 to \$721 per month. At that time, several studies were available documenting the costs of HIV/AIDS care in the early to mid-1990s, the period immediately preceding the introduction of protease inhibitors that have since come to be used in combination antiretroviral therapy. These studies showed that monthly care costs were about \$1500 for people living with AIDS, \$1000 for those in earlier disease stages, and \$4500 for those in the last 6 months of life. Thus, the study showed that capitation amounts being paid by Medicaid managed care programs in these nine States were substantially lower than the costs of HIV/AIDS care. The study also noted that in one State, one MCO had nearly four times its fair share of enrollees with HIV/AIDS, placing it at considerable financial risk.

The study recommended that State Medicaid programs consider examining options to assure that such MCOs receive equitable reimbursement for HIV/AIDS care to assure their financial viability. It also identified several options, like risk adjustment, that States had just begun to adopt.

2. R. Conviser, D. Aschman, et al. HIV capitation risk adjustment conference report. Washington, D.C.: Kaiser Family Foundation #1321, 1997 (69 + viii pages).

A variety of Medicaid managed care reimbursement options were discussed at length at an invitational conference on risk adjustment for HIV. The conference, held in Washington, D.C., in May 1997, was co-sponsored by HRSA's HAB and the Center for

Managed Care, the Henry J. Kaiser Family Foundation, the Office of the Assistant Secretary of Health for Planning and Evaluation, the Health Care Financing Administration, and the National Academy for State Health Policy.

The conference brought together HIV service consumers and consumer advocates, providers, representatives of managed care organizations, representatives of State Medicaid programs and health departments, health services researchers, and Federal government employees. In presentations, panels, and breakout sessions, participants addressed a variety of policy, methodological, and implementation questions on risk adjustment for HIV in Medicaid programs.

The conference report raised a variety of HIV reimbursement, access, and quality of care issues from consumer, provider, MCO, and State perspectives. It contains a description of the global risk-adjustment mechanisms that were instituted in 1997 by Maryland and Colorado and the HIV-specific reimbursement plans that were under consideration at that time in New York State. Several alternative approaches to setting special HIV/AIDS rates are discussed, along with methodological and implementation issues. The report concludes with a discussion of attendees' recommendations and future research needs. Recommendations included the following:

- ◆ Diagnosis-based risk adjustment is appropriate for high-cost conditions in places where there is a critical mass of patients.
- ◆ Risk adjustment for HIV/AIDS could serve as a step toward more comprehensive health-based payment systems.
- ◆ Provider networks should include experienced HIV providers and should have information systems capable of tracking care costs.
- ◆ Uniform and comprehensive encounter data sets are needed to create and maintain risk-adjusted payment methodologies.
- ◆ There must be ongoing data collection and analysis on the cost of HIV/AIDS care, which can change substantially with the introduction of new care modalities.
- ◆ An internet website for tracking Medicaid waivers would be useful to stimulate thinking and planning among State programs.
- ◆ Similarly, there needs to be ongoing evaluation of capitation rate methodologies and outcomes.
- ◆ More generally, there need to be financial and outcomes models that will support the development of capitation rates for HIV/AIDS.

3. R. Conviser, S. Gamliel, and L. Honberg. Health-based payment for HIV/AIDS in Medicaid managed care programs. *Health Care Financing Review* 19,3 (Spring 1998): 63-82.

This study follows up on the work described above, discussing reasons why health-based payment systems are needed in Medicaid programs to ensure quality care for enrollees

with HIV/AIDS and equity for the MCOs that enroll them. Important issues identified by people affected by managed care are discussed in the paper and listed in table 1 below. The paper also documents AIDS-specific capitation rates that had been adopted in several California counties, Maryland’s statewide program, a Massachusetts plan, three counties of Ohio (as a pilot program, since discontinued), and a portion of Utah. It also describes transitional enhanced AIDS reimbursement rates being given to high HIV enrollment MCOs in New York State and a Special Needs Plan being considered there for future adoption.

This paper describes the two general health-based payment systems that had been implemented at that time, Colorado’s Disability Payment System and Maryland’s Ambulatory Care Group methodology. Both of these methods group Medicaid enrollees into categories with roughly equal costs of care, based on their diagnoses from a recent previous year. Colorado’s method has a base rate that depends on Medicaid eligibility category, age, gender, and urban/rural residence, and it makes additional payments to MCOs on the basis of enrollee diagnoses that fall into eighteen payment categories. Maryland’s methodology is less transparent but assigns each enrollee to a unique payment category. Unlike Colorado, Maryland has a capitation rate for AIDS that is separate from its general risk-adjustment methodology. However, the methodology does apply to enrollees with HIV (non-AIDS), who can be assigned to any of 17 general payment categories that have widely varying capitation levels. The paper also sketches several non-Medicaid experiments with health-based payment systems in Washington, California, and Minnesota. Evaluation, implementation, and future research needs are discussed.

<p>TABLE 1. Medicaid Managed Care Issues from Various Perspectives</p> <p>State Medicaid Agency Concerns</p> <ul style="list-style-type: none"> Operating within legislatively-imposed budgetary constraints while accommodating the growth of eligible populations Providing fair reimbursement to MCOs while creating incentives for them to provide efficient care for high-risk and special needs populations Limiting opportunities for MCOs to ‘game’ the reimbursement system Getting from MCOs the thorough and timely data needed for health-based payments Monitoring MCO performance to ensure fair enrollment practices, grievance procedures, and quality care Creating financial and other incentives for MCOs to develop care systems for chronically ill and disabled populations Designing MCO contracts that limit the State’s liability <p>Managed Care Organization Concerns</p> <ul style="list-style-type: none"> Maintaining profitability while assuring protection against undue financial risk Pacing managed care implementation to allow for the development of adequate provider networks, referral patterns, information systems, and member services

TABLE 1, continued.

Having to collect and use data in unaccustomed ways
Limiting the administrative burdens associated with developing and maintaining management information systems (to collect encounter and other data)
Developing ways to identify enrollees eligible for enhanced capitation rates while maintaining enrollee confidentiality
Monitoring data to ensure that clinical conditions related to disabilities appear in encounter records (where they are often currently taken for granted)

Provider Concerns

Adapting to changes in the business and care environments
Negotiating payments that will protect their financial viability without compromising the quality of care or imposing undue administrative burdens
Having reimbursement mechanisms flexible enough to cover the costs of new medications and other emerging modalities of care
Creating linkages with culturally diverse patient (psychosocial) support systems to draw and keep enrollees in care
Obtaining and using management information systems to assess cost-effectiveness and treatment outcomes
Developing standardized measures to allow for the evaluation of care quality
Receiving adequate information to keep up with rapid changes in HIV care

Consumer and Consumer Advocate Concerns

Ensuring consumer input into the design of Medicaid managed care programs
Access to experienced HIV care providers as principal providers
Timely access to specialty and ancillary services and investigational therapies
Coordination of health services with necessary social services
Unbiased information to help choose among MCOs and identify experienced providers
Culturally competent educational materials about using managed care systems
Timely external grievance processes to assure MCO accountability to enrollees
Having MCOs develop appropriate ways (e.g., protocols and unique patient identifiers) for sharing of necessary information among providers while ensuring enrollee confidentiality
Access to out-of-network providers in rural areas

4. R. Conviser. Risk adjustment in Medicaid managed care, *HRSA Care ACTION*, June 1998: 6-7.

This paper provides a brief summary of issues that face provider organizations seeking adequate reimbursement for HIV care from State Medicaid managed care programs and discusses several innovative financing strategies that State programs have adopted. It is

meant to be a user-friendly summary of some information contained in the *Health Care Financing Review* article (item #3 in this report).

5. R. Conviser. Medicaid managed care reimbursement for HIV and its implications for quality care. Proceedings from a June 2-3, 1999 conference on 12 Steps to HIV Managed Care. Alexandria, VA: Infectious Diseases Society of America, HIV Quality Care Network, 2000: 79-93.

This paper grew out of a presentation made at the *12 Steps to HIV Managed Care* conference held in 1999. It updates information contained in the previous reports, detailing the following strategies for equitable AIDS reimbursement and quality HIV care that had been adopted in various State Medicaid programs:

- ◆ Health-based payment systems (global risk adjustment),
- ◆ AIDS-specific reimbursement rates,
- ◆ Carve-outs (e.g., for certain antiretroviral medications and viral load tests),
- ◆ Risk pools (funds set aside to be distributed to MCOs with high losses),
- ◆ Risk corridors (limiting MCOs' profits and losses),
- ◆ Stop-loss insurance (against catastrophic losses from a single enrollee), and
- ◆ Centers of excellence (with enhanced care standards for HIV care).

Examples of each type of reimbursement strategy are discussed, as are the AIDS reimbursement amounts being paid to MCOs in the State programs cited. These are shown in table 2 on the following page. The conference as a whole was targeted at HIV providers; hence the paper concludes with a discussion of implications of MCO reimbursement for physician reimbursement.

6. B. Singer, S. Gamliel, R. Conviser. Developing a managed care delivery system for people with HIV/AIDS. *The American Journal of Managed Care* 5, 11 (November 1999): 123-127.

This paper frames and introduces several other papers in the *AJMC* that describe HAB's Special Projects of National Significance. These 5-year projects examined the capitation of services for HIV and AIDS care, ending in the fall of 1999. Most of the projects were instrumental in helping to launch Medicaid AIDS capitation rate experiments, including programs in Maryland, Boston, Los Angeles County, and New York State. The paper addresses aspects of frameworks for program success, including reimbursement rates, economic environments, organizational structures, fiscal issues, access to quality care, and networks and linkages. It concludes by acknowledging the difficulty of balancing access, cost, and quality care for people with all chronic diseases, especially those living with HIV.

TABLE 2.**Strategies for Equitable AIDS Reimbursement and Quality HIV Care in Medicaid Programs**

Strategy	Description	Examples
Health-Based Payment System (Global Risk Adjustment)	Bases capitation for all Medicaid enrollees on the average health status of each MCO's enrollees in a past year	<ul style="list-style-type: none"> ◆ Ambulatory Payment Group method adopted in Maryland, 7/97 ◆ Disability Payment System adopted in Colorado, 10/97, and in Oregon, 6/98; New Jersey planned for 2000 ◆ Major Diagnostic Class system in a voluntary Indiana program
AIDS-Specific Reimbursement Rate	Pays a special AIDS rate for each enrollee documented with AIDS (generally by the 1993 CDC definition, which includes people with CD4+ counts <200)	<ul style="list-style-type: none"> ◆ Two AIDS rates in Maryland (Baltimore/elsewhere) and in one Massachusetts MCO (active/advanced AIDS) ◆ AIDS add-on to categorical eligibility rates in Salt Lake County ◆ Enhanced reimbursement in New York mainstream plans and some California county plans
Carve-Out	Pays for medications, viral load tests, and/or other services on a FFS basis above and beyond the capitation rate	<ul style="list-style-type: none"> ◆ Protease inhibitors in Colorado, Maryland, a Massachusetts specialty plan, Utah, and several California county programs ◆ Arizona makes a retrospective monthly payment for enrollees documented to be using protease inhibitors
Risk Pool	Sets aside funds to be reallocated to MCOs with disproportionate shares of high-cost enrollees	<ul style="list-style-type: none"> ◆ Southeastern Pennsylvania ◆ Tennessee has two pools, one for high-cost enrollees and one for new technologies
Risk Corridor	Each MCO shares profits and losses outside a specified band (e.g., $\pm 5\%$) with the State	<ul style="list-style-type: none"> ◆ Special Needs Plans (SNPs) in New York State ◆ Oregon is using a risk corridor-like mechanism to <u>limit</u> adjustments paid to MCOs
Stop-Loss Insurance	Limits MCOs' exposure from high-cost patients by covering amounts above a threshold	<ul style="list-style-type: none"> ◆ Available to California counties ◆ Adopted in New York ◆ Available 1997-99 in Maryland but since discontinued
Centers of Excellence	Develop special programs to ensure enrollee access to specialists, supportive services	<ul style="list-style-type: none"> ◆ Tennessee network ◆ SNPs in New York

7. R. Conviser and M. Murray. The challenge of providing quality care in Medicaid managed care programs. *The AIDS Reader* 10, 2 (February 2000): 96-101.

This is similar to the paper in the *12 Steps to HIV Managed Care* conference proceedings (#5), with a focus upon the implications of managed care for HIV providers. The paper arrays State Medicaid programs along a continuum of HIV reimbursement strategies from the least to the most comprehensive, as shown in table 3.

TABLE 3. HIV Reimbursement Strategies From Least to Most Comprehensive (by State)					
High-risk pool	Drug carve-out	Comp. risk adjustment*	AIDS rate only†	AIDS rate + comp. RA‡	Special needs program¶
TN, PA	AZ, MD, MA, NJ , NY, UT	CO, IN, NJ , OR	MA, UT	MD	NY
*Comprehensive risk adjustment system based on patients' clinical diagnoses. † AIDS-specific rate without comprehensive risk adjustment. ‡ Both AIDS-specific capitation rate and comprehensive risk adjustment. ¶Accepts only enrollees with HIV/AIDS and family members to age 19. New Jersey is implementing risk adjustment and a drug carve-out in 2000.					

8. R. Conviser, M. Murray, and D. Lau. Medicaid managed care reimbursement for HIV and its implications for access to care. *American Journal of Managed Care*, 6 (September 2000): 122-131.

A national study (the *HIV Cost and Services Utilization Study*) has shown that Medicaid enrollees did not have the same access to protease inhibitor antiretroviral therapy in 1996-97 as did privately insured HIV patients. By 1996, about 40 percent of all Medicaid enrollees nationwide had become participants in managed care arrangements; by 1998, this percentage had exceeded 50 percent, and it has continued to grow. This paper examines implications of Medicaid managed care reimbursement policies for access to care for PLWH, citing the various mechanisms that States have adopted to promote equitable reimbursement for MCOs.

One of the new programs for which monthly capitation rates are given in the paper is New York State's Special Needs Plans (SNPs) for HIV/AIDS. Rates in this program, to be instituted during 2001, will range from \$246 for Aid to Dependent Children/Home Relief children with HIV Statewide to \$2,867 for Supplemental Security Income adults with AIDS in New York City. The full range of rates is shown in table 4. This program is to serve not only PLWH but also their family members to age 19.

TABLE 4. Initial Capitation Rates for New York’s HIV SNPs (to the nearest dollar)				
HIV Status	HIV/Non-AIDS			
Category	ADC/Home Relief Adult	ADC/Home Relief Child	SSI Adult	SSI Child
New York City	\$459		\$737	
Downstate Metro	\$610		\$625	
Rest of State	\$413		\$534	
Statewide		\$246		\$609
HIV Status	AIDS			
New York City	\$2,187		\$2,867	
Downstate Metro	\$1,613		\$2,356	
Rest of State	\$1,016		\$1,191	
Statewide		\$1,302		\$1,779

This paper also documents examples both of States in which certain MCOs have disproportionate shares of PLWH enrollees (Maryland, Oregon, and Tennessee) and of provider organizations that have gone out of business or ceased to enroll new Medicaid beneficiaries because of losses incurred from HIV care (in Florida and Michigan).

9. M. Murray, D. Lau, and R. Conviser. Delivery and financing mechanisms for people living with HIV in California. HIV/AIDS Bureau, HRSA, 2000.

California has perhaps the most diverse array of Medicaid managed care programs in the country, under a series of section 1915(b) waivers from the Federal government. There are six Medicaid managed care models, and counties have the option of choosing which of those models to adopt. Three of them—Two-Plan, Community Organized Health Systems, and Geographic Managed Care—mandate enrollment in managed care. The other three—Prepaid Health Plans, Primary Care Case Management, and Special Projects—have voluntary enrollment. Enrollees in counties with one of the latter three models may elect to receive Medicaid services paid for on the traditional fee-for-service basis.

This pre-publication paper documents publicly available capitation rates for HIV/AIDS care from those counties that have adopted the Two-Plan, Prepaid Health Plan, and Primary Care Case Management models. In 12 counties with a Two-Plan model, which has both a public and a private insurer, AIDS capitation rates ranged from \$962 to \$1123, excluding protease inhibitors and mental health services. In five counties with Prepaid Health Plans, rates ranged from \$692 to \$1925, with no carve-outs. One county used a Primary Care Case Management program with a special AIDS rate. This program was one of the SPNS-funded HIV capitation programs described in #6, and its combined

outpatient and inpatient rates for this program totaled \$1796, excluding protease inhibitors. In most other California counties, the capitation rates were substantially lower than actual care costs.

10. C. Lubinski, J. Bartlett, M. Murray, R. Conviser, et al. Center for HIV Quality Care, Infectious Diseases Society of America, HIV Quality Care Network, 1999-2002.

Following upon one of the recommendations of the HIV Capitation Risk Adjustment Conference (#2), the HIV/AIDS Bureau began funding a Center for HIV Quality Care in 1999 as a Special Project of National Significance. This project is gathering information on topics addressed in the papers described above, relating to HIV/AIDS capitation rates in Medicaid managed care programs. Among the responsibilities of the center are to conduct research on Medicaid managed care programs, paying special attention to HIV issues; gather information on standards of HIV care; survey research on HIV care costs; and post findings on a website.

State Medicaid Program Profiles and Capitation Rates. Information being collected on State Medicaid programs (both those that have instituted managed care and those that remain on a fee-for-service basis) includes covered benefits, barriers (such as restrictive eligibility requirements) to receiving these benefits, and limits on or exclusions of key services. A special section of each State profile is devoted to the presence or absence of Medicaid program provisions for people with HIV/AIDS; this information is being posted on the web at <<http://www.idsociety.org/HIV/CEN/ToC.htm>>. Health care profiles will have been completed for all States by 2001. The website contains a glossary of key State profile terms. The Center has also been updating information on reimbursement rates paid to MCOs by State Medicaid programs. Website entries highlight benefits that are carved out of the rate and the States' methods for adjusting rates by age, eligibility category, illness (if applicable), etc. Information is included for SSI enrollees and for dual eligibles, i.e., people with both Medicaid and Medicare coverage. These State reports also include capitation rates for Medicare+Choice.

Quality of Care Standards. As a part of its charge, the Center is gathering and making available standards of care for HIV, including ancillary as well as primary care services.

Cost of Care. In its second and third years, the Center will be gathering HIV/AIDS care cost information. Some of this information will come from literature reviews; some will be obtained under subcontract with the New York State AIDS Institute.

11. S.H. Fakhraei, J. Kaelin, and R. Conviser. Comorbidity-based payment methodology for Medicaid enrollees with HIV/AIDS. Center for Health Program Development and Management, University of Maryland, Baltimore County and HIV/AIDS Bureau, HRSA, 2000.

An analysis of Medicaid data from Maryland in recent years reveals that there is nearly as much variability in the costs of HIV care as in the costs of AIDS care, although a higher proportion of AIDS patients are in the higher cost categories. Given such variability, it may be inappropriate for Maryland to be paying MCOs quite generous capitation rates for AIDS (ranging from about \$1800 to \$2150 per member per month, with protease inhibitor, viral load test, and mental health care carve-outs) but far lower rates for HIV (ranging from about \$45 to \$1100).

This HAB-funded study explores Medicaid HIV/AIDS reimbursement methodologies that take into account comorbidities experienced by PLWH enrollees. It describes two models. The first uses three base payment categories—for enrollees with asymptomatic HIV, symptomatic HIV, and AIDS—and has eight categories for additional capitation payments based upon patients' comorbidities. The second model has two base payment categories, for HIV and AIDS, and four comorbidity payment categories. Under either model, a diagnosis in any of the comorbidity categories would result in an additional payment to the enrollee's MCO. Not surprisingly, the first model yields capitation payments that are closer to the actual cost of care, while the second is easier to administer. Enrollees with a history of injection drug use had more comorbidities, and thus higher costs, than did other enrollees with HIV.

Because managed care encounter data were of such poor quality in some MCOs, even in late 2000, Maryland's Medicaid program decided to delay adoption of a comorbidity payment methodology until mid-2001. However, as an interim measure, the State decided to pay special capitation rates of about \$1400 per month for HIV and about \$1800 per month for AIDS. In contrast with previous payment methodologies used in the State, both rates include antiretroviral medications.

12. M. Murray. The relationship between CARE Act funding mechanisms and Medicaid managed care. HIV/AIDS Bureau, HRSA, 2000.

This study examines the relationship between Medicaid and CARE Act programs in seven States—CA, CO, MD, MA, NY, OK, and TN—with respect to access to care, delivery of health care services, and financing of HIV/AIDS services.

Most States do not provide health care to people living with HIV—non AIDS (since one must meet disability criteria to qualify for Medicaid through the SSI program). Four of the States studied (MA, NY, ME, TN) had expanded or were in the process of expanding

Medicaid coverage for PLWH. Maine had received a waiver solely to provide Medicaid coverage for PLWH (that has yet to take effect), and Massachusetts was seeking an amendment to its existing waiver (subsequently awarded early in 2001) to allow PLWH to enroll into its program. Most of States' medical resources were concentrated in urban areas; access to care in rural areas varied tremendously. Mostly rural Tennessee had expanded access to care through the Centers of Excellence program whereby physicians with expertise in treating PLWH were responsible for patient care in nine centers throughout the State. Likewise, Maryland provided care to uninsured PLWH (with CARE Act funds) in rural parts of the State through a group of clinicians who travel to rural areas (mostly the Eastern Shore). However, care for PLWH in rural Oklahoma and Colorado was limited.

New York's Special Needs Plans (SNPs), and Tennessee's 'Centers of Excellence' program were specifically geared toward the needs of PLWH, offering coordinated outpatient and inpatient services in settings designed to provide aggressive early and acute interventions. Maryland had several Medicaid managed care contract provisions specific to PLWH, including AIDS case management, substance abuse treatment, drug carve-outs, and an AIDS-specific capitation rate. The inclusion of ancillary services in its Medicaid program allowed CARE Act Title I funds to be used for other services such as food, rent, and utility assistance. All States studied enrolled their SSI populations into risk-based managed care. Some (CA, MA, NY) did so on a voluntary basis, while the remainder mandated that the SSI population enroll in managed care. States like Oklahoma with low Medicaid reimbursement rates tended to limit patients' benefits by restricting the number and types of optional services offered, for example, limiting the number of prescription medications or imposing co-pays on covered benefits. States whose Medicaid agencies placed limits on the benefits package or required co-pays on covered services also often restricted services provided by the CARE Act.

C. Studies on Care Quality, Access, and Cost

13. S. Glied. The likely impact of Medicaid managed care upon the demand for CARE Act services in New York City. Medical and Health Research Association of New York City, 1998.

The purpose of this local evaluation study, one of three focusing on managed care funded in FY97, was to forecast the potential effects of the introduction of Medicaid managed care on programs funded through Ryan White CARE Act funds in New York City. At the time of the study, New York State was developing its Special Needs Plans (SNPs) for PLWH and their families. The study's principal source of data was the Community Health Advisory and Information Network (CHAIN) Client Survey (Wave 3, 1996). This longitudinal study of HIV-positive persons in care in New York City collects information

regarding sociodemographic characteristics as well as experiences with access to and use of medical and social services. In wave three of the survey, conducted between February 1996 and March 1997, 480 respondents were interviewed. The CHAIN data were adjusted to reflect the demographic and stage of illness characteristics of the city's AIDS population. Administrative data from Medicaid, ADAP, and Title I-funded services were used to reconcile CHAIN spending figures to New York City averages. This was necessary because it was impossible to determine exact payers from the CHAIN client survey.

The best estimate of the effect of SNP enrollment was an increase in mental health visits to CARE Act-funded services of 8,600 visits (about 8 percent of current caseload). The study also predicted an annual increase in demand for substance abuse services of 900 visits (about 2 percent of current caseload); an annual increase in demand for case management services of 2,900 visits (about 1 percent of current caseload); and an annual increase in demand for nutrition services of 150 visits (about 1 percent of current caseload). Maximum estimates were much higher, but they were based on the assumption of very severe cutbacks in Medicaid service provision and on the assumption that all reductions in visits would translate into increased demand at CARE Act-funded programs.

The results suggested that any change in the demand for CARE Act-funded services would not be very sensitive to the composition of the population enrolled in managed care, with three exceptions. Men who have sex with men (MSM) use many more mental health services than do injection drug users (IDU), and since this is an area where forecast effects on CARE Act-funded programs are relatively large, disproportionate enrollment of MSM could substantially increase the demand for these services. Blacks use considerably more case management services than either whites or Latinos, so that disproportionate enrollment of blacks could increase the case management burden on CARE Act-funded programs. Finally, women use slightly more of each of the four services than do men. Disproportionate enrollment of women could increase the demand for CARE Act-funded services across all four service areas.

14. E. Wolff, L. Eldred, and C. Weston. Assessing the impact of Medicaid managed care on Ryan White-funded organizations in Maryland. Maryland AIDS Administration, Department of Health and Mental Hygiene, 1998.

HealthChoice, Maryland's Medicaid managed care program, began enrolling clients in July 1997. In this study, the Maryland AIDS Administration, Department of Health and Mental Hygiene, assessed the impact of HealthChoice during its first year of operation on clients, services, budget, and staff at CARE Act Title I- and II-funded community providers.

Of the 92 CARE Act Title I- and II-funded provider organizations in Maryland, 55 (60 percent) were selected for participation in the study; 51 (93 percent) of these agreed to

participate. To be selected, sites had to be funded directly from the Maryland AIDS Administration and providing direct client services. In addition, Baltimore City and Baltimore County programs had to have served >25 CARE Act clients in 1997 to be included. Finally, if an organization had multiple CARE Act-funded programs, the program serving the largest number of clients was included in the sample. Nineteen (37 percent) of the participating organizations were health departments, 12 (23 percent) were community-based organizations, seven were community health centers, five were hospital-affiliated clinics, three were hospices, and the remaining five were of other types.

The study used a three-part instrument. Part one captured organizational data and client demographics from CARE Act Quarterly Administrative Reports (QAR's). Part two, completed by participants before the interview, included primarily closed-ended questions to collect further descriptive information about the organization and to assess HealthChoice's impact on staff, clients, and finances. Part three consisted of in-person interviews of CEOs (24 percent) and program directors (73 percent).

Nearly half (43 percent) of the participants indicated they were contracting with MCOs to provide HIV-related services to Medicaid clients. Private agencies (56 percent) were more likely to contract than public agencies (29 percent) ($p=.058$). More than half (63 percent) of the participants reported that HealthChoice changed their HIV-related services between July 1997 and June 1998. Though 45 percent reported a change in overall number of clients served, there were no differences exceeding 15 percent in clients' sociodemographic characteristics. The service area most greatly affected was case management, with 55 percent of case management providers reporting changes in quantity and/or scope of services provided.

During the study time period, highly active antiretroviral therapy (HAART) came into widespread use. Most of the participants (80 percent) indicated that HAART had changed their HIV-related services, and private and public agencies reported no significant difference in the impact of either HealthChoice or HAART on services. When asked which had had a greater impact on their services, 39 percent mentioned HAART and 29 percent mentioned HealthChoice.

HealthChoice had an effect on program staff and budget. Nearly one-fourth of the participants (22 percent) reported that HealthChoice had changed their number of staff, and twice as many (44 percent) reported that it had affected their overall budget. Most participants (80 percent) reported that the amount of CARE Act Title I or II funds requested was unaffected as a result of HealthChoice. However, half (49 percent) expected that the amount requested over the next year would change as a result of HealthChoice.

Qualitative responses from several open-ended questions were coded and categorized. Forty percent of participants reported that HealthChoice had had no positive effect upon them. Among those reporting a positive effect, half (55 percent) indicated that client care had been

enhanced. Additionally, 21 percent stated that HealthChoice had had a beneficial effect upon their organization. However, ninety percent of the participants indicated that HealthChoice had had at least one negative effect. Eighty percent of them made reference to HealthChoice system issues, such as difficulty with client eligibility, enrollment, or referrals. About half (56 percent) were concerned that HealthChoice resulted in quality of care poorer than that provided under the prior fee-for-service system. Finally, two-fifths (40 percent) of the respondents indicated that HealthChoice had had a detrimental effect on their organization, and two-fifths (38 percent) reported that HealthChoice had had a negative effect on case management services.

In the first year that HealthChoice was implemented, CARE Act-funded agencies' services, budget, and staff were affected. Private agencies were more likely to contract with MCOs than public agencies. Of all CARE Act-funded services, case management was affected more than others. Since MCOs are required to provide case management services, agencies that do not contract with MCOs may lose their ability to provide case management to many of their clients.

A majority of the many negative responses to HealthChoice were related to system issues such as enrollment. These issues are common when a large medical financing system is transitioning from fee-for-service to managed care, and it is anticipated that many of them will improve with time. Contracting with MCOs may be a critical factor in predicting survival in the changing arena of health services delivery. Other factors, such as management experience, attitudes toward HealthChoice, collaboration with other agencies, and change in agency goals and funding may also contribute to organizational survival.

Further change among agencies was expected in the second year of HealthChoice as its impact was more fully realized. Agencies providing free services may find it difficult to continue this practice unless they pursue new funding sources. Interestingly, participation in this study may have had a beneficial effect on agencies by prompting them to examine their agency critically in light of HealthChoice. In short, while some organizations may effectively adapt to these changes, others will change their mission, nature, and scope of work, or they may cease providing services altogether. This study may lead to a greater understanding of how agencies successfully adapt to the new Medicaid managed care environment and assist agencies in other States in developing strategies to face these challenges.

15. B. Akil and C.L. Pearce. Evaluation study of the County of Orange Health Care Agency and CalOPTIMA HIV-related services. County of Orange Health Care Agency, 1998.

This local evaluation study, also funded in FY97, compared several measures of care frequency and outcomes at a CARE Act-funded clinic—The County of Orange Health Care Agency (HCA) Special Disease Clinic—and a Medicaid managed care program, CalOPTIMA. The latter provided care at both a university-based health clinic and through contracted physicians in their private offices; study measures were thus generated for three types of

sites. Patients studied had received a minimum of 12 consecutive months of care from either HCA or a CalOPTIMA provider between January 1996 and August 1998. Existing data sets were used, and the study was limited to individuals receiving antiretroviral therapy for HIV infection.

More than 73 percent of study subjects at all sites were male. A majority of HCA patients (51 percent) were Hispanic, while a majority of CalOPTIMA patients at both academic (52 percent) and physician practice settings (61 percent) were white. Men having sex with men was the primary HIV risk exposure reported by HCA and CalOPTIMA academic health clinic patients (60 percent and 51 percent, respectively); CalOPTIMA private physician patients reported injection drug use as their major risk factor (44 percent). Potential confounders and important covariates were considered in all multivariate analyses. Bivariate and multivariate Poisson regression was used to model the number of service deliveries for each of the three study populations. Logistic regression was used to model the odds of having a CD4+ cell count increase of at least 50 cells from the baseline count to the final measurement.

In multivariate analyses (with controls for risk factor, gender, and CD4+ count), patients of CalOPTIMA private physicians had significantly more visits with physicians, physician assistants, or nurse practitioners than patients receiving care at the CalOPTIMA academic setting or HCA, by a ratio of roughly 4:2:1. Nursing visits were significantly higher in the CalOPTIMA physician settings and significantly lower at the academic setting than at HCA. However, HCA patients had significantly more social work/case management visits than did those at either type of CalOPTIMA setting.

The odds of having a CD4+ cell count increase of 50 during the study period did not differ significantly for HCA and CalOPTIMA private physician patients after adjusting for baseline CD4+ count and the rate of medical visits. However, given the same controls, CalOPTIMA academic health clinic patients were 89 percent less likely to have such an increase than were HCA patients. Thus, although patients receiving care in managed care settings had access to more health services than those receiving care in a public health setting, there was no commensurate improvement in the medical outcome investigated.

16. J. Keruly, R. Conviser, and R. Moore. The association of medical insurance and other factors with receipt of antiretroviral therapy. Johns Hopkins Medical Institutions and HIV/AIDS Bureau, HRSA, 2000.

This paper (which will be published during 2001 by the *American Journal of Public Health*) reports on a study of 959 patients enrolled in the Johns Hopkins HIV clinic for at least two visits and 90 days between 1996 and 1999. The clinic characterized its

patients as being at least 80 percent commercially insured, at least 80 percent government insured (mostly Medicaid), at least 80 percent uninsured (nearly all were recipients of CARE Act-funded services), and 20-80 percent uninsured (also CARE Act service recipients). Demographic characteristics examined included age, sex, race, urban/non-urban residence, HIV risk factor, and education. Other variables analyzed in relation to receipt of highly active antiretroviral therapy (HAART) included clinical markers (CD4+ counts and viral loads), proportion of missed visits, and presence of a psychiatric diagnosis.

Patients with commercial insurance were significantly more likely than government-insured or uninsured patients to have access to HAART during the first part of the study period (January 1996-March 1997). While differences persisted into the remaining part of the study period (April 1997-December 1998), they were smaller and were no longer statistically significant. Caucasian race was significantly associated with better access to HAART in the first part of the study period but not in the second. Injection drug use was a deterrent to HAART access in both parts of the study period but was a stronger deterrent in the first part. Missing more than 25 percent of scheduled visits was also associated with poorer access to HAART, and it was most highly associated with a failure to reach an undetectable viral load, even with controls for injection drug use.

17. B. Williams, M. Murray, D. Harris, and R. Conviser. The quality of HIV services in New Mexico's Medicaid program. University of New Mexico Health Sciences Center and HIV/AIDS Bureau, HRSA, 2001.

Partners in Care/Ryan White (PIC/RW) has been New Mexico's sole Title III program since 1991 and has maintained a quality assurance program since 1994, monitoring its Statewide network of clinical providers for adherence to standards of care. These standards (modified DHHS guidelines) are established by the program's Medical Director in consultation with a medical advisory board and distributed to all providers annually. Program staff conduct on-site chart audits to verify compliance 6 months after distribution of the standards.

The primary purpose of this study is to determine whether practice location, provider characteristics (e.g., specialty, practice type, practice location, HIV experience), or patient characteristics (e.g., demographics, risk factor, insurer, clinical indicators) are associated with adherence to established standards of HIV care. Sixty-three of the network's primary care clinicians who provided care to HIV patients for at least 6 months between January 1, 1997 and June 30, 2000 are included.

A random sample of 448 patients enrolled in PIC/RW, stratified by provider, and receiving care for at least 6 months from the same provider, is to be analyzed. Of these patients,

81 had more than 1 year's data. Clinical indicators were obtained from a retrospective review of patients' charts.

18. J. Bailey, D. Van Brunt, S. Raffanti, G. Somes, M. Murray, and R. Conviser. The impact of the Ryan White CARE Act on quality and outcomes of care for HIV/AIDS in a Statewide Medicaid managed care program. University of Tennessee, Memphis, and HIV/AIDS Bureau, HRSA, 2001.

Tennessee is one of several States that have expanded Medicaid eligibility to provide insurance coverage to people who would otherwise be uninsured. Hence, in addition to those with AIDS who may qualify for Medicaid through disability coverage, many people in earlier stages of HIV disease receive Medicaid coverage. Between 1993 and 1997, about one-half of Tennessee's people living with HIV and AIDS received some Medicaid coverage and more than 35 percent received at least 320 days' coverage.

Because Tennessee has not had to rely exclusively on the CARE Act funds to provide care for uninsured PLWH, there is a potential for it to use these funds to improve systems of care for PLWH. However, the capitation rates that the TennCare (Medicaid) program pays to MCOs are quite low. Even when risk pool amounts are added to the standard capitation rates, Medicaid reimbursement remains substantially below the cost of HIV and AIDS care. In response to this problem, consumers, providers, State agencies, and managed care organizations (MCOs) have organized and developed a Statewide HIV/AIDS Centers of Excellence program with the intent of improving the quality of care. The nine centers participating in the program receive CARE Act funding.

With support from the Center for Healthcare Strategies, Tennessee conducted an evaluation of HIV care within TennCare from 1992 through 1997. During that period there was a decline in hospitalizations among people with HIV from 33 percent to 16 percent and a decline among those with AIDS from 44 percent to 22 percent. Other indicators of quality of care, such as rates of filling prescriptions for antiretroviral and prophylactic drugs and rates of opportunistic illnesses, also showed improvement. However, deaths from HIV/AIDS during this period declined more slowly in Tennessee than in the Nation as a whole or in neighboring southern States.

For 2000-2001, HAB is funding a continuation study that seeks to evaluate access, quality, and outcomes of HIV and AIDS care within TennCare. The TennCare administrative claims database has also been linked with the Statewide HIV/AIDS Reporting and Surveillance System (HARS) database of the Tennessee Department of Health and Vital Records. This allows investigators to track and monitor care quality and outcomes for all persons served by TennCare known to be living with HIV and AIDS. The continuation study will expand and improve the quality monitoring database for these enrollees to include 1998 and 1999. It will also allow the investigators to define sources

of care for each enrollee so that exposure to the Centers of Excellence, and particularly to CARE Act support, can be estimated. The study's objectives are to produce and refine quality and accessibility of HIV/AIDS care indicators, to determine how service receipt is linked with patient outcomes, and to determine whether exposure to RWCA-funded Centers of Excellence is associated with improved care process and outcome measures.

19. R. Moore et al. Development of a multi-site HIV database to ascertain HIV resource utilization. Infectious Diseases Society of America and Johns Hopkins Medical Institutions, 1999-.

This multi-year study is being coordinated by the Agency for Healthcare Research and Quality, with additional funding from HRSA and the Substance Abuse and Mental Health Services Administration (SAMHSA). Since the introduction of protease inhibitor combination therapy late in 1995, both the course of HIV disease and the cost of HIV care have changed dramatically for many patients. There have been substantial drops in HIV-related morbidity and mortality, and pharmaceuticals have supplanted hospitalizations as the major source of HIV/AIDS care costs. As a result of these changes, historical estimates of the cost of HIV care are no longer useful, and there is a need to collect real-time estimates of resource use associated with HIV care. (This was a recommendation of the HIV Capitation Risk Adjustment Conference; see #2.) This study will allow for a description of changing resource use in a rapidly changing therapeutic milieu. It will also allow for analyses of the relation between service delivery costs and client characteristics, including sociodemographic attributes and clinical stage of disease.

The HIV Quality Care Network, a section of the Infectious Diseases Society of America, is conducting this study. In its first year, the study collected and analyzed 6 months of service utilization data (from the first half of 1998) from 16 medical centers around the country that serve more than 10,000 HIV and AIDS patients. Nearly all of the participating centers receive Ryan White CARE Act funding for clinical or other services. Data are being collected for both halves of 1999, and sites were added in several HIV epidemic epicenters (including both southern and northern California, Florida, and Texas). The study will provide information more recent than that collected in the HIV Cost and Services Utilization Study (HCSUS) conducted in 1996-97. This information will be useful in assessing care costs in both CARE Act and Medicaid programs and in setting capitation rates for HIV in managed care programs.

Analysis of a subset of data from the pilot year showed results very similar to those reported from HCSUS, despite the non-representative patient population in the network of participating sites. Not surprisingly, hospitalization was more frequent for patients in later disease stages and for injection drug users than for people with other HIV risk factors. Overall, 15 percent of patients had hospital admissions in the 6-month study

period. Use of HAART was associated with lower hospitalization rates (13 percent vs. 16 percent for those not on antiretroviral therapy) but with increased outpatient visit rates (4.1 average visits in six months vs. 2.8). Additional years' data will make longitudinal analyses possible.

D. Conclusion

This research program began in 1996 by documenting that the introduction of managed care into Medicaid programs threatened both access to and quality of care for PLWH. By the following year, several States had begun adopting innovative models for financing the care of PLWH in their Medicaid managed care programs. Several of the studies previously described have tracked State Medicaid programs' gradual adoption of strategies to protect the financial viability of MCOs—strategies such as global health-based payment, AIDS-specific rates, and other mechanisms to protect MCOs against catastrophic losses. By the end of 1999, with funding from the HIV/AIDS Bureau's Special Projects of National Significance program, the Center for HIV Quality Care (#10) had begun to gather information systematically on State Medicaid programs' eligibility standards, benefits, and reimbursement mechanisms. This information is being posted on a website, and information for all States will be available by mid-2001. Of course, Medicaid is a changing arena, making it necessary to monitor this information continually to assure its accuracy. But the website should make it easier for providers, planning bodies, and consumer advocates to assess the Medicaid context for CARE Act programs in all States.

To determine the adequacy of Medicaid reimbursement for HIV, it is necessary to track the costs of care. One of the studies described (#11) has shown that HIV and AIDS care costs vary with patients' comorbidities. It is also clear that historical care cost information has been rendered obsolete for most PLWH as a result of the availability of HAART. Hence, along with AHRQ, SAMHSA, and other agencies, HRSA has been participating in the development of a multi-site center to collect timely information on resource use by PLWH (#19). Preliminary findings from 1998 suggest that this information is comparable to that yielded by far more expensive studies that have used national probability samples. Data being collected by this study will be made available to the public during 2001 on the AHRQ website, allowing researchers to conduct their own analyses. This information should be useful to CARE Act grantees in estimating the costs of care and to Medicaid programs in establishing HIV and AIDS reimbursement rates.

Part of the mission of the Center for HIV Quality Care is to summarize quality of care standards across a range of health and support services. It is fulfilling this goal by creating links on its website to other sites that contain such standards. Related issues will be increasingly salient in the coming years as a result of the legislation passed late in 2000 reauthorizing the CARE Act, requiring that grantees document the quality of HIV care they are providing. Several completed local evaluation studies (#s 13-15) have

examined relationships between Medicaid and CARE Act programs. Additional studies, currently underway (#s 17-18), are examining HIV quality of care indicators in CARE Act and Medicaid programs in New Mexico and Tennessee. All of these studies are expected to yield indicators that CARE Act programs can use in assessing and assuring the quality of the services they are delivering.