THE PARADIGM SHIFT IN MEDICAID:
WOMEN WITH HIV UNDER MANAGED CARE*

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I. INTRODUCTION

In *The Structure of Scientific Revolutions*, Thomas Kuhn rejects the concept of "development-by-accumulation," which describes scientific advancement as based on a progression of ideas, each incorporating all that precede it, and ultimately yielding a new understanding. He views scientific revolutions as "non- cumulative developmental episodes in which an older paradigm is replaced in whole or in part by an incompatible new one." Although Kuhn's book addressed scientific revolutions, his concept of paradigm shifts has influenced many different fields of thought, and can be applied to the area of HIV/AIDS prevention and care.

The delivery of publicly-funded health care is undergoing a paradigm shift. Historically, Medicaid operated under national fee-for-service systems. These systems focused on acute, episodic interventions with reimbursements for providers' fees that were defined for specific services. Currently, however, Medi-

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2. Id. at 92.
caid operates primarily under managed care plans. These plans consist of state-associated delivery systems that focus on cost control and care management; providers are paid a predetermined, or “capitated,” dollar amount per patient to provide certain levels of care. This shift to capitated reimbursement necessarily affects the methods that women, including those with HIV, use to access primary health and specialty care.

This Article addresses three issues of importance to the HIV/AIDS care of women under Medicaid managed care systems: changes concerning access to services women will face; how coordinated quality services will be delivered; and whether reimbursement rates will be sufficient to cover the costs of care.

II. THE PARADIGM SHIFT

This shift from fee-for-service care to managed care has been marked by two changes, both of which may have significant implications for the health care of women with HIV/AIDS. First, Medicaid has been decentralized, moving from a federally-driven system into a state-driven system. At the same time, Medicaid has been disconnected from general public assistance. Second, a growing number of states have opted for capitated managed care systems.

Three important statutes underlie the decentralization of Medicaid and its separation from general public assistance. The first is the Omnibus Budget Reconciliation Act of 1981 (OBRA). OBRA provides the legal flexibility for states to request permission to alter the required health care provisions for eligible individuals under publicly funded programs such as Medicaid.

As a result, states are able to expand coverage of eligible populations, alter benefits packages, and introduce managed care systems.

The second is the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA). PRWORA abolished Aid to Families with De-
pendent Children (AFDC),\textsuperscript{13} created the Temporary Assistance for Needy Families (TANF)\textsuperscript{14} block grant program, and gave states the authority to design their own public assistance programs.\textsuperscript{15} This statute is significant for the effects it has had on both the decentralization of Medicaid and its separation from general assistance. Under the old AFDC program, families that met the eligibility requirements automatically received Medicaid assistance according to prescribed federal regulations.\textsuperscript{16} Under the new TANF program, however, states are given discretion to determine levels of entitlements for welfare recipients, as well as eligibility requirements for receiving them.\textsuperscript{17} Because the TANF program does not enroll recipients automatically in Medicaid as the AFDC program had, former AFDC program recipients may no longer be eligible for Medicaid assistance.\textsuperscript{18} The reverse also may occur, as people may be eligible for medical assistance but ineligible for the TANF program.\textsuperscript{19}

The third statute is the Balanced Budget Act of 1997 (BBA).\textsuperscript{20} The BBA outlines instances in which a state may implement a Medicaid managed care program without first seeking a waiver from federal requirements.\textsuperscript{21} As a result, states have additional flexibility to structure their management of covered health care.\textsuperscript{22}

The second change resulting from the shift from fee-for-service to managed care is that a growing number of states have opted for capitated managed care systems. Under capitated managed care, providers receive a per-member per-month fee, rather than a procedure-based or service-based reimbursement.\textsuperscript{23} Capitated fees cover expenditures associated with a prescribed package of bene-

\textsuperscript{13} The AFDC program was authorized in Title IV of the Social Security Act of 1935, Pub. L. No. 74-271, 49 Stat. 620, 627-29 (42 U.S.C. §§ 601-676 (1994)).
\textsuperscript{16} See 42 C.F.R. § 435.110(a) (1997).
\textsuperscript{17} See 42 C.F.R. § 430.0 (1997).
\textsuperscript{18} Another difference between the two programs involves funding limitations: while funding for AFDC increased in response to increased demand, the funding for TANF is fixed. See Greg J. Duncan & Gretchen Caspary, Welfare Dynamics and the 1996 Welfare Reform, 11 Notre Dame J.L. Ethics & Pub. Pol’y 605, 608 (1997). When states have to cut corners in order to manage their limited funds, see Ann Marie Rotondo, Helping Families Help Themselves: Using Child Support Enforcement to Reform Our Welfare System, 33 Cal. W. L. Rev. 281, 287 (1997), women with HIV/AIDS may feel the pinch.
\textsuperscript{21} See id.
\textsuperscript{22} With the flexibility granted by the PRWORA and BBA, states could, among other things, expand services such as primary care case management, modify eligibility requirements such as the percentage above the poverty level at which individuals qualify for Medicaid, or mandate that Medicaid participants enroll in managed care.
\textsuperscript{23} See HIV CAPITATION RISK ADJUSTMENT, supra note 5, at 1.
fits for the client. To change from a Medicaid fee-for-service plan to a capitated managed care plan, a state either must request a waiver under section 1915 or section 1115 of the Social Security Act, or must meet the requirements of the BBA. Under the BBA, a state must write beneficiary protections, develop quality assurance standards, and assure that timely payment requirements are included in contracts. Upon either receiving a section 1915(b) waiver approval or qualifying for an exemption, a state may mandate enrollment for eligible populations in managed care by county. A section 1115 waiver offers a state additional freedom to modify Medicaid requirements, including rules on benefits, provider qualification and payment rules, and administrative requirements.

As states institute a wide variety of managed care plans for TANF and Supplemental Security Income (SSI) recipients, they must ensure that the per-member payments are sufficient to cover the needs of HIV/AIDS patients, fifty-three percent of whom are dependent on Medicaid. Additionally, each state’s Medicaid plan must be monitored to ensure that HIV care, regardless of the

31. See Diane Rowland & Kristina Hanson, Medicaid: Moving to Managed Care, HEALTH AFF., Fall 1996, at 150, 150-52 (describing the dramatic increase in states’ use of managed care programs).
32. See 42 U.S.C.A. § 1381 (1994); see also Alison Barnes, The Policy and Politics of Community-Based Long-Term Care, 19 NOVA L. REV. 487, 515 n.161 (1995) (noting that “[SSI] provides a guaranteed minimum income for individuals who are aged, blind, or disabled, who have insufficient workforce participation to be eligible for [Social Security Disability Income].”).
33. See JEFFREY S. CROWLEY, NATIONAL ASS’N OF PEOPLE WITH AIDS, MAKING MEDICAID MANAGED CARE WORK: AN ACTION PLAN FOR PEOPLE LIVING WITH HIV 5 (1997) [hereinafter AN ACTION PLAN]. In addition, 90% of HIV-positive children are dependent upon Medicaid. See id.
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variation under which it is provided, meets or exceeds treatment guidelines for women.\textsuperscript{34}

III. WOMEN LIVING WITH HIV/AIDS

HIV/AIDS is a growing concern for and among women in the United States.\textsuperscript{35} Recent surveillance data suggest that between one-third and one-half of all HIV testing is performed on women between the ages of fifteen and forty-four.\textsuperscript{36} According to the data, between 120,000 and 160,000 women are living with HIV in the United States;\textsuperscript{37} in 1996 alone, 13,820 adult or adolescent women were diagnosed with AIDS,\textsuperscript{38} more than seventy-nine percent of whom were women of color.\textsuperscript{39} HIV/AIDS has emerged as a major health concern, particu-


\textsuperscript{36} See Tracey E. Wilson et al., HIV-Antibody Testing: Beliefs Affecting the Consistency Between Women’s Behavioral Intentions and Behavior, 26 J. APPLIED PSYCHOL. 1734, 1735 (1996). Many women, however, do not discover that they are infected with the virus until they arrive at an emergency room, a physician’s office, or a hospital for care. See Pascale M. Wortley et al., HIV Testing Patterns: Where, Why, and When Were Persons with AIDS Tested for HIV?, 9 AIDS 487, 490 (1995) (finding that many persons diagnosed with AIDS between 1990 and 1992 were not tested until they were admitted to an acute care facility).


\textsuperscript{38} See HIV/AIDS SURVEILLANCE REPORT 1996, supra note 37, at 10 tbl.3.

\textsuperscript{39} See id. at 12 tbl.5. Moreover, of those females diagnosed with AIDS through December 1996, over 70% were under the age of forty. See id. at 16 tbl.9.
larly among young African-American and Latina women—women who historically have constituted healthy and, therefore, low-cost populations when compared to the Medicaid population as a whole.

Despite the high number of women with HIV/AIDS, the clinical care that women receive has been developed through research conducted primarily with men. However, significant differences exist in the health care needs of women based on gender, behavior, modes of transmission, and gynecological conditions. For example, certain opportunistic infections occur more frequently in women than in men. Moreover, gynecological conditions associated with HIV disease can complicate the treatment of women. Pregnancy also raises unique complications for HIV care; the introduction of effective treatments, such as zidovudine to prevent vertical transmission of HIV from mother to fetus, requires early detection of the disease, more frequent medical visits, and an increased use of pharmaceuticals.

Furthermore, early studies found that HIV disease progressed more quickly in women than in men from the time of diagnosis; more recent clinical research has offered findings that indicate that gender differences in disease progression

40. See Cu-Uvin et al., supra note 35, at 316 (finding that almost 75% of women with AIDS in the United States are African-American or Latina, although they comprise only 20% of American women).


43. See Cu-Uvin et al., supra note 35, at 318-20. For example, the occurrence of candida esophagitis and extensive chronic ulcerative disease secondary to herpes simplex are gender related. See id. at 318 tbl.I, 319.

44. See DHHS HIV/AIDS WORK GROUP, supra note 41, at 13-16.


may result from women’s lack of access to HIV care. This may cause significant differences in how HIV affects women and men, as women repeatedly report difficulties in accessing services, ranging from a lack of knowledge of available services to the lack of resources to secure them.

Women with HIV disease face numerous obstacles to the procurement of essential services. Because HIV/AIDS correlates with poverty, and women are more likely than men to be poor, uninsured, or underinsured, women are more likely to receive insufficient medical care. Medical appointments may leave patients waiting for hours, yet result only in a schedule of tests and a handful of unaffordable prescriptions. Moreover, if an infected woman also is responsible for an infected child, the medical needs of both must be met. The medical setting in which a mother receives care, however, may not be structured to accommodate a mother and child together. Language and cultural differences can complicate further the struggle many women experience in acquiring

47. See Ancello-Park & De Vincenzi, supra note 41; Howard L. Minkoff & Jack A. DeHovitz, Care of Women Infected with the Human Immunodeficiency Virus, 266 JAMA 2253, 2253-58 (1991); Richard Rothenberg et al., Survival with the Acquired Immunodeficiency Syndrome, 317 NEW ENG. J. MED. 1297, 1300 tbl.2 (1987). Similarly, the use of new pharmaceuticals such as protease inhibitors requires routine and frequent access to medical services. See Steven G. Deeks et al., HIV-1 Protease Inhibitors: A Review for Clinicians, 277 JAMA 145, 151-52 (1997). But see Beverly E. Sha et al., HIV Infection in Women: An Observational Study of Clinical Characteristics, Disease Progression, and Survival for a Cohort of Women in Chicago, 8 J. ACQUIRED IMMUNE DEFICIENCY SYNDROMES & HUMAN RETROViroLOGY 486, 494 (1995) (noting that in their study, insurance status, as an indicator of access to health care, did not influence the survival time of women with AIDS).


49. See DHHS HIV/AIDS WORK GROUP, supra note 41, at 5-20.


51. See Ethier et al., supra note 50, at 216.

52. See id.

53. See id. One study found that more women than men received Medicaid, and that this was a critical factor in compromising women’s access to care and the quality of that care. See id. at 218.


55. See Patricia Antoniello, The Voices of Women with HIV Infection, in PRIMARY CARE OF WOMEN AND CHILDREN WITH HIV INFECTION: A MULTIDISCIPLINARY APPROACH 1, 3-4 (Patricia Kelly et al. eds., 1995). Even infants who are not infected with HIV require medical care and general care, posing another problem for infected mothers. See id.

In addition to these obstacles to basic care, women infected with HIV also may have additional needs such as HIV education, case management, and the provision of social services such as housing, transportation, public assistance, psychological health services, support groups, nutrition assistance, pastoral care, child care, and legal services.

An additional layer of complexity arises from the fact that HIV is rarely an isolated problem for infected women. HIV-positive women come from diverse social, cultural, and economic backgrounds, and many struggle with domestic violence, poverty, homelessness, or inadequate housing. Furthermore, because a large percentage of identified HIV-positive women are intravenous drug users, many women also may need drug treatment and mental health services. These complex health and social needs of women with HIV must be considered as the states determine their Medicaid reimbursement fees for managed care plans and define the eligible populations for Medicaid coverage.

57. See generally Johanna Daily et al., Women and HIV Infection: A Different Disease?, in WOMEN, POVERTY, AND AIDS, supra note 50, at 125, 125-44 (illustrating, through the stories of two women, how women with language and cultural differences require medical services that build in specific language and cultural support); see also Dawn F. Smith & Janet S. Moore, Epidemiology, Manifestations, and Treatment of HIV Infection in Women, in WOMEN AND AIDS, supra note 50, at 1, 18 (noting the additional difficulties faced by “non-English-speaking, low-literacy, and drug-using women” in receiving appropriate HIV treatment).

58. One source has defined case management as follows:

A patient-centered process which has been used to augment and coordinate existing care systems. Its goals are to access health and mental health care for patients; provide or obtain social support services; and, empower patients, family members, and significant others. The means of achieving these goals include providing education; creating connections between careseekers and caregivers; promoting active participation of the patient, family, and significant others in developing care plans; and acknowledging and complementing the important support given by family and significant others.

59. See Mardge H. Cohen & Patricia Kelly, HIV Disease in the Primary Care Setting, in PRIMARY CARE OF WOMEN AND CHILDREN WITH HIV INFECTION, supra note 55, at 9, 9-18; see also CENTER FOR WOMEN POLICY STUDIES, MEDICAID MANAGED CARE, supra note 7, at 9 (“Of particular importance in assuring access to medical care are ‘enabling services,’ such as transportation and case management (coordination of care). . . .”); cf. DARLENE SHELTON ET AL., U.S. DEPT OF HEALTH & HUMAN SERVS., HIV/AIDS HEALTH CARE, UTILIZATION & MEDICAL ADHERENCE ISSUES AMONG HIV SEROPOSITIVE AFRICAN AMERICAN WOMEN IN MIAMI: THE ROLE OF THE FAMILY AND THE EXTENDED KINSHIP NETWORK 23 (1993) (exploring influences on health care utilization, and reporting the importance of access to transportation and child care, family support, and possible pregnancy or substance abuse); Selbin & Del Monte, supra note 50, at 116-19.

60. See Carol Levine & Machelle Harris Allen, Social Interventions in the Care of Human Immunodeficiency Virus (HIV)-Infected Pregnant Women, 19 SEMINARS IN PERINATOLOGY 323, 324 (1995).

61. See HIV/AIDS SURVEILLANCE REPORT 1996, supra note 37, at 12 tbl.5 (noting that 45% of women reported with AIDS through 1996 were intravenous drug users); see also Weissman et al., supra note 54, at 401-02.
IV. CAN RESEARCH HELP?

States’ experience with Medicaid managed care for elderly and disabled beneficiaries is not extensive. As of 1996, only five states had more than one year of experience with mandated Medicaid managed care systems for individuals with disabilities: Arizona, Oregon, Tennessee, Utah, and Virginia. Another eleven states voluntarily had operated similar programs for a year or more, but fewer than twenty percent of the eligible Medicaid populations were enrolled.

Given the few states involved and the limited coverage that exists for individuals with disabilities in those states, there is little information available on managed care plans for women with HIV. Research on the effects of managed care on disabled populations with private insurance, however, can provide some insight as to what can be expected for the Medicaid-funded care of women with HIV. A study of 12,997 health maintenance organization (HMO) patients suffering from at least one of five diseases—arthritis, asthma, epigastric pain/ulcer, hypertension, or otitis media—identified a strong correlation between the severity of illness and the frequency of health resource utilization. Especially applicable to the care of women with HIV is the finding that limitations on reimbursement for pharmaceuticals were associated with increased numbers of ambulatory and emergency room visits, and a greater number of hospitalizations. This finding has significant implications for the future health care of women with HIV/AIDS. Because it is expected that pharmaceuticals will become one of the more expensive facets of HIV care, managed care plans may consider limiting coverage for HIV pharmaceuticals and associated tests. If women with HIV/AIDS anticipate that the costs of pharmaceuticals might exceed reimbursement levels, they will be likely to reduce their use of such pharmaceuticals and, therefore, suffer a gap in care. While managed care plans may save money in the short run, in the long run they would lose money, as such a strategy would tend to increase opportunistic infections, as well as overall medical costs.

Another potential disadvantage of managed care may surface if health plans receive the same reimbursement rates for both sick and healthy clients.

62. See CENTER FOR WOMEN POLICY STUDIES, MEDICAID MANAGED CARE, supra note 7, at 8; U.S. GEN. ACCOUNTING OFFICE, MEDICAID MANAGED CARE: SERVING THE DISABLED CHALLENGES STATE PROGRAMS 4-5, 24-25 (1996). While only a few states have long-term experience with Medicaid managed care, Medicaid managed care has become very widely-used in recent years. See Sara Rosenbaum, A Look Inside Medicaid Managed Care: A Study of Medicaid Contracts Sheds Light on the Program’s Transition to Managed Care, HEALTH AFF., July-Aug 1997, at 266, 266 (noting that in 1997, nearly 40% of all Medicaid beneficiaries were enrolled in managed care).

63. See U.S. GEN. ACCOUNTING OFFICE, supra note 62, at 4, 24-25.

64. See id.

65. See CENTER FOR WOMEN POLICY STUDIES, MEDICAID MANAGED CARE, supra note 7, at 8-9.

66. See Susan D. Horn et al., Intended and Unintended Consequences of HMO Cost-Containment Strategies: Results from the Managed Care Outcomes Project, 2 AM. J. MANAGED CARE 253, 259-60 (1996).

67. See id. at 259.


These plans will suffer financially if they enroll large numbers of HIV-positive clients due to the high costs of their care. Research shows that in managed care systems, both risk adjustment for HIV/AIDS and the use of HIV/AIDS medical specialists as primary care physicians can assist in increasing access to quality care for women. Risk adjustment procedures base capitation rates on the insured’s individual health status and recent health care expenditures. This technique can be beneficial especially for people with chronic illnesses such as HIV/AIDS, whose patterns of health care expenditures are more predictable than those of the general population. Risk adjustment methods, therefore, can assure that providers receive adequate per-member per-month reimbursement for care. Additionally, access to specialists for primary care assures appropriate treatment, which can prevent costly hospitalizations and opportunistic infections.

Additional studies have found that preventive and screening services are provided more frequently to clients in HMOs than to those in fee-for-service programs. While screening for HIV/AIDS was not included in the studies, Medicaid managed care may be able to identify HIV-positive women more quickly by providing earlier testing, diagnosis, and linkages to treatment.

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act’s Special Projects of National Significance (SPNS) Program is testing models of capitated care to examine the tension between HIV health care delivery under Medicaid managed care and fee-for-service plans, and to assess the possibilities for delivering appropriate care to women with HIV/AIDS. Six individual projects are examining the provision of managed HIV/AIDS services in different

70. See William J. Aseltyne et al., HIV Disease and Managed Care: An Overview, 8 J. ACQUIRED IMMUNE DEFICIENCY SYNDROMES & HUMAN RETROVIROLOGY S11, S19-S20 (Supp. 1 1995).

71. Research has shown that physicians with specialized HIV/AIDS knowledge are more likely than other practitioners to prescribe appropriate pharmaceuticals and provide state-of-the-art care. See Mari M. Kitahata et al., Physicians’ Experience with the Acquired Immunodeficiency Syndrome as a Factor in Patients’ Survival, 334 NEW ENG. J. MED. 701, 704-05 (1996).

72. See generally HIV CAPITATION RISK ADJUSTMENT, supra note 5. An example of a successful risk adjustment policy is Maryland’s Medicaid managed care program, HealthChoice, which has developed a capitated model based on these two methods. See id. at 20. Maryland’s Department of Health and Public Hygiene has agreed to supplemental payments for HIV care. See id. In addition, Hopkins AIDS-Medicaid Capitated Care HMO at Johns Hopkins University will provide AIDS care to Medicaid recipients. See LAWRENCE BARTLETT & PATRICIA RUTH HITZ, KAISER FAMILY FOUND., DELIVERING HIV CARE IN A MANAGED CARE ENVIRONMENT: ISSUES AND STRATEGIES (1996). Moreover, to ensure the solvency of the plan, the new, high-cost AIDS medications are excluded from the capitation arrangement and paid for on a fee-for-service basis. See HIV CAPITATION RISK ADJUSTMENT, supra note 5, at 21.

73. See HIV CAPITATION RISK ADJUSTMENT, supra note 5, at 3.

74. See id.

75. See id.; TONY DREYFUS ET AL., KAISER FAMILY FOUND., USING PAYMENT TO PROMOTE BETTER MEDICAID MANAGED CARE FOR PEOPLE WITH AIDS 4 (1997).

76. See Amy B. Bernstein, Women’s Health in HMOs: What We Know and What We Need to Find Out, 6 WOMEN’S HEALTH ISSUES 51, 55-58 (1996).

77. See generally id. at 51-59.

78. See 42 U.S.C.A. § 300ff-101 (West Supp. 1997). The SPNS Program is authorized under Part F of the CARE Act to support the development and evaluation of innovative and replicable models for delivering health and support services to people with HIV. See id.
arenas, including community-based settings, university-based medical center settings, and community health center settings. Each health care project is either fully or partially-capitated. To date, only one project evaluation, that of the Visiting Nurses Association of Los Angeles, a not-for-profit home care agency, has reached a sufficient stage to report results. These early results show improved patient medical condition and increased patient satisfaction with the care received, and research indicates that similar home care programs decrease overall costs.

At the same time, research shows that women with HIV require more costly and continuous care than the healthier women who constitute the majority of TANF program recipients on Medicaid. This raises an important issue for women enrolled in Medicaid managed care plans—access to coordinated care. It remains to be seen whether, under the new system, HIV-positive women who are Medicaid recipients will have access to the full range of services they need, including care for HIV, opportunistic infections, and related gynecological infections.

V. THE NEW FEDERAL ROLE

The states’ movement to Medicaid managed care is changing the historical roles of many federal agencies. In order to be positioned properly to safeguard vulnerable and underserved populations, the agencies must be responsive to the realities of the health care market where fee-for-service plans, partially-capitated managed care plans, and fully-capitated managed plans exist concurrently.

79. The six projects are funded at the following institutions: the Johns Hopkins University, the East Boston Neighborhood Health Center, the AIDS Healthcare Foundation, the Visiting Nurses of Los Angeles, and the New York State AIDS Institute, see BARTLETT & HITZ, supra note 72, at app. C, and Duke University Medical Center, see SPECIAL PROJECTS OF NATIONAL SIGNIFICANCE (SPNS) PROGRAM, U.S. DEP’T HEALTH & HUMAN SERVS., PARTNERSHIP STEERING COMMITTEE GRANT PROJECT ABSTRACTS 8 (1997) [hereinafter GRANT PROJECT ABSTRACTS].

80. See GRANT PROJECT ABSTRACTS, supra note 79, at 2-3.


82. See id. (manuscript at 26-27).

83. See id. (manuscript at 4).

84. See CENTER FOR WOMEN POLICY STUDIES, MEDICAID MANAGED CARE, supra note 7, at 8-9.

85. Cf. Tami Mark & Curt Mueller, Access to Care in HMOs and Traditional Insurance Plans, HEALTH AFF., Winter 1996, at 81, 82-83 (finding that HMO patients complained of more unmet health care needs than patients in traditional plans); see also supra notes 58-59 and accompanying text.

86. See generally AN ACTION PLAN, supra note 33; see also U.S. GEN. ACCOUNTING OFFICE, MEDICAID: STATES’ EFFORTS TO EDUCATE AND ENROLL BENEFICIARIES IN MANAGED CARE 18-19 (1996); cf. Shelton et al., supra note 56, at 23.

87. Many federal agencies, including the Centers for Disease Control and Prevention (CDC), the Food and Drug Administration (FDA), the National Institutes of Health (NIH), the Agency for Health Care Policy Research (AHCPR), the Health Care Financing Administration (HCFA), and the Health Resources and Services Administration (HRSA) have been involved with HIV/AIDS since the beginning of the epidemic in the early 1980s.
Due to the decentralization of Medicaid, the separation of general public assistance from medical care, and the growth of capitated Medicaid managed care, the federal government’s role in health care delivery may shift. Instead of setting rates for fee-for-service reimbursements, the federal government likely will perform the functions of oversight, enforcement of approved state waivers, and monitoring of exempt state plans. Moreover, in order to ensure compatibility with state Medicaid managed care systems, the federal government will need to re-examine targeted HIV/AIDS funding streams such as the Ryan White CARE Act and the Centers for Disease Control and Prevention (CDC) prevention cooperative agreements.

One challenge facing these agencies involves the use of clinical trials. The participation of managed care recipients in clinical trials has become a point of negotiation and discussion at the NIH and the FDA. Clinical trials allow women with HIV to gain access to new medications, while at the same time testing the effectiveness of new treatments in women. Historically, managed care networks have sponsored research on the outcomes and effectiveness of

90. See HMO-Based Research Programs Form New Research Network; Lewin-VHI Managed Care Report Released, “The Blue Sheet” (F-D-C Reports, Inc.) 4, 4-5 (Feb. 21, 1996) [hereinafter “The Blue Sheet”].
FDA-approved treatments rather than participating in federally-sponsored clinical research.92

A second challenge that the federal health agencies face concerns the review and monitoring of state waivers of fee-for-service plans. While current federal efforts have focused on initial state waiver review, discussions also are underway with respect to ongoing efforts to monitor the states’ progress in implementing Medicaid managed care, including whether states have been able to maintain access to medical services and to assure appropriate treatments such as obstetrical care for women with HIV.93 For HRSA in particular, both waiver review and monitoring move the agency beyond its traditional role of funding health services for vulnerable populations94 to one of assuring the availability of quality health care.95 While most of the criteria used for waiver review apply to all individuals living with HIV, some, such as coverage for gynecological care, are unique to women.96 The review of state waivers and subsequent monitoring efforts will require the federal agencies to focus on the quality and accessibility of HIV/AIDS services by managed care plans, including enrollment procedures and post-enrollment support, benefit designs, payment systems, patient satisfac-

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92. See “The Blue Sheet”, supra note 90, at 5.
93. HCFA and HRSA are holding a series a staff meetings to better coordinate HIV care among Medicaid and Ryan White CARE Act programs. See HUMAN RESOURCES & SERVS. ADMIN., MANAGED CARE STRATEGIC PLAN: RYAN WHITE CARE ACT PROGRAMS 6 (1997).
94. See HIV CAPITATION RISK ADJUSTMENT, supra note 5, at 65 app. D.
96. Examples of what is covered in HRSA reviews include:

To what extent will a PCCM [primary care case management] model disrupt provider-patient relationships, or limit choice of provider and access to experienced HIV care, specialty care, treatments and services for Medicaid beneficiaries with HIV/AIDS?

... Are there plans for ongoing meetings between Medicaid staff and the State AIDS Director, health plan management, medical directors, HIV infected beneficiaries and family members, providers, and advocacy groups? How will these stakeholders participate in the monitoring of the utilization of HIV services, HIV-related quality of care, and health outcomes for PLWH [people living with HIV], including asymptomatic HIV-infected beneficiaries?

... To what extent does the proposal indicate awareness of the incidence and prevalence of AIDS and HIV-infection among Medicaid beneficiaries within categorical populations? Is there recognition that the TANF population may contain substantial numbers of PLWH, including asymptomatic PLWH, who require early intervention delivered by experienced HIV-care providers?

... What additional provisions are to be made during enrollment to assist PLWH who may be homebound, unable to understand procedures (they may have mental disabilities), or are not aware of the critical need for responding/or unable to respond in the required time frames?

HEALTH RESOURCES & SERVS. ADMIN., MEDICAID MANAGED CARE WAIVERS AND POPULATIONS WITH SPECIAL HEALTH CARE NEEDS: KEY ISSUES OF SPECIAL CONCERN TO PEOPLE LIVING WITH HIV INFECTION (PLWH) 1-5 (draft working paper June 13, 1997) (on file with the Duke Journal of Gender Law & Policy).
tion, the quality of clinical care (such as gynecological care for women), and patient grievance procedures.97

A third challenge that the federal agencies face involves supporting the development of new models of HIV/AIDS care to respond to local differences in populations affected by the epidemic, as well as evaluating differences in state policies.98 Currently, the SPNS program99 funds the development of six such capitation models,100 each located in states that applied for, and in some instances, received, section 1115 waivers.101 These programs are investigating risk adjustment rates for HIV, linkages between health care and appropriate support services for women, and the integration of health care for mothers and their children.102

A final challenge for the federal government is the reexamination of its targeted HIV/AIDS funding streams. When the Ryan White CARE Act103 was formulated, state Medicaid programs were primarily fee-for-service reimbursement programs. Most CARE Act funds are distributed by grantees based on service needs and on a state’s ability to reach underserved populations. Notices of contract awards by eligible metropolitan areas (EMAs) and by states provide a lump sum calculated from a line-item organizational budget that includes personnel, administrative overhead, and contract and/or subcontract dollars.104 Because the paradigms of health care delivery have changed, this method of allocating funds will need to be reassessed if the health care providers who receive these funds participate in Medicaid managed care. One suggested method for future funding would link awards to the rate of return on CARE Act “investments” using health outcome measurements and/or improvements in the quality of life of clients.105 In addition, direct funding of services for women and children living

97. See Office of Inspector Gen., Dep’t of Health & Human Servs., Medicaid Managed Care and HIV/AIDS (1997) (unpublished draft on file with authors). At the same time, HCFA has undertaken a number of monitoring efforts, see James P. Hadley & Linda F. Wolf, Monitoring And Evaluating the Delivery of Services Under Managed Care, HEALTH CARE FINANCING Rev., Summer 1996, at 1, 1-4, but none is specifically HIV-related, see generally Elizabeth A. McGlynn, Choosing Chronic Disease Measures for HEDIS: Conceptual Framework and Review of Seven Clinical Areas, in MANAGED CARE AND CHRONIC ILLNESS: CHALLENGES AND OPPORTUNITIES 18 (Peter D. Fox & Theresa Fama eds., 1996).


100. See supra note 79 and accompanying text.

101. The most comprehensive and complex model is New York’s section 1115 waiver which, with the accompanying state legislation, authorizes the creation of Special Needs Plans (SNP) for Medicaid recipients who are HIV-positive. Recipients can choose to receive care either from a general HMO or from an SNP. SNPs are HMOs certified by the state to provide comprehensive and capitated health services to HIV-positive persons eligible for Medicaid. In return for agreeing to provide comprehensive HIV care, the HMO becomes eligible for risk-adjusted reimbursement. See New York Health Care Reform Act of 1996, N.Y. PUB. HEALTH LAW § 2807-f (McKinney Supp. 1997-1998). For further information on section 1115 waivers, see discussion supra notes 25-30 and accompanying text.

102. See generally HIV CAPITATION RISK ADJUSTMENT, supra note 5.


104. See Walter Moreau, U.S. Dep’t. of Health & Human Servs., Tools and Strategies to Assure the Cost and Outcome Effectiveness of CARE Act Services 34 (1997).

105. See id. at 6.
with HIV/AIDS may need to be reconfigured based upon the services and populations covered by Medicaid managed care.

VI. Conclusion

The paradigm shift from fee-for-service to managed care encompasses many changes, including changes in emphasis from acute, episodic interventions to preventive care, changes in access to care for the populations to whom care is delivered, and changes in the cost reimbursement mechanisms. While some specific aspects of the paradigm shift, such as the coverage of pharmaceuticals, are important to all individuals living with HIV/AIDS, others, such as the access of TANF recipients to specialty care and children’s health care, particularly are significant for women given women’s complex care and treatment needs. Furthermore, the supportive services that would be included in a comprehensive continuum of care, which traditionally may not have been viewed as included in health care, such as the provision of housing, or follow-up after substance abuse treatment, must be provided if medical treatment is to be effective.

The complexity of the new Medicaid managed care plans and the differences among states in eligibility and coverage make the federal health agencies’ monitoring of states’ coverage of HIV/AIDS care critical. In order for Medicaid managed HIV/AIDS care to benefit women, and especially for women of color, federal agencies and providers of HIV/AIDS care will have to collaborate to ensure that each state’s plan is able to deliver affordable, accessible, and quality care. Otherwise, notwithstanding the opportunities afforded by the paradigm shift, cost containment principles will be achieved at the expense of individuals’ health care.