AIDS, MEDICAID, AND WOMEN

LAURENCE LAVIN*

I. INTRODUCTION

The AIDS epidemic continues to cause illness and death to millions of people in the world[1] despite recent promising advancements in treatments.[2] While the overall death rates from AIDS are decreasing in the United States,[3] the number of women with AIDS is increasing.[4] According to Dr. Alexandra Levine, a member of the Presidential Advisory Council on HIV and AIDS, "The majority of women with AIDS and HIV [in the United States] are relatively young, come from an impoverished background, and represent minorities," and "they do not have the same access to the health care system as men."[5] Living with the Human Immunodeficiency Virus (HIV) affects many aspects of a person's life. Much of the impact of HIV is on patients' health; consequently, health care concerns become paramount given that access to treatment and monitoring of the progress of HIV appears to delay and deter the onset of disability and death. Unfortunately, there are many gaps in the health care system in the United States that prevent persons with HIV, especially women, from accessing the early care that holds so much hope.

This Article discusses the legal context within which these gaps in health care exist. Part II presents an overview of HIV disease and the emerging standard of care. Part III explores alternative sources of health care insurance coverage available to persons with HIV, focusing on insurance coverage through the

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* J.D., Villanova University, 1965. Larry Lavin is the Director of the National Health Law Program. The author would like to thank the staff of the National Health Law Program for their assistance.

1. The United Nations reports 11.7 million deaths from AIDS since the beginning of the epidemic in the late 1970s, with an estimated 2.3 million deaths in 1997. *See* UNAIDS/WHO Working Group on Global HIV/AIDS and STD Surveillance, *Report on the Global HIV/AIDS Epidemic* (Nov. 26, 1997) <http://www.unaids.org/highband/document/epidemio/report97.html#top>.

2. *See* Charles C. J. Carpenter et al., *Antiretroviral Therapy for HIV Infection in 1997: Updated Recommendations of the International AIDS Society—USA Panel*, 277 JAMA 1962, 1963 (1997).

3. *See* CENTERS FOR DISEASE CONTROL & PREVENTION, U.S. DEP'T OF HEALTH & HUMAN SERVS., NO. 1, HIV/AIDS SURVEILLANCE REPORT 22-23 (1997) [hereinafter HIV/AIDS SURVEILLANCE REPORT 1997]; *see also* Tara Meyer, *Study Shows First Downturn in AIDS*, SEATTLE TIMES, Aug. 19, 1997, at A2 (noting that the total estimated deaths of persons with AIDS in the United States in 1996 decreased from 50,140 to 38,780).

4. *See* HIV/AIDS SURVEILLANCE REPORT 1997, *supra* note 3, at 25 (chronicling the increase in the number of women estimated to be living with AIDS in the United States from 12,500 in 1991 to 44,400 in 1996); Pat Phillips, *No Plateau for HIV/AIDS Epidemic in US Women*, 277 JAMA 1747, 1747 (1997); Pascale M. Wortley & Patricia L. Fleming, *AIDS in Women in the United States: Recent Trends*, 278 JAMA 911, 911-16 (1997).

5. Phillips, *supra* note 4, at 1747.

Medicaid program, which is the primary insurance program for persons with AIDS. Part IV discusses Medicaid eligibility issues and services, including recent changes in the law. Part V examines new issues of access and quality in the rapid enrollment of Medicaid beneficiaries in managed care plans. Part VI concludes with recommendations to improve women's access to health care through Medicaid.

II. HIV DISEASE AND THE EMERGING STANDARD OF CARE

The Human Immunodeficiency Virus (HIV) causes Acquired Immune Deficiency Syndrome (AIDS).[6] The official definition of AIDS is developed by the U.S. Centers for Disease Control and Prevention (CDC).[7] HIV kills and impairs the cells of the immune system, so that a variety of opportunistic infections that would be warded off by a healthy immune system instead cause illness and death.[8] The dramatic reduction in death rates from AIDS in the United States has been attributed in part to the early detection, monitoring, and treatment of HIV.[9] Testing for the presence of HIV and its progress in the body has enabled physicians to determine when to begin treatment with powerful new drugs that in clinical trials often reduce the amount of HIV in an infected person's body to undetectable levels.[10] Recent therapies have been successful in preventing the replication of the virus in the body and thereby forestalling the deterioration of the immune system and its susceptibility to opportunistic infections.[11]

The first American cases of the disease later known as AIDS were reported in 1981.[12] Only recently have therapies been developed that inhibit HIV disease progression and reduce mortality.[13] New drugs, recently approved by the Food and Drug Administration (FDA), slow the spread of HIV in the body by interrupting viral replication; they can delay the onset of opportunistic infections.[14] These advancements, however, are not without risks. The newest class of HIV-fighting drugs (protease inhibitors) have been extremely effective in short term studies; however, these drugs often produce significant side effects and, when not used appropriately or interrupted in their use, can lead to the rapid development of viral resistance to the drugs.[15] Only one protease inhibitor is recom-

6. *See* Office of Communications, National Inst. of Health, *Fact Sheet: The Evidence that HIV Causes AIDS* (visited Jan. 24, 1998) <http://www.niaid.gov:80/factsheets/evidhiv.htm>.

7. *See id.* ("[T]he CDC currently defines AIDS in an adult or adolescent age 13 years or older as the presence of one of 25 conditions indicative of severe immunosuppression associated with HIV infection.").

8. *See id.*

9. *See* Centers for Disease Control & Prevention, *Update: Trends in AIDS Incidence, Deaths, and Prevalence—United States, 1996*, 277 JAMA 874, 875 (1997).

10. *See* John W. Mellors et al., *Plasma Viral Load and CD4 sup + Lymphocytes as Prognostic Markers of HIV-1 Infection*, 126 ANNALS INTERNAL MED. 946 (1997); William T. Shearer et al., *Viral Load and Disease Progression in Infants Infected with Human Immunodeficiency Virus Type 1*, 336 NEW ENG. J. MED. 1337, 1337, 1341 (1997).

11. *See* Steven G. Deeks et al., *HIV-1 Protease Inhibitors*, 277 JAMA 145, 146, 148, 152 (1997).

12. *See* Richard Rothenberg et al., *Survival with the Acquired Immunodeficiency Syndrome: Experience with 5833 Cases in New York City*, 317 JAMA 1297, 1297 (1987).

13. *See* Deeks et al., *supra* note 11, at 148, 152.

14. *See id.* at 146.

15. *See id.*

mended to be used at a time, and the current recommended optimal use is in combination with two of a number of other drugs called transcriptease inhibitors.[16] In addition, two tests have been developed to measure the risk of disease progression: one measures the number of CD4+ lymphocyte cells,[17] which are the main target of the virus; the other test measures the plasma RNA levels (virus load).[18] These new drugs and tests have combined to give physicians and patients powerful tools to combat HIV.[19]

In June 1997, the United States Department of Health and Human Services (DHHS) published draft guidelines for the use of these antiviral agents in HIV-infected adults and adolescents.[20] These guidelines reinforce earlier knowledge that testing and monitoring the status of HIV provides physicians with important information about the risk of HIV's progression to AIDS.[21] The new tools, including viral load tests and protease inhibitors in combination with transcriptease inhibitors, specifically are recommended as important therapies that physicians should consider in treating persons with HIV.[22] In discussing the considerations for initiating therapy in patients, the guidelines state: "It has been demonstrated that antiretroviral therapy provides clinical benefit in HIV-infected individuals with advanced HIV disease and immunosuppression."[23] The guidelines also recommend antiretroviral therapy for asymptomatic individuals, noting that

> [f]actors that would lead one to initiate early therapy include the real or potential goal of maximally suppressing viral replication; preserving immune function; prolonging health and life; decreasing the risk of drug resistance due to early suppression of viral replication with potent therapy; and decreasing drug toxicity by treating [a] healthier patient.[24]

Recommended therapies include an analysis of the difficult choices of when to begin or change therapies, and to factor in the unknown long-term effects of the new drugs.[25]

The complexities of HIV care described in these guidelines and in medical reviews of their use[26] suggest that HIV disease requires expert specialty care.[27]

16. *See* U.S. Dep't of Health & Human Servs., *Report of the NIH Panel to Define Principles of Therapy of HIV Infection*, ¶¶ 5.1-.6 (visited Jan. 27, 1997) <http://www.hivatis.org/princbck.pdf> (draft); Carpenter et al., *supra* note 2, at 1964-65.

17. *See* U.S. Dep't of Health & Human Servs., *supra* note 16, ¶¶ 2.6-.11; Carpenter et al., *supra* note 2, at 1963. In 1993, the CDC revised its definition of AIDS to include all HIV-infected people who have fewer than 200 CD4+ cells. *See* Office of Communications, *supra* note 6. Healthy adults usually have CD4+ T-cell counts of 1000 or more. *See* NATIONAL LAWYERS GUILD AIDS NETWORK, AIDS PRACTICE MANUAL: A LEGAL AND EDUCATIONAL GUIDE 2-25 n.103 (3d ed. 1992).

18. *See* U.S. Dep't of Health & Human Servs., *supra* note 16, ¶¶ 2.1-.5.

19. *See* Deeks et al., *supra* note 11, at 151-52.

20. *See* U.S. Dep't of Health & Human Servs., *supra* note 16.

21. *See id.* ¶¶ 2.1-.11.

22. *See id.* ¶¶ 5.1-.8.

23. *See* Panel on Clinical Practices for Treatment of HIV Infection, *Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents* 4 (Nov. 5, 1997) <http://www.hivatis.org/guide6.pdf>.

24. *See id.* at 5.

25. *See id* at 4-15.

The Report of the Office of AIDS Research of the National Institutes of Health Panel to Define Principles of Therapy of HIV Infection expressed a strong concern that therapeutic success in treating HIV will depend upon a thorough understanding of HIV disease and the complexities of therapeutic choices.[28] These complicated developments and considerations related to HIV care led ineluctably to the troubling question of whether a primary care physician may be obligated to learn more than is possible in a general practice.[29]

In the developed world, therefore, these newly-available drug therapies are reducing the speed at which HIV-infected people are developing AIDS and, in the United States, these drugs are being credited with contributing, in 1996, to the first decrease in new AIDS cases since the epidemic began.[30] Access to testing, monitoring, and treatment are critical tools in the fight against AIDS. Whether they are available to persons with HIV in the United States depends upon whether the person has private or public health insurance and whether they live in a state that provides or pays for these services in some other manner. The combination therapies to treat HIV cost approximately $10,000 a year.[31] These costs may well be offset if a person stays healthy and is able to continue or to resume income-producing activity.[32] Unfortunately, the lack of universal health care in the United States keeps the promise of these dramatic medical advances from many people with HIV.

III. MEDICAID AND HEALTH CARE IN THE UNITED STATES

In 1965, Congress enacted legislation establishing the Medicaid program.[33] It replaced an earlier program (embodied in the Kerr-Mills Act) of grants to the states to finance medical care for the elderly poor.[34] Copying elements of that program, Medicaid is a joint federal-state program, administered by the states in accordance with federal standards. Medicaid traditionally has been linked to eligibility for cash welfare benefit programs such as Aid to Families With Dependent Children (AFDC)[35] and Supplemental Security Income (SSI).[36] Medicaid,

26. *See generally* Deeks et al., *supra* note 11 (assessing the pharmacokinetics and drug interactions, safety profiles, and clinical efficacies of the four protease inhibitors currently approved by the FDA).

27. *See* Charles E. Lewis, *Management of Patients with HIV/AIDS: Who Should Care?*, 278 JAMA 1133, 1133 (1997); Abigail Zuger & Victoria L. Sharp, *HIV Specialists: The Time Has Come*, 278 JAMA 1131, 1132 (1997).

28. *See* U.S. Dep't of Health & Human Servs., *supra* note 16, at 2.

29. *See* Zuger & Sharp, *supra* note 27, at 1131.

30. *See* Lisa M. Krieger, *Big Drop In State AIDS Deaths, 60 Percent Fewer Die in 1997: S.F. Follows Trend*, S.F. EXAMINER, Jan. 9, 1998, at A2; David Perlman, *AIDS Deaths Down 12% Nationally: Prevention Efforts, New Drugs Credited*, S.F. CHRON., Feb. 28, 1997, at A1; Gordon Slovvt, *Deaths from AIDS Drop Significantly in State and Nation*, STAR-TRIB. (Minneapolis-St. Paul), Feb. 28, 1997, at 1A; *supra* note 3 and accompanying text.

31. *See* Deeks et al., *supra* note 11, at 151.

32. *See id.*

33. *See* 42 U.S.C. §§ 1396-1396v (1994), as amended by 42 U.S.C.A. §§ 1396-1396v (West Supp. 1997); 42 C.F.R. §§ 430-499 (1997); *see also* John K. Iglehart, *The American Health Care System: Medicaid*, 328 NEW ENG. J. MED. 896, 896 (1993).

34. *See* Iglehart, *supra* note 33, at 896.

35. *See* 42 U.S.C. §§ 601-617 (1994), *as amended by* 42 U.S.C.A. §§ 601-617 (West Supp. 1997).

thus, generally is not available until a person is impoverished and has become severely disabled or fits into a specifically-defined eligible group.[37] Each state has the option to participate in Medicaid,[38] and all states do. Medicaid was enacted with Medicare, which provides health care insurance for elderly and disabled persons eligible for Social Security.[39] Medicare, unlike Medicaid, is available to eligible people regardless of income or assets.[40] It generally is not available, however, for a non-elderly person until she has been determined eligible for Social Security Disability Insurance (SSDI) for at least twenty-four months.[41] As the medical advances in treatment described in this Article prolong the lives of those with HIV and AIDS, more solvent persons who become disabled are likely to live long enough to qualify for Medicare. Of great significance to persons with HIV, however, is the fact that Medicare does not cover the cost of prescription drugs.[42]

Notably, by limiting coverage under these programs to specific groups, Congress avoided establishing a universal health care system. The lack of universal healthcare in the United States results in a complicated and often cruel patchwork system of healthcare for persons with HIV. Medicaid has become the primary insurer of persons with AIDS in the United States.[43]

In an effort to respond to concerns about thousands suffering from HIV who either have no health insurance or have limited coverage,[44] Congress has appropriated funds on an annual basis for HIV care and drug treatment under the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990,[45] which includes the AIDS Drug Assistance Program (ADAP).[46] The states that contribute to, and operate, ADAPs are finding, however, that these funds are inadequate to meet the growing costs of treating low-income persons with

36. *See id.*

37. *See* JANE PERKINS ET AL., NATIONAL HEALTH LAW PROGRAM, AN ADVOCATE'S GUIDE TO THE MEDICAID PROGRAM 1.1 (1993).

38. *See id.* at 2.1.

39. *See* 42 U.S.C. §§ 1395-1395ccc (1994), *as amended by* 42 U.S.C.A. §§ 1395-1395ggg (West Supp. 1997); *see also* Iglehart, *supra* note 33, at 896.

40. *See* PERKINS ET AL., *supra* note 37, at 1.2 n.1.

41. *See* 42 U.S.C. § 426(b)(2)(A) (1994).

42. *See* HEALTH CARE FIN. ADMIN., U.S. DEP'T OF HEALTH & HUMAN SERVS., YOUR MEDICARE HANDBOOK 1997 19 (1997) [hereinafter YOUR MEDICARE HANDBOOK 1997] (noting that Medicare does not cover most prescription drugs).

43. Medicaid is the primary payer of medical care for more than half of all people living with HIV/AIDS and for 90% of all children with HIV/AIDS. *See* TONY DREYFUS ET AL., NATIONAL ACADEMY FOR STATE HEALTH POLICY, USING PAYMENT TO PROMOTE BETTER MEDICAID MANAGED CARE FOR PEOPLE WITH AIDS 1 (1997) (citation omitted).

44. *See* NATIONAL ALLIANCE OF STATE TERRITORIAL AIDS DIRS. & AIDS TREATMENT DATA NETWORK, STATE AIDS DRUG ASSISTANCE PROGRAMS: A NATIONAL STATUS REPORT ON ACCESS 7 (1997) [hereinafter STATE ADAPS].

45. *See* 42 U.S.C. § 300ff (1994). The CARE Act was reauthorized in 1996 for another five years. *See* 42 U.S.C.A. §§ 300ff-13, -101 (West Supp. 1997).

46. *See* 42 U.S.C. § 300ff-26 (1994). The ADAPs section of the CARE Act recently was amended, *see* 42 U.S.C.A. § 300ff-26 (West Supp. 1997), and last year received a $285.5 million appropriation, *see* Department of Labor, Health and Human Services, and Education, and Related Agencies Appropriations Act, 1988, Pub. L. No. 105-78, 111 Stat. 1467, 1478.

HIV.[47] As a result, states are limiting who can participate as well as what drugs are provided.[48]

Persons who are eligible for Medicaid are entitled to covered services when medically necessary.[49] By contrast, programs such as those funded under the Ryan White CARE Act are block grants to the states subject to the availability of the appropriation; neither the federal government nor the state is under an obligation to provide the services when funds are exhausted.[50]

Other sources of health insurance or care increasingly are less available as non-profit health care facilities are converted to for-profit entities[51] and are ceasing to provide charity care, and Medicaid Disproportionate Share Hospital Payments[52] to the states used for indigent care are reduced. Therefore, those with HIV, who are without private health insurance and live in a state that does not provide drug therapy under ADAP or some other state program, must wait until they are impoverished and disabled to qualify for Medicaid and thereby become eligible for Medicaid services, including the most important preventive service, prescription drugs.[53] Whether it is ethical or cost-effective to delay treating a person who may be irrevocably damaged by a disease such as HIV becomes a core question for policymakers and society.

IV. MEDICAID ELIGIBILITY AND SERVICES

A. Medicaid Eligibility

Medicaid is a federal program of medical insurance for the poor established by Title XIX of the Social Security Act and funded by the federal government and the states.[54] States must meet minimum federal rules in order to receive federal matching dollars.[55] Because states set their own financial eligibility criteria and have flexibility to design the benefit package,[56] however, there is variation among states in eligibility and services covered under their programs. This state variation in Medicaid has led to the conclusion that "the greatest inequity in the

47. *See* STATE ADAPS, *supra* note 44, at 10-14.

48. *See id.* at 8-9.

49. *See* 42 U.S.C. 1396a(a)(10) (1994); *cf.* Goldberg v. Kelly, 397 U.S. 254 (1970) (holding that welfare recipients are entitled to pre-deprivation process).

50. *See* 42 U.S.C. § 300ff (1994), *as amended by* Ryan White CARE Act Amendments of 1996, 42 U.S.C.A. § 300ff (West Supp. 1997).

51. *See* Jack Needleman et al., *Hospital Conversion Trends*, HEALTH AFF., Mar.-Apr. 1997, at 187, 189-90.

52. Hospitals that provide medical treatment to a disproportionate share of low-income patients receive an adjustment to their Medicaid reimbursement rate, which is intended to help the hospitals offset the costs of providing care to the uninsured and under-insured. *See* 42 U.S.C. § 1396r-4 (1994).

53. *See* 42 U.S.C. § 1396d(a)(12) (1994).

54. *See* PERKINS ET AL., *supra* note 37, at 1.1.

55. *See* 42 U.S.C.A. § 1396a(a)(A)(2), (c) (West Supp. 1997); 42 U.S.C.A. § 1396b (West Supp. 1997).

56. *See* 42 U.S.C. § 1396a(a)(10) (1994).

American health care system exists not between the nonpoor and the poor, but between the insured poor and the uninsured poor."[57]

Medicaid eligibility is limited to low-income people who receive cash assistance, low-income children and pregnant women, low-income disabled persons, and other groups specified in the federal statute.[58] People eligible for Medicaid can be divided into three categories: 1) the mandatory categorically needy; 2) the optional categorically needy; and 3) the medically needy.[59] Federal law requires states to provide Medicaid eligibility to the mandatory categorically needy: those who meet the income, resource, and family composition rules of the old AFDC program in effect in their state as of July 16, 1996;[60] those receiving SSI;[61] and pregnant women and children who have family incomes below specified poverty levels.[62] States have the option to provide coverage to other needy individuals through selecting the optional categorically needy. An example of an optional categorically needy group are individuals receiving hospice care.[63] States also may choose to cover "medically needy" individuals, who look like AFDC or SSI recipients, except for high medical expenses, which are counted against income to determine eligibility.[64] In states with medically needy programs, persons with HIV who have high medical expenses may be able to qualify for Medicaid.[65]

1. Categorically Needy

The mandatory categorically needy are individuals who automatically qualify for Medicaid because they either are eligible and receive some other form of public assistance such as SSI, or they fit into specified groups of low-income families and children, or they are low-income aged, blind, or disabled individuals.[66] Prior to enactment of new welfare legislation in 1996, low-income families and children eligible for AFDC automatically were eligible for Medicaid.[67] When

57. Thomas C.W. Joe et al., *Arbitrary Access to Care: The Case for Reforming Medicaid*, HEALTH AFF., Spring 1985, at 59, 60.

58. *See* 42 U.S.C. § 1396a(a)(10)(A) (1994); *see also* Iglehart, *supra* note 33, at 896. For example, to qualify for AFDC in 1996, the annual income for a family of three had to be below $1968 in Alabama, below $2448 in Arkansas, and below $6996 in Tennessee. *See* Health Policy Studies Div., National Governors' Ass'n, *State Medicaid Coverage of Pregnant Women and Children*, MCH UPDATE, Winter 1996, at 1 tbl.3 [hereinafter MCH UPDATE].

59. *See* PERKINS ET AL., *supra* note 37, at 3.1.

60. *See* 42 U.S.C.A. § 1396u-1 (West Supp. 1997).

61. *See* 42 U.S.C. § 1396a(a)(10)(A)(i)(II) (1994).

62. *See* 42 U.S.C. § 1396a(a)(A)(10)(A)(i)(III), (IV), (VI), (VII) (1994) (as amended by § 6401 of the Omnibus Reconciliation Act of 1989 (OBRA-89), Pub. L. No. 101-239, 103 Stat. 2106, 2258).

63. *See* 42 U.S.C.A. § 1396a(a)(10)(A)(ii) (West Supp. 1997); 42 C.F.R. § 435.201, .210-12, .217, .220, .222-23, .225, .227, .230, .232, .234, .236 (1996).

64. *See* 42 U.S.C.A. § 1396a(a)(10)(C) (West Supp. 1997); 42 C.F.R. § 435.301 (1996).

65. The following states have medically needy programs: California, Connecticut, District of Columbia, Florida, Georgia, Hawaii, Illinois, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Montana, Nebraska, New Hampshire, New Jersey, New York, North Carolina, North Dakota, Oklahoma, Oregon, Pennsylvania, Rhode Island, Tennessee, Texas, Utah, Vermont, Virginia, Washington, West Virginia, and Wisconsin. *See* PERKINS ET AL., *supra* note 37, at 3.23 n.125.

66. *See id.* at 3.1.

67. *See* 42 U.S.C. § 1396a(a)(10)(A)(i)(I) (1994); 42 C.F.R. § 435.110 (1996).

Congress ended AFDC and replaced it with Temporary Assistance to Needy Families (TANF) in 1996, it preserved Medicaid eligibility for families qualifying for cash assistance in a formula that requires states to provide Medicaid coverage to those who would have been eligible for the state's AFDC program as of July 16, 1996.[68] Persons who qualify for SSI because of blindness or disability also are categorically eligible,[69] as are others who fit into specified groups of low-income families and children, or low-income aged, blind, or disabled individuals.[70] Each of these categories is very important to women with HIV, but because each presents its own set of access problems, they will be discussed separately.

2. Categorically Needy—Welfare Recipients

In changing the federal welfare law, the Personal Responsibility and Work Opportunity Act of 1996 created TANF, a new program of block grants to the states.[71] TANF replaced AFDC, the federal cash assistance program administered by the states.[72] In changing the welfare cash assistance program, Congress preserved Medicaid eligibility for families and children whose incomes would have qualified them for cash assistance under a state's AFDC program on July 16, 1996.[73] Because states could set their own AFDC income levels, there is wide variation among the states in these eligibility levels.[74]

The "de-linking" of Medicaid eligibility from eligibility for TANF "was intended to assure that poor families with dependent children would continue to have access to medical assistance."[75] For a variety of reasons, however, the new rules are creating additional barriers to Medicaid access. First, many low-income individuals may not understand that they can be or continue to be eligible for Medicaid even if they are not eligible for, or do not wish to receive, TANF cash assistance. Except for the obligation to conduct outreach under the Medicaid Early and Periodic Screening, Diagnosis, and Treatment (EPSTD)[76] Program to Medicaid-eligible children, states only have limited responsibility to inform or enroll eligible women, or men, in the Medicaid program.[77] Under TANF, state programs to place applicants for cash assistance in jobs may divert them into work programs without advising them how to apply for Medicaid.[78] In addition,

68. *See* 42 U.S.C.A. § 1396u-1 (West Supp. 1997).

69. *See* 42 U.S.C.A. § 1396a(a)(10)(A)(i)(II) (West Supp. 1997); 42 C.F.R. § 435.120 (1996).

70. See 42 U.S.C.A. § 1396a(a)(10)(A)(i) (West Supp. 1997); *see also* PERKINS ET AL., *supra* note 37, at 3.1-.5.

71. *See* Personal Responsibility and Work Opportunity Reconciliation Act of 1996, Pub. L. No. 104-193, 110 Stat. 2105, 2112, 2112-13 (amending 42 U.S.C. § 601).

72. *See* 110 Stat. 2112, 2112-13.

73. *See* 42 U.S.C.A. § 1396u-1.

74. *See* MCH UPDATE, *supra* note 58, at tbl.3.

75. Claudia Schlosberg & Joel D. Ferber, *Access to Medicaid Since the Personal Responsibility and Work Opportunity Reconciliation Act*, 31 CLEARINGHOUSE REV. 528, 531 (1998).

76. *See* 42 U.S.C.A. § 1396a(a)(A)(43)(A) (West Supp. 1997); *see also* Stanton v. Bond, 504 F.2d 1246, 1251 (7th Cir. 1974) (discussing the importance of Medicaid's Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Program in addressing the health care needs of indigent children).

77. *Compare* 42 U.S.C.A. § 1396a(a)A(43), *and* 42 C.F.R. § 441.56(a) (1996) (requiring outreach to Medicaid-eligible children), *with* 42 C.F.R. § 435.905 (1996) (listing general informing requirements).

78. *See* Schlosberg & Ferber, *supra* note 75, at 530-31, 535-36.

one of the sanctions states can use if a welfare recipient fails to meet a state's work requirements is the denial of Medicaid benefits to the adult recipient.[79] Thus by "de-linking" welfare and Medicaid eligibility, federal welfare reform has ended an important method of ensuring that eligible people were being enrolled in Medicaid.

As a result, unless a person becomes ill and seeks care at a facility that enrolls her in a state Medicaid program, she may not know of her ability to access the primary care essential for the prevention and treatment of diseases such as HIV. Medicaid-eligible women therefore may end up with irreversibly deteriorated immune systems before they know they can access care.[80] Low-income women who are at high risk of HIV infection, such as intravenous drug users, especially are affected by these welfare law changes, as they may be less informed or less exposed to information about Medicaid eligibility.

As women walk away from the welfare system for whatever reason, Medicaid enrollment could drop as drastically as the welfare rolls. According to the Clinton Administration, in the first sixteen months of the new law, through December 1997, welfare rolls in the United States declined by 2.2 million, to a total of slightly less than 10 million enrollees.[81] It is unclear what impact such declines will have on Medicaid rolls. Close attention needs to be paid to outreach efforts and enrollment by the states of women and children in eligible families for whom early HIV care could be a matter of life or death.

3. Pregnant Women and Adolescent Girls

States must also provide Medicaid to all pregnant women with incomes of up to 133% of the federal poverty threshold.[82] Services for women covered under this category are limited to pregnancy-related services (including prenatal, delivery, postpartum, and family planning services) and to other services related to a condition that may complicate pregnancy. Because the use of the antiretroviral drug ZDV by pregnant women has been shown to reduce the transmission of HIV to newborns,[83] such care has qualified for coverage. Moreover, early treatment of a pregnant woman is likely to prevent the child from contracting HIV.[84] It therefore is important that women in this category be aware of their potential eligibility for Medicaid. Unless a woman realizes that she might be eligible for care, she may delay seeking care until too far along in pregnancy

79. *See* 42 U.S.C.A. § 1396u-1(b)(3) (West Supp. 1997); *see also* 42 U.S.C.A. § 608(a)(11) (West Supp. 1997); Schlosberg & Ferber, *supra* note 75, at 532-34.

80. *See* SARAH C. SHUPTRINE & GENNY G. MCKENZIE, THE SOUTHERN INST. ON CHILDREN & FAMILIES, INFORMATION OUTREACH TO REDUCE WELFARE DEPENDENCY: A NORTH CAROLINA WELFARE REFORM INITIATIVE 1 (1996) (finding that 76% of survey respondents answered questions about Medicaid coverage incorrectly).

81. *See* Robert Pear, *Number on Welfare Rolls Dips Below 10 Million*, N.Y. TIMES, Jan. 21, 1998, at A13.

82. *See* 42 U.S.C.A. § 1396a(a)(10)(A)(i)(III), (IV) (West Supp. 1997); 42 U.S.C.A. § 1396d(n) (West Supp. 1997).

83. *See* U.S. Public Health Service Recommendations for Use of Antiretroviral Drugs During Pregnancy for Maternal Health and Reduction of Perinatal Transmission of Human Immunodeficiency Virus Type 1 in the United States: Request for Comment, 62 Fed. Reg. 36,809 (1997); Carpenter et al., *supra* note 2, at 1967.

84. *See* sources cited *supra* note 83.

to benefit from early treatment. This is, thus, another category of Medicaid-eligible persons for whom affirmative outreach action by states is a matter of life or death.

4. Categorically Needy—Disability Related

States are required to provide Medicaid to all poor, aged, blind, or disabled persons who qualify for federal SSI benefits, except for those states that have opted to use more restrictive disability or financial eligibility standards than the federal SSI program in certain circumstances.[85] Most people with HIV who become eligible for Medicaid have done so through their SSI disability determination.[86] These disability rules are rooted in policies that link health care eligibility to the ability to work.[87] While they may be logical in the work context, they present a contradiction when applied as a test for when to provide care of persons with diseases, such as HIV. Not surprisingly, this eligibility category has received the most criticism from AIDS advocates because it requires a person with HIV to reach a possibly irreversible decline in their health status before becoming eligible for the treatments that prevent disease progression.

All states use the standard of disability under the federal SSI program except those that choose to use an even more restrictive standard authorized by statute.[88] Disability determinations by SSI are guided by a listing of impairments including functional impairments.[89] The standard for determining whether a person is disabled is that the person must be unable to "engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than twelve months."[90] The SSI disability listing in HIV cases requires documentation that a woman has HIV and is experiencing one or more conditions that evidence the deterioration of the immune system and that indicate that a person would have difficulty performing activities of daily living.[91]

If a person's condition does not meet or equal a listing, she only can qualify if she is unable to return to previous work and, based on her age, education, and previous work history, is unable to perform other work in the national economy.[92] It is cruelly ironic that this part of federal policy requiring a disability determination to be eligible for health care under Medicaid exists at the same time as the federal Department of Health and Human Services (DHHS) National Institutes of Health guidelines call for early treatment of HIV.

85. *See* 42 U.S.C.A. § 1396a(f) (West Supp. 1997).

86. *See* Marilyn Rymer Ellwood et al., *Medicaid Eligibility Patterns for Persons with AIDS in California and New York, 1982-1987*, 4 J. ACQUIRED IMMUNE DEFICIENCY SYNDROMES 1036, 1037 (1991) (noting that the "most common pathway to Medicaid eligibility for PWAs is through the Supplemental Security Insurance (SSI) program").

87. *See, e.g.*, 20 C.F.R. § 416.901-.998 (1997) (defining criteria and procedures for determining disability under Title XVI of the Social Security Act in various situations).

88. *See* 42 U.S.C. § 1396a(f) (1994).

89. *See, e.g.*, 20 C.F.R. § 416.901-.998.

90. 42 U.S.C. § 1382c(a)(3)(A) (1994).

91. *See* 20 C.F.R. pt. 404, subpt. P, app. 1, § 14.08 (1997).

92. *See* 42 U.S.C. §§ 423(d)(2)(A), 1382c(a)(3)(B) (1994).

Of importance to persons with disabilities was an amendment to the Medicaid law in 1997. The Balanced Budget Act of 1997 expanded Medicaid coverage for people with disabilities by giving states the option of extending the program to individuals in families whose income is less than 250 percent of poverty and who, but for their earnings, would have been eligible as qualified severely impaired individuals.[93]

To overcome the barrier to early HIV care that the disability requirement presents, AIDS Action, a leading AIDS advocacy organization, has requested a Medicaid-eligibility expansion for low-income people with HIV.[94] While Congress has the authority to expand Medicaid coverage to low-income persons with HIV, no such legislation has been introduced as of this writing. Some states have begun to look into seeking federal waivers under section 1115 of the Social Security Act[95] to expand coverage to low-income persons with HIV. The section 1115 waiver provision authorizes an "experimental, pilot, or demonstration project which, in the judgment of the Secretary, is likely to assist in promoting the objectives" of the Medicaid statute.[96] Section 1115 waivers requesting authority to expand coverage to previously uninsured persons have been granted in many states.[97] Although not mandated by statute, DHHS requires section 1115 proposals to be cost-neutral.[98] State-by-state waivers would, of course, increase variations among the states' Medicaid eligibility requirements.

5. Drug and Alcohol-Related Disability

People with HIV can qualify for SSI, and, therefore, Medicaid, based upon a determination of disability due to causes other than HIV or on the basis of HIV

93. *See* Balanced Budget Act of 1997, Pub. L. No. 105-33, § 4733, 111 Stat. 251, 522 (amending 42 U.S.C. § 1396a).

94. *See* Daniel Zingale, AIDS Action, *Enact AIDS Action's Reinventing Medicaid Plan* (Sept. 23, 1997) (visited Feb. 4, 1998) <http://www.aidsaction.com/reinvent.html>; *see also* Robert Pear, *Clinton to Seek More Money to Help Pay for AIDS Drugs*, N.Y. TIMES, Dec. 30, 1997, at A5. While disease-specific coverage is unusual, it is not without precedent. Medicare covers certain services for persons with End Stage Renal Disease. *See* YOUR MEDICARE HANDBOOK 1997, *supra* note 42, at 3, 18. In addition, Congress recently expanded services specifically for persons with tuberculosis. *See* 42 U.S.C.A. § 1396a(z)(2)(F) (West Supp. 1997).

95. *See* 42 U.S.C. § 1315(a) (1994). For example, Maine is considering requesting four separate waivers to implement the expansion of Medicaid coverage: 1) income eligibility regulations in section 1902(a)(10)(A) of the Social Security Act, 42 U.S.C. § 1396a(a)(10(A) (1994), to permit individuals with income up to thirty-five percent of the federal poverty level to access services; 2) disability regulations located in section 1614 of the Social Security Act, 42 U.S.C. § 1382 (1994), to permit those with infection to access combination therapies so that they will not progress to AIDS; 3) amount, duration, and scope regulations located at section 1902(a)(10)(B) of the Social Security Act, 42 U.S.C. § 1396a(a)(10(B) (1994), so that waiver recipients can access the smaller package of waiver services, thereby precluding the future need for the full range of Medicaid services; and 4) residency regulations located in section 1902(b) of the Social Security Act, 42 U.S.C. § 1396a(b) (1994), to impede residents of other states moving to Maine to access services not available in their home states. If Maine cannot waive residency requirements, they propose to cap the number of eligible individuals. *See* Telephone Interview with Irvin Rich, Health Insurance Specialist, Health Care Financing Admin., Boston Regional Office (Nov. 10, 1997).

96. 42 U.S.C. § 1315(a) (1994).

97. *See* NATIONAL HEALTH LAW PROGRAM, SECTION 1115 MEDICAID WAIVERS: AN ADVOCATE'S PRIMER 6 (Oct. 1994).

98. *See* Policies and Procedures, 59 Fed. Reg. 49,250 (1994).

combined with other impairments.[99] An alcohol or drug addiction disability determination thus has allowed some persons with HIV to qualify for Medicaid and therefore to obtain needed HIV services including prescription drugs.[100] In 1996, however, Congress established a thirty-six month period, at the end of which if an SSI recipient remains addicted to drugs or alcohol, her benefits will cease.[101] Since injecting drug users constitute thirty-four percent of U.S. women with AIDS in 1996,[102] this eligibility category was another important entry point to Medicaid for women.

Notices to persons who were receiving SSI because of alcohol or drug addiction were distributed in June 1996 and benefits generally were terminated on December 31, 1996.[103] If SSI is terminated because a person is determined no longer to be disabled and the termination is appealed, states must continue Medicaid coverage until the final resolution of the appeal.[104] States, however, do not always continue Medicaid coverage in these situations.[105]

Interrupting HIV drug therapy can cause drug resistance;[106] thus, a lapse in Medicaid coverage that causes an ongoing drug therapy to be stopped has the potential for irrevocable harm. These risks are high for women who lose Medicaid eligibility because of changes in the law regarding drug or alcohol-related disability.

6. Immigrant Medicaid Eligibility Issues

With few exceptions, the Personal Responsibility and Work Opportunity Reconciliation Act of 1996[107] barred qualified aliens from receiving SSI after September 30, 1997, and gave states the option to ban or restrict Medicaid for them.[108] The Balanced Budget Act of 1997 restored SSI eligibility to qualified aliens receiving benefits as of August 22, 1996, if they were residing lawfully in the United States on that date. In addition, aliens who were residing lawfully in the

99. *See* 42 U.S.C.A. § 1396a(a)(10)(A)(i)(II) (West Supp. 1997).

100. *See* 20 C.F.R. pt. 404, subpt. P, app. 1 § 12.09 (1997).

101. *See* 42 U.S.C. § 423(d)(2)(C) (West Supp. 1997).

102. *See* CENTERS FOR DISEASE CONTROL & PREVENTION, U.S. DEP'T OF HEALTH & HUMAN SERVS., NO. 2, HIV/AIDS SURVEILLANCE REPORT 12 tbl.5 (1996).

103. *See* Contract with America Advancement Act of 1996, Pub. L. No. 104-121, 110 Stat. 852.

104. *See* 42 C.F.R. § 431.230 (1996); HEALTH CARE FINANCING ADMIN., U.S. DEP'T OF HEALTH & HUMAN SERVS., PUB. 45-3, STATE MEDICAID MANUAL, ELIGIBILITY, PT. 3, § 3272.2 (1989).

105. *See* Thorington v. James, No. 97-T-638-N (M.D. Ala. June 4, 1997) (challenging Alabama's January 1, 1997 termination of Medicaid benefits of all persons who lost their SSI because of substance abuse restrictions without regard to whether an appeal was pending); *see also* Russell v. Smith, 97-CV-3085 (N.D. Ga. filed Oct. 9, 1997) (challenging the termination of Medicaid benefits for children losing SSI) (copy of case and case history on file with the *Duke Journal of Gender Law & Policy)*. California also terminated Medicaid benefits for substance abusers losing SSI on December 31, 1996 regardless of whether an appeal was filed. When threatened with litigation, California restored Medicaid benefits. *See* Interview with Gerald McIntyre, Directing Attorney, National Senior Citizens Law Center, in Los Angeles, Cal. (Dec. 22, 1997) (pleadings on file with that office).

106. *See* Deeks et al., *supra* note 11, at 145.

107. Pub. L. No. 104-193, 110 Stat. 2105.

108. *See id.* § 401, 110 Stat. 2261 (to be codified at 8 U.S.C. § 1611); 42 U.S.C. § 601 (West Supp. 1997) (providing the effective dates of the new welfare laws); *see also Welfare Changes and Medicaid for Immigrants*, AN ANALYSIS OF THE NEW WELFARE LAW AND ITS EFFECTS ON MEDICAID RECIPIENTS (National Health Law Program et al., Los Angeles, Cal.), Aug. 1996, at 8, 8-10.

United States on August 22, 1996, can become eligible for SSI if they are qualified aliens[109] and meet disability standards in the future. While states have the option to bar qualified aliens from Medicaid, they cannot deny Medicaid eligibility to qualified aliens eligible for SSI in the states where receipt of SSI automatically confers Medicaid eligibility.

7. Transitional Medicaid Coverage

The success of current HIV therapies in preventing the onset of AIDS could allow people with HIV to continue working or to return to work. Thus, a woman could face the dilemma of losing her Medicaid coverage and possibly interrupting a drug therapy regimen covered by Medicaid if she returns to work and thereby increases her income. Medicaid, however, provides transitional coverage for six months for persons who have increased income from employment, if there is at least one child in the family and the family was eligible for cash assistance in three of the six months preceding termination of the cash assistance.[110] After this six-month period, states must offer an additional six months of coverage to families whose income is below 185 percent of federal poverty guidelines but can require premium payments.[111]

Gaining eligibility for Medicaid is a complex process. It requires knowledge on the part of beneficiaries, as well as state administrative practices that make the application processes easy to use. For a woman with HIV, Medicaid eligibility barriers include: 1) knowing she is eligible or being informed she may be eligible; 2) knowing how to apply; and 3) knowing how to appeal if she is denied eligibility. State efforts to reduce these barriers will be critical to the ability of low-income women to obtain HIV treatment and care.

B. Services Covered Under Medicaid

Under federal law, states must provide Medicaid beneficiaries with a broad range of services.[112] Congress did not define a minimum level of each service, but federal regulations require that services be "sufficient in amount, duration, and scope to reasonably achieve their purpose."[113] In addition, states may not deny or reduce the amount, duration, or scope of such services arbitrarily to an otherwise-eligible individual solely because of their diagnosis, type of illness, or

109. *See* 8 U.S.C.A. § 1641(b) (West Supp. 1997) (defining a "qualified alien").

110. *See* 42 U.S.C. §§ 1396a(a)(1), 1396r-6(a)(1), (3)(A) (1994).

111. *See* 42 U.S.C. § 1396r-6(b)(3)(A)(iii)(III) (1994).

112. *See* 42 U.S.C.A. §§ 1396a(a)(10)(A), 1396d(a) (West Supp. 1997); 42 C.F.R. § 440.210 (1996). The services covered by Medicaid that are most important to persons at risk for, or living with, HIV include: inpatient and out patient hospital services; laboratory and x-ray services; nursing facility services for those twenty-one or older; early and periodic screening, diagnostic, and treatment services for those under twenty-one; family planning services and supplies; and physician services. *See* 42 U.S.C.A. § 1396d(a)(1)-(5) (West Supp. 1997). In addition, states at their option may pay for the following services: home health care, private duty nursing, dental services, physical therapy and related services, prescription drugs, hospice care, case management services, respiratory care services, home and community based care for functionally disabled elderly individuals, personal care services, and other specified services. *See* 42 U.S.C.A. § 1396(d)(a)(7)-(8), (10)-(12), (18)-(20), (22), (24)-(25) (West Supp. 1997). Transportation and other travel related expenses necessary to medical care may also be provided. *See* 42 C.F.R. § 440.170(a) (1996).

113. *See* 42 C.F.R. § 440.230(b) (1996).

condition.[114] States also may place appropriate limits on a service based on such criteria as "medical necessity" or on utilization-review criteria.[115] Limits on the number of physician visits per month, hospital days per year, and number of prescription drugs per month have been imposed by various states.[116] For any service, states must provide the amount of care required by most persons needing the service.[117] Services available to any individual in a categorically-needy or medically-needy group must be equal in amount, duration, and scope for all persons within the group.[118]

Utilization controls such as prior authorization, second surgical opinions, and pre-admission screening also are allowable cost saving measures by the states.[119] States are permitted to impose nominal cost sharing, including co-payments on certain recipients;[120] excluded from cost sharing are hospice services, pregnancy services, family planning services, emergency services, and services provided to health maintenance organization enrollees.[121]

1. Prescription Drugs

The success of prescription drugs for treatment of HIV makes their coverage under any insurance program extremely important. While prescription drugs are an optional medical service that states may elect to provide,[122] once a state chooses to provide them it is bound to act in compliance with the Medicaid Act and its regulations in implementing the services.[123] States therefore are required to assure that "[e]ach service must be sufficient in amount, duration, and scope to reasonably achieve its purpose."[124]

The application of this requirement to AIDS drugs was tested in *Weaver v. Reagan*,[125] which held that Missouri's Medicaid program "may not deny coverage of AZT to AIDS patients who are eligible for Medicaid and whose physicians have certified that AZT is a medically necessary treatment."[126] Missouri had denied AZT coverage to persons with AIDS despite a transmittal letter from the Health Care Financing Administration (HCFA) of the DHHS urging states to

114. *See* 42 C.F.R. § 440.230(c) (1996).

115. *See* 42 C.F.R. § 440.230(d) (1996).

116. *See* PERKINS ET AL., *supra* note 37, at 4.3.

117. *See generally* Alexander v. Choate, 469 U.S. 287, 303 (1985) (holding that a state may reduce its Medicaid coverage—specifically the number of inpatient hospital days covered—even if the reduction disproportionately affects handicapped individuals).

118. *See* 42 U.S.C.A. § 1396a(a)(10)(B) (West Supp. 1997).

119. *See* 42 U.S.C.A. § 1396a(a)(30) (West Supp. 1997).

120. *See* 42 U.S.C.A. § 1396a(a)(14) (West Supp. 1997).

121. *See* 42 U.S.C. § 1396o (1994).

122. *See* 42 U.S.C. § 1396(d)(12) (1994).

123. *See* Ellis v. Patterson, 859 F.2d 52, 56 (8th Cir. 1988) (holding that once Arkansas undertook organ transplants under Medicaid, it must reasonably fund them); Meyers v. Reagan, 776 F.2d 241, 243 (8th Cir. 1985) (holding that Iowa's decision to include "physical therapy and related services" in its plan bound it to do so in compliance with the Social Security Act).

124. *See* 42 C.F.R. § 440.230(b) (1996).

125. 886 F.2d 194 (8th Cir. 1989).

126. *See id.* at 200.

cover AZT for persons with AIDS.[127] Most recently, HCFA, in a June 19, 1996, letter to state Medicaid directors, required the states to cover the three protease inhibitors that have been approved by the FDA.[128]

2. Home and Community-Based Waivers

States can provide home and community-based services to any group or groups of individuals who would be eligible for Medicaid if institutionalized, and but for the services, would be institutionalized in a hospital or nursing facility.[129] To do so, states must obtain a waiver of Medicaid guidelines from DHHS requiring services be comparable, statewide, and only for financially eligible individuals.[130] These home and community-based waivers allow states to provide care in place of hospital or nursing home care. Such waivers may include optional Medicaid services that are not available to other Medicaid recipients, such as private duty nursing and respite care, and services that are not strictly medical in nature, such as case management, homemaker services, home health aides, and personal care. Sixteen states have obtained home and community-based services waivers specifically for persons with HIV and AIDS.[131] The services authorized under the waivers vary but almost all include case management, skilled nursing care, personal care, and respite care.[132] These are important services that allow persons with AIDS to stay in their homes when they are experiencing illness.

V. MEDICAID MANAGED CARE

To control Medicaid expenditures and to increase access to health care, states are requiring Medicaid recipients to enroll in managed care plans. Nearly forty percent of all Medicaid beneficiaries were enrolled in managed care by 1997.[133] Under managed care, states often contract with health plans to provide a defined set of services for a monthly payment for each beneficiary covered. Under managed care some or all of the risk of the cost of care is transferred from the payer (the state) to the provider. If the cost of a beneficiary's care is less than the number of payments received, the provider makes a profit. If it is more, the provider suffers a loss. The incentive to provide too much care in the traditional "fee-for-service" scheme can become an incentive to skimp on care in managed care. Because large numbers of healthy AFDC-linked women and children are

127. *See* Health Care Fin. Admin., U.S. Dep't Health & Human Servs., HCFA Pub. 17, Program Memorandum: Medicaid State Agencies 1 (Feb. 1997) (Transmittal No. 87-1).

128. *See* Letter from Sally K. Richardson, Director, Medicaid Bureau, Health Care Financing Administration, to State Medicaid Directors 1 (June 19, 1996) (on file with the *Duke Journal of Gender Law & Policy*).

129. *See* 42 U.S.C.A. § 1396a(a)(10)(A)(ii)(VI) (West Supp. 1997).

130. *See* 42 U.S.C.A. §§ 1396a(a)(10)(A)(ii)(VI), 1396n(b)-(e) (West Supp. 1997).

131. *See* Written Communication from Division of Benefits, Coverage & Payment of the Administrative Center for Medicaid & State Operations (Nov. 12, 1997) (listing home and community-based waivers targeted specifically to AIDS patients) (on file with the *Duke Journal of Gender Law & Policy*).

132. *See id.*

133. *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.

covered by many states' managed care programs, these contracts have been attractive to commercial managed care organizations. Increasingly, states are planning to mandate enrollment of their Medicaid-eligible populations on SSI due to disability into managed care.[134] It is not yet clear whether managed care organizations will view these populations as a lucrative market as well.

State managed care contracts are important legal documents that define and guide the rights and responsibilities of the state, the managed care organizations, and often the Medicaid beneficiaries who are third-party beneficiaries under the contract. These contracts add to the legal obligations that the Medicaid statute and regulations prescribe. Advocates increasingly must look at the details of these contracts to determine how they address issues of importance to persons with HIV, such as pharmaceutical coverage.[135] Contracts may or may not use a drug formulary,[136] which may or may not include the drugs a person needs. The contract may or may not clarify coverage if a managed care organization decides not to cover a certain procedure. Unfortunately, a review of over eighty state Medicaid managed care contracts by the National Health Law Program has found the contracts vague on matters of importance to persons with HIV.[137] By contrast, some states, such as Pennsylvania, have included provisions that provide for things such as an emergency seventy-two hour supply of drugs.[138] In addition, other states, such as Tennessee, have expedited appeals of denials of services by the managed care organization.[139]

Because Medicaid covers so many people with HIV, how a state pays for HIV/AIDS care will impact the way services are delivered and the quality of such care.[140] While the goal of capitated managed care[141] may be to limit the growth of expenditures, the incentives to provide primary care and treatment to prevent illness and to provide coordinated comprehensive care significantly can benefit Medicaid beneficiaries with HIV.[142] In contracting with managed care

134. *See* U.S. GEN. ACCOUNTING OFFICE, MEDICAID MANAGED CARE: SERVING THE DISABLED CHALLENGES STATE PROGRAMS 22-34 (1996).

135. For an in-depth discussion, see Jane Perkins & Kristi Olson, *An Advocate's Primer on Medicaid Managed Care Contracting*, 31 CLEARINGHOUSE REV. 19 (1997).

136. *See* JEFFREY S. CROWLEY, NATIONAL ASS'N OF PEOPLE WITH AIDS, MAKING MEDICAID MANAGED CARE WORK: AN ACTION PLAN FOR PEOPLE LIVING WITH HIV 22 (1997) [hereinafter AN ACTION PLAN] (defining "formulary" as a list of drugs that "an insurance company or managed care organization agrees to provide to their beneficiaries, when prescribed by their health care provider. Drugs not on the formulary are not covered by the health plan. The use of formularies is a cost-containment strategy employed . . . to limit access to high-cost medications.").

137. This information is based on the National Health Law Program's review of over 80 contracts and requests for proposals during 1996.

138. *See* OFFICE OF MED. ASSISTANCE PROGRAMS, DEP'T OF PUB. WELFARE, COMMONWEALTH OF PENNSYLVANIA REQUEST FOR PROPOSAL FOR A MANDATORY MEDICAL ASSISTANCE MANAGED CARE PROGRAM FOR BUCKS, CHESTER, DELAWARE, MONTGOMERY, AND PHILADELPHIA COUNTIES § II.F.1, at 38 (Apr. 22, 1996).

139. *See* Daniels v. Wadley, No. 3:79-3107-NA-CV, slip op. at 14-15 (M.D. Tenn. May 14, 1996) (order modifying second consent decree) (on file with the *Duke Journal of Gender Law & Policy*).

140. *See* DREYFUS ET AL., *supra* note 43, at 8-9.

141. Capitation is the payment of a set dollar amount per covered person per month to physicians, hospitals, and other providers in hopes of conserving health care resources. *See* AN ACTION PLAN, *supra* note 136, at 8-9.

142. *See* DREYFUS ET AL., *supra* note 43, at 4.

plans, states should make sure they include provisions that assure access to needed services and that create incentives to reach out to covered populations and to provide preventive care. For persons with HIV, these provisions should include a capitation rate high enough to cover needed services and to provide enough profit incentive to enroll people with HIV; a sufficient number of providers with expertise in HIV care; and a range of services needed by persons with HIV such as substance abuse treatment, home health care, prescription drugs, hospice care, and, of particular importance for women at risk of HIV infection, family planning services.[143]

States set capitation rates in various ways. Some states pay higher capitation rates to plans that attempt to enroll people with high levels of need and a lower rate to plans that enroll disproportionately low-risk members.[144] Other states exclude services, such as prescription drugs, home and community based services, inpatient hospital care, and hospice care from what the plan must cover for the capitated rate.[145] The cost of care for people with HIV predictably is higher than the cost of care for the average AFDC-eligible Medicaid beneficiary.[146] In a five-state survey for the period 1992-1994,[147] average annual Medicaid expenditure for a person with AIDS was $22,836, as compared to $1954 for a person with no chronic disease, and $12,678 for a person with high cost diabetes.[148] Maryland recently set its AIDS monthly capitation rate at $2161 for people with AIDS living in Baltimore City and $1812 for those outside of the city.[149] Excluded from that rate are the costs of protease inhibitors and viral load testing, which will be reimbursed by the state on a fee-for-service basis.[150] HIV capitation rate setting thus should include a consideration of all of these factors to achieve a fair sharing of risk between the state and the plan and to provide the incentive for quality care by the plan.[151] A plan with an adequate number of HIV specialists and an adequate capitation rate for AIDS is more likely to attract people with HIV.[152] A woman unaware of her HIV status, however, may not consider these factors in choosing a plan. Because Medicaid covers so many AFDC-eligible women not yet disabled, ensuring that plans have incentives to conduct outreach and testing can increase enormously a woman's chance of benefiting from HIV treatment advances.[153]

143. *See generally id.* at 4-7; AN ACTION PLAN, *supra* note 136, at 4-8.

144. *See* DREYFUS ET AL., *supra* note 43, at 8.

145. *See id.* at 19-20.

146. *See id.* at 4.

147. *See* Richard Kronick et al., *Diagnostic Risk Adjustment for Medicaid: The Disability Payment System*, HEALTH CARE FINANCING REV., Spring 1996, at 7, 16.

148. *See id.* at 21; DREYFUS ET AL., *supra* note 43, at 5.

149. *See* DREYFUS ET AL., *supra* note 43, at 25.

150. *See id.* The range of Maryland's capitation rates in 1995 for AFDC recipients was $50.07 to $472.93 depending upon sex, age, and geographic location. *See* DEPARTMENT OF HEALTH & MENTAL HYGIENE, STATE OF MARYLAND, HEALTH MAINTENANCE ORGANIZATION—MEDICAL ASSISTANCE: CONTRACT AGREEMENT 54 (Effective Date: 7/1/95 to 6/30/96).

151. *See* DREYFUS ET AL., *supra* note 43, at iv.

152. *See id.* at 6.

153. *See id.* at 7.

The changing nature of HIV health care treatment protocols and costs increases the complexities of delivering quality HIV care in a managed care setting.[154] Achieving the potential of quality managed care for women with HIV will require a commitment by states to write demanding managed care contracts, to set adequate capitation rates, and to monitor aggressively the quality of care being provided.[155]

VI. CONCLUSION

The AIDS epidemic continues to claim the lives of millions of people worldwide. In the United States, a decrease in death rates from AIDS is attributed to early treatment with powerful new therapies. The numbers of women with AIDS in the United States is increasing, and women's difficulty in accessing health care services is a cause of the increase.

Medicaid's comprehensive services offer poor women HIV-preventive and needed health care if they know that they may be eligible, if they know how and where to apply, and if they in fact fit into one of the categories of eligible people. Many low-income women with or at risk of HIV are eligible for Medicaid because they are pregnant or because they are in families that meet income requirements. Changes in the federal welfare laws have resulted in new state policies complicating Medicaid-eligibility procedures. Some of these changes create new barriers to Medicaid, while others offer help to maintain Medicaid coverage. Unless a low-income woman has Medicaid or private health insurance, she may not have access to HIV therapies until she becomes disabled and then qualifies for Medicaid. Ending SSI disability for substance abusers without reassessing their Medicaid eligibility under other categories could interrupt, and thus create resistance to, their HIV therapies. By conducting aggressive outreach activities, states can enroll Medicaid-eligible women early enough to allow them to reap the benefits of HIV detection and treatment that can save their lives and can reduce their health care costs. Managed care can improve access to, and coordination of, health services, but plans should be designed so that there are adequate services and payments to assure quality. Expanding Medicaid eligibility and services to allow preventive care for low-income persons with HIV would reduce health care costs in the short-term and, more importantly, save lives in the long run.

154. *See id.*

155. *See id.* at i.