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# AIDS AND ACCESS TO CARE: LESSONS FOR HEALTH CARE REFORMERS

*Michael T. Isbell*<sup>†</sup>

## INTRODUCTION

John McGann<sup>1</sup> had been employed by H&H Music Co. for more than five years when he was diagnosed with AIDS in December 1987. Although he was devastated by his diagnosis, McGann drew comfort from the fact that his company's health plan would cover the costs of his medical care. The H&H plan provided lifetime benefits of \$1 million for each employee.

After recovering from AIDS-related pneumonia, McGann returned to work in early 1988, and informed his employer of his diagnosis. Shortly thereafter, H&H announced that it would terminate its group health plan and replace it with a self-funded plan effective August 1, 1988. H&H's self-funded health plan maintained its \$1 million coverage for all classes of employees except one. For employees with AIDS, H&H's new plan capped lifetime benefits at \$5,000.

McGann quickly exhausted his company's AIDS allotment and began paying for his medical care from his own savings. When his savings evaporated, he was forced to rely on the charity of friends. While his legal challenge to H&H's policy was pending, McGann died, having accumulated tens of thousands of dollars in unpaid medical bills. McGann's life partner pursued the litigation, but the United States Supreme Court, at the request of the Bush Administration, formally declined to hear the case, letting stand a federal decision upholding H&H's discriminatory benefits plan.

America responded with outrage. Rather than regard McGann as merely another gay man who had succumbed to AIDS, Americans widely identified with McGann. The nation's leading newspapers printed critical articles and editorials. Mainstream organizations such as the American Medical Association swiftly made common cause with people with HIV.

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<sup>1</sup> The facts described in this introduction are based on the case *McGann v. H&H Music Co.*, 946 F.2d 401 (5th Cir. 1991), *cert. denied sub nom. Greenberg v. H&H Music Co.*, 113 S. Ct. 482 (1992). This factual scenario provides a prime example of the problem this Article addresses.

Leading politicians — including the President — vowed to place health care reform at the top of the nation's agenda. After decades of cost-shifting, medical profiteering, and progressive division of the insurance risk pool into countless discrete units, diverse Americans appeared ready to acknowledge their commonality of interests.

The health care crisis is comprised of countless individual stories like John McGann's — stories of people who fell into poverty or who suffered needless illness solely because they had no way of paying for medical care. The true test of health care reform will be a human one: How will the John McGanns fare in a reformed system? America's choices will determine whether the country will finally embrace the basic human right to medical care, or continue to elevate profits over the most fundamental of humanitarian interests.

This Article argues that the experience of people living with HIV offers a clear snapshot of the breadth and depth of the crisis in health care financing. By analyzing the recorded experience of HIV-positive individuals, policymakers may discern the failures of existing health care delivery mechanisms and the elements necessary for meaningful health care reform. After summarizing the medical and economic characteristics of the AIDS epidemic, this Article describes the experience of people with HIV who have private or public forms of health care delivery. Then, the Article explores additional barriers to health care access. Finally, the Article identifies six principles to guide efforts to reform the health care system.

## I. BACKGROUND

### A. THE HEALTH CARE CRISIS

The United States has the costliest medical system in the world,<sup>2</sup> yet Americans score poorly on standard health indexes.<sup>3</sup> While medical spending in this country is increasing faster than the rate of inflation,<sup>4</sup> nearly 40 million Americans lack some

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<sup>2</sup> See Robert G. Evans et al., *Controlling Health Expenditures — The Canadian Reality*, 320 NEW ENG. J. MED. 571 (1989).

<sup>3</sup> The United States ranks twenty-third globally in infant mortality and sixteenth in life expectancy. Philip J. Hilts, *Demands to Fix U.S. Health Care Reach a Crescendo*, N.Y. TIMES, May 19, 1991, (The Week in Review), at 1.

<sup>4</sup> Medical spending rose 10.5% in 1990, *U.S. Health Care Spending*

form of health coverage.<sup>5</sup> Understandably, public confidence in the health care system has plummeted in recent years.<sup>6</sup> Those fortunate enough to have insurance coverage increasingly assume that they will lose coverage should they become ill.<sup>7</sup>

The disintegration of America's health care system has triggered unprecedented efforts to create broad-based health care reform.<sup>8</sup> Although some health policy analysts view the AIDS epidemic as a problem divorced from broader strategies to improve health care access for all Americans,<sup>9</sup> many commentators and policy-makers believe the AIDS epidemic has heightened America's awareness of the need for reform.<sup>10</sup> This Article expands on the latter view: not only does highlighting our failure with AIDS show us the *need* for reform, it also shows us specifically where we failed, and how to improve.

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*Increased 10.5% in 1990*, WALL ST. J., Oct. 3, 1991, at B13; 12.1% in 1991, Milt Freudenheim, *Health Costs Up 12.1% Last Year, a Study Finds*, N.Y. TIMES, Jan. 28, 1992, at D2; and 13.2% in 1992. Robert Pear, *Health-Care Costs Up Sharply Again, Posing New Threat*, N.Y. TIMES, Jan. 5, 1993, at A1. U.S. health care spending is expected to top \$1 trillion in 1994. *U.S. Health Care Outlays Hit New Records*, HEALTH CARE REFORM WK., Jan. 11, 1993, at 2 [hereinafter HEALTH CARE REFORM WK.].

<sup>5</sup> See NATIONAL COMM'N ON AIDS, AIDS: AN EXPANDING TRAGEDY — THE FINAL REPORT OF THE NATIONAL COMMISSION ON AIDS 1, 67 (1993) [hereinafter NCOA, FINAL REPORT].

<sup>6</sup> According to a recent opinion poll, nearly 90% of Americans say that the health care system should be overhauled. Stuart M. Butler, *A Tax Reform Strategy to Deal With the Uninsured*, 265 JAMA 2541, 2541 (1991); see also Stephen Braun, *A Queasy Feeling on Health Care*, L.A. TIMES, Apr. 25, 1992, at A1.

<sup>7</sup> Thomas Bodenheimer, *Underinsurance in America*, 327 NEW ENG. J. MED. 274, 275 (1992).

<sup>8</sup> Observers often cite publication of the May 15, 1991 issue of the Journal of the American Medical Association as a key passage in the latest, most intense wave of policy scrutiny regarding health care reform. The issue included more than a dozen articles outlining various approaches to health care reform. This spring, the Clinton administration convened an interdisciplinary task force of more than 400 people to draw up a blueprint for reform. See Dana Priest, *Anonymity Is Buzzword for Health "Worker Bees"*, WASH. POST, Feb. 17, 1993, at A17.

<sup>9</sup> See NCOA, FINAL REPORT, *supra* note 5.

<sup>10</sup> See George D. Lundberg, *National Health Care Reform: The Aura of Inevitability Intensifies*, 267 JAMA 2521, 2521 (1992); see also NCOA, FINAL REPORT, *supra* note 5.

## B. THE HIV EPIDEMIC

1. *Basic Characteristics of HIV*

The term "AIDS" refers to the final, most serious stage in the continuum of diseases produced by infection with the Human Immunodeficiency Virus.<sup>11</sup> The virus weakens the body's immunity to disease, rendering its host susceptible to a variety of opportunistic illnesses that normally do not threaten persons whose immune systems are intact.<sup>12</sup> Although HIV is never technically latent once infection occurs, a person who contracts the virus normally remains free of symptoms for several years.<sup>13</sup> Symptoms arise as the host's immune system becomes progressively compromised. This failure is characterized by the loss of CD+4 cells, key actors in the body's cell-mediated immune system.<sup>14</sup> Studies suggest that the average interval between primary infection and full-blown AIDS is 10 years or longer.<sup>15</sup>

More than one million Americans are currently infected with HIV,<sup>16</sup> while nearly 290,000 have been diagnosed with AIDS and almost 180,000 have died as of March 1993.<sup>17</sup> Although gay and bisexual men continue to account for the

<sup>11</sup> Giuseppe Pantaleo et al., *The Immunopathogenesis of Human Immunodeficiency Virus Infection*, 328 NEW ENG. J. MED. 327 (1993). HIV cannot be casually transmitted. It is contracted in various ways: (1) through certain forms of unprotected sexual intercourse, primarily anal and vaginal intercourse; (2) from mother to neonate; and (3) through exchange of blood, which is generally a result of needle sharing during injection drug use. See Gerald H. Friedland & Robert S. Klein, *Transmission of the Human Immunodeficiency Virus*, 317 NEW ENG. J. MED. 1125 (1987).

<sup>12</sup> The AIDS surveillance definition currently used by the Centers for Disease Control (CDC) includes 26 HIV-related disease manifestations. *1993 Revised Classification System for HIV Infection and Expanded Surveillance Case Definition for AIDS Among Adolescents and Adults*, 41 MORBIDITY & MORTALITY WKLY. REP. RR-17, at 1 (Dec. 18, 1992) [hereinafter *Revised Classification*].

<sup>13</sup> Pantaleo et al., *supra* note 11, at 327.

<sup>14</sup> See Andrew N. Phillips et al., *Immunodeficiency and the Risk of Death in HIV Infection*, 268 JAMA 2662, 2662 (1992) (noting that risk of HIV-related death accelerates sharply when the patient's CD+4 count falls below 50).

<sup>15</sup> Pantaleo et al., *supra* note 11, at 327.

<sup>16</sup> NCOA, FINAL REPORT, *supra* note 5, at 5.

<sup>17</sup> CENTERS FOR DISEASE CONTROL, HIV/AIDS SURVEILLANCE REPORT 3, 12 (May 1993).

majority of reported AIDS cases, recent years have seen a growth in the proportion of heterosexually acquired cases of HIV infection.<sup>18</sup> HIV attacks all racial and ethnic groups in all areas of the country, whether rich or poor, adult or child, urban or rural.<sup>19</sup>

## 2. Health Care Needs of Persons with HIV

People with HIV consume a wide range of medical services. Individuals who are at risk of infection but who are unaware of their HIV status demand sensitive counseling and access to HIV antibody testing, as well as the services of a primary care provider who recognizes risk factors for HIV infection.<sup>20</sup> During the asymptomatic stage of HIV infection, patients require periodic monitoring of their immune systems, as changes in immunologic markers may signal the need to commence anti-retroviral therapy or prophylaxis for various opportunistic diseases.<sup>21</sup>

HIV care is primarily delivered in relatively inexpensive outpatient settings.<sup>22</sup> Outpatient prescription drug therapy accounts for as much as 92 percent of early intervention services.<sup>23</sup> Nevertheless persons with HIV often need hospitalization, particularly during later stages of AIDS. In most major metropolitan areas, however, HIV care is concentrated in a handful of hospitals, especially public or teaching institutions.<sup>24</sup>

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<sup>18</sup> See *Update: Acquired Immunodeficiency Syndrome — United States, 1992*, 42 MORBIDITY & MORTALITY WKLY. REP. 547, 548 (1993).

<sup>19</sup> See generally NATIONAL COMM'N ON AIDS, AMERICA LIVING WITH AIDS (1991) (providing an overview of the AIDS/HIV crisis and suggesting strategies of individual and collective action to help combat the epidemic) [hereinafter NCOA, AMERICA LIVING WITH AIDS].

<sup>20</sup> Mark D. Smith, *Primary Care and HIV Disease*, 6 J. GEN. INTERNAL MED. S56 (1991).

<sup>21</sup> See Paul A. Volberding, *Recent Advances in the Medical Management of Early HIV Disease*, 6 J. GEN. INTERNAL MED. S7 (1991).

<sup>22</sup> NCOA, AMERICA LIVING WITH AIDS, *supra* note 19, at 75.

<sup>23</sup> KAREN DAVIS ET AL., FINANCING HEALTH CARE FOR PERSONS WITH HIV DISEASE: POLICY OPTIONS — TECHNICAL REPORT PREPARED FOR THE NATIONAL COMMISSION ON AIDS 31 (1991).

<sup>24</sup> NCOA, AMERICA LIVING WITH AIDS, *supra* note 19, at 52. In 1987, fewer than 5% of the nation's hospitals were treating more than one half of all AIDS cases. Dennis P. Andrulis et al., *The 1987 US Hospital AIDS Survey*,

As a prerequisite to meaningful health care, many patients with HIV may need drug or alcohol treatment,<sup>25</sup> stable housing,<sup>26</sup> or mental health services. Moreover, because HIV infection may make patients vulnerable to a variety of opportunistic diseases, HIV care frequently requires the services of various medical specialists.<sup>27</sup> Dental care, for example, constitutes a principal component of standard HIV-related medical management. HIV-infected patients — including those with early, undiagnosed disease — often display oral lesions.<sup>28</sup>

Available treatments for HIV disease have significant limitations, including potentially debilitating side effects, limited efficacy, and a tendency to produce resistance.<sup>29</sup> For many HIV-related conditions, no backup therapy exists. Some opportunistic diseases still have no approved treatments, and many lack approved prophylactic regimens.<sup>30</sup> To respond to their varied medical needs, experts recommend a range of long-term care options for HIV-positive patients,<sup>31</sup> including home or community-based care.<sup>32</sup> Long-term health care may reduce

262 JAMA 784, 793 (1989).

<sup>25</sup> See Earnest Drucker, *Drug Users with AIDS in the City of New York: A Study of Dependent Children, Housing, and Drug Addiction Treatment*, in THE AIDS READER 144 (Nancy McKenzie ed., 1991).

<sup>26</sup> See Peter Arno, *Housing, Homelessness, and the Impact of HIV Disease*, in THE AIDS READER 177, 180 (Nancy McKenzie ed., 1991); John Raba et al., *Homelessness and AIDS*, in UNDER THE SAFETY NET 215, 218 (Philip W. Brickner et al. eds., 1990).

<sup>27</sup> Smith, *supra* note 20. Persons with AIDS also need standard preventive care. Common ailments such as measles or influenza may be life-threatening in patients with HIV disease. John F. Jewett & Frederick M. Hecht, *Preventive Health Care for Adults with HIV Infection*, 269 JAMA 1144, 1147 (1993).

<sup>28</sup> PHYSICIAN'S ASS'N FOR AIDS CARE, NEWS RELEASE, Jan. 23, 1991.

<sup>29</sup> See Margaret I. Johnston & Daniel F. Hoth, *Present Status and Future Prospects for HIV Therapies*, 260 SCIENCE 1286, 1286-87 (1993); Lawrence Corey & Thomas R. Fleming, *Treatment of HIV Infection — Progress In Perspective*, 326 NEW ENG. J. MED. 484 (1992).

<sup>30</sup> See John Mills & Henry Masur, *AIDS-Related Infections*, SCI. AM., Aug. 1990, at 50.

<sup>31</sup> NCOA, AMERICA LIVING WITH AIDS, *supra* note 19, at 53.

<sup>32</sup> Andrea Tramarin et al., *An Economic Evaluation of Home-Care Assistance for AIDS Patients: A Pilot Study in a Town in Northern Italy*, 6 AIDS 1377, 1377-78 (1992); see also Jesse Green, *Long-Term Care: A Long-Term Commitment*, in THE AIDS READER 286 (Nancy McKenzie ed., 1991).

AIDS-related medical expenses by as much as 12 percent from diagnosis to death.<sup>33</sup>

## 2. *Financing HIV Care*

During the early years of the AIDS epidemic, commentators feared that AIDS would bankrupt the health care system.<sup>34</sup> Experience, however, has revealed such fears to be baseless. Medical spending on people with HIV currently accounts for roughly 1 percent of health care spending in the United States.<sup>35</sup> Even according to the most dire scenarios, the disease is unlikely ever to consume more than 2 percent of medical spending.<sup>36</sup> Doctor Fred Hellinger, of the federal Agency for Health Care Policy and Research, explains that "HIV may be viewed in the future as a moderately expensive, chronic illness, and not as a catastrophically expensive, fatal illness."<sup>37</sup>

In the mid-1980s, experts widely cited the figure of \$147,000 as the average cost of treating a single case of AIDS.<sup>38</sup> In 1993, however, experts estimate that the "lifetime cost of treating a person with HIV from the time of infection until death is approximately \$119,000."<sup>39</sup> This includes a \$50,000 price tag for HIV-related treatment prior to diagnosis of full-blown AIDS.<sup>40</sup> Leading economists report that AIDS-related medical costs have "fallen [in recent years] as a result of a

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<sup>33</sup> Daniel M. Fox, *Financing Health Care for Persons with HIV Infection: Guidelines for State Action*, 16 AM. J.L. & MED. 223, 227-28 (1990).

<sup>34</sup> Robert A. Padgug & Gerald M. Oppenheimer, *AIDS, Health Insurance, and the Crisis of Community*, 5 NOTRE DAME J.L. ETHICS & PUB. POL'Y 35, 35 (1990).

<sup>35</sup> Federal economists estimate that people with HIV will account for \$6.7 billion in medical spending in 1993. Fred J. Hellinger, *Forecasting the Medical Care Costs of HIV in the United States from 1993 through 1996*, Abstract No. PO-D28-4223, IX Int'l Conf. on AIDS, June 6-11, 1993. Overall health care spending for the same period is expected to amount to \$940 billion. HEALTH CARE REFORM WK., *supra* note 4, at 2.

<sup>36</sup> NCOA, AMERICA LIVING WITH AIDS, *supra* note 19, at 68.

<sup>37</sup> Fred J. Hellinger, *The Lifetime Cost of Treating a Person with HIV*, 270 JAMA 474, 474 (1993).

<sup>38</sup> NCOA, AMERICA LIVING WITH AIDS, *supra* note 19, at 68.

<sup>39</sup> Hellinger, *supra* note 37, at 474.

<sup>40</sup> *Id.*



reduction in the use of inpatient hospital services."<sup>41</sup> Thus HIV-related medical costs, though substantial, compare favorably with medical expenses for other chronic conditions.<sup>42</sup>

Unfortunately, early images of AIDS as a "catastrophically expensive" condition endure in health care financing for people infected with HIV. Due to the private sector's concerted strategy to avoid HIV-related medical costs,<sup>43</sup> the percentage of HIV-related costs borne by private insurers has declined steadily throughout the epidemic.<sup>44</sup> According to one study, gay men with AIDS are thirty-three times more likely to lack health coverage than gay men who have not been diagnosed with the disease.<sup>45</sup> This disparity is not limited to gay men: individuals with HIV disease lose insurance coverage regardless of their gender, race, ethnicity, or socioeconomic status.<sup>46</sup>

Private insurers' removal of HIV-positive individuals from the risk pool has impeded efforts to spread HIV-related costs over a broad base.<sup>47</sup> Public programs have been forced to compensate for private insurers' refusal to cover HIV-related costs.<sup>48</sup> In Los Angeles, public programs cover only 1 percent of

<sup>41</sup> *Id.*

<sup>42</sup> *Id.*; NCOA, AMERICA LIVING WITH AIDS, *supra* note 19, at 68.

<sup>43</sup> See JILL EDEN ET AL., OFFICE OF TECHNOLOGY ASSESSMENT, AIDS AND HEALTH INSURANCE: AN OTA SURVEY 4 (1988).

<sup>44</sup> Jesse Green & Peter S. Arno, *The 'Medicaidization' of AIDS: Trends in the Financing of HIV-Related Medical Care*, 264 JAMA 1261, 1265 (1990) (noting a "marked shift in the payer distribution [between 1983 and 1988 among AIDS patients] toward Medicaid and away from private insurance").

<sup>45</sup> Nancy E. Kass et al., *Loss of Private Health Insurance Among Homosexual Men with AIDS*, 28 INQUIRY 249, 253-54 (1991).

<sup>46</sup> Daniel Fife & James McAnaney, *Private Medical Insurance Among Philadelphia Residents Diagnosed with AIDS*, 6 J. AIDS 512 (1993).

<sup>47</sup> See Padgug & Oppenheimer, *supra* note 34.

<sup>48</sup> Defending its exclusion of many people with HIV, the health insurance industry argued in the 1980s that, if it were required to foot the bill for HIV care, "the resulting barrage of claims would bankrupt many insurance companies and could cause premiums for individual policy-holders to soar 500% a year." Lisa M. Tonery, *AIDS: A Crisis in Health Care Financing*, 40 FED. INS. & CORP. COUNS. Q. 133, 137 (1990). Yet the commercial insurance industry's own financial data demonstrate the absurdity of claims that HIV threatened the viability of private insurers. See Maria del R. Rodriguez, *AIDS Cost Monitoring as a Tool for Policy Making: The Experience of Two Insurance Companies*, Abstract No. 5407, VIII Int'l Conf. on AIDS, July 19-24, 1992; Jon Eisenhandler & Robert A. Padgug, *Empire Blue Cross and Blue Shield: The First 7,500 Cases*, V Int'l Conf. on AIDS, June 1989 (cited in

the health care costs of gay men without AIDS; they fund 20 percent of the medical care provided to gay men with the disease.<sup>49</sup> Medicaid, which pays for 11 percent of health care spending in the United States, covers 25 percent of AIDS-related spending.<sup>50</sup> Medicaid covers medical costs for 45 percent of persons infected with HIV.<sup>51</sup>

According to experts in the federal Health Care Financing Administration, infected persons typically have private coverage at the point of diagnosis but tend to lose it as the disease progresses.<sup>52</sup> Upon loss of coverage, persons with HIV move to "self-pay," depleting personal resources in order to finance medical care. After becoming sufficiently pauperized and/or ill to qualify for public assistance, patients generally look to Medicaid for health coverage.<sup>53</sup>

Specifically, America's health care plan fails people infected with HIV in two ways. First, a significant and increasing number have no health care coverage at all. By 1990, an estimated one in four people with full-blown AIDS lacked any form of health coverage.<sup>54</sup> Two years later, a national study concluded that roughly 25 percent of persons known to be HIV-positive lacked health insurance.<sup>55</sup>

Second, the fragmented, episodic quality of health care for the HIV-ill precludes many patients from developing the primary care relationship needed to enable them to mediate the complicated world of HIV-related medical and social services.<sup>56</sup>

Padgug & Oppenheimer, *supra* note 34, at 36).

<sup>49</sup> INSTITUTE FOR HEALTH POL'Y STUD., *HIV DISEASE: HEALTH CARE POLICY ISSUES* 75 (1990).

<sup>50</sup> Green & Arno, *supra* note 44, at 1261.

<sup>51</sup> Dennis P. Andrulis et al., *Comparisons of Hospital Care for Patients With AIDS and Other HIV-Related Conditions*, 267 *JAMA* 2482, 2484 (1992).

<sup>52</sup> Green & Arno, *supra* note 44, at 1265.

<sup>53</sup> HEALTH CARE FIN. ADMIN., *GUIDE TO EFFECTIVE COLLABORATIVE SERVICE DELIVERY AND FINANCING PRACTICES FOR PERSONS WITH HIV INFECTION AND AIDS* 5 (1990).

<sup>54</sup> Padgug & Oppenheimer, *supra* note 34, at 42.

<sup>55</sup> Andrulis et al., *supra* note 51, at 2784.

<sup>56</sup> In accordance with data indicating heavy reliance by Medicaid beneficiaries on public hospital emergency rooms for primary care, for example, economists have discovered "a disproportionate number of hospitalizations of AIDS patients with Medicaid beginning at the emergency room, unmediated by a physician responsible for continuing care." Green & Arno, *supra* note 44, at 1265.

Doctors Jesse Green and Peter Arno observe that "the notion that AIDS is a chronic illness that should be increasingly managed by primary care physicians is jeopardized by the continuing erosion of the financial basis on which office-based care in the United States rests — namely private health insurance coverage."<sup>57</sup> In its analysis of America's health care coverage for people with HIV, the rest of this Article addresses both problems in detail.

## II. PRIVATE COVERAGE FOR HIV CARE

Three out of four workers look to employment-based benefits for health coverage.<sup>58</sup> Roughly 90 percent of privately insured persons rely on group coverage, while the remaining 10 percent — 14.5 million Americans — retain individual policies.<sup>59</sup> These figures reinforce the idea that sound health insurance relies on the premise that future costs of unknown medical risks ought to be spread over as broad a base as possible.<sup>60</sup>

Perhaps to avoid the perceived "catastrophic" cost of caring for HIV-infected individuals, private insurers have departed from the risk-sharing essence of rational health care financing. Indeed, the private insurance industry has singled out HIV disease for discriminatory treatment and has "attempt[ed] to impose a kind of moral judgement in the determination of coverage and payment of benefits for HIV related charges."<sup>61</sup> While exhaustively analyzing the private sector's response to AIDS during the 1980s, the Congressional Office of Technology Assessment discovered a calculated strategy involving commercial insurers, Blue Cross and Blue Shield plans, and private health maintenance organizations ("HMOs") to avoid "exposure" to the financial impact of AIDS.<sup>62</sup>

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<sup>57</sup> *Id.*

<sup>58</sup> John D. Rockefeller, *A Call for Action: The Pepper Commission's Blueprint for Health Care Reform*, 265 JAMA 2507, 2508 (1991).

<sup>59</sup> Henry T. Greely, *AIDS and the American Health Care Financing System*, 51 U. PITT. L. REV. 73, 122 (1989).

<sup>60</sup> *Id.* at 75.

<sup>61</sup> REPORT TO THE COMMISSIONER FROM THE TASK FORCE ON HIV/AIDS INSURANCE ISSUES 4 (1992) [hereinafter CALIFORNIA HIV TASK FORCE].

<sup>62</sup> EVE NICHOLS, INSTITUTE OF MEDICINE, EXPANDING ACCESS TO INVESTIGATIONAL THERAPIES FOR HIV INFECTION AND AIDS 57 (1991).

This section describes the experience of HIV-infected individuals with private health coverage. It begins with a discussion of the individual and small group market, then analyzes the experience of HIV-positive individuals with large group plans and HMOs. Finally, the section explores coverage gaps prevalent in all forms of private coverage.

#### A. INDIVIDUAL AND SMALL GROUP PLANS

Because small companies do not employ enough workers to make cost-spreading feasible, a separate market exists for small groups and individuals unconnected to any group.<sup>63</sup> Premiums are substantially higher for individuals and small groups than for large corporations.<sup>64</sup> Insurers doing business in the small group market typically employ highly discriminatory underwriting practices in an effort to avoid poor medical risks.<sup>65</sup> Moreover, they manipulate policy coverage to provide themselves with higher premiums for less coverage.<sup>66</sup>

Insurers' first line of defense against HIV-related costs in the small group market is avoidance of HIV-infected individuals altogether. Carriers often successfully avoid HIV-positive individuals through "red-lining," a strategy insurance companies use to refuse to write policies in certain zip codes, for certain occupations, or for applicants with particular demographic characteristics.<sup>67</sup> With respect to AIDS, insurers use red-lining to exclude gay men from coverage.<sup>68</sup>

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<sup>63</sup> See Alain C. Enthoven & Richard Kronick, *Universal Health Insurance Through Incentives Reform*, 265 JAMA 2532, 2533 (1991).

<sup>64</sup> Constance Matthiessen, *The Squeeze on Small Businesses: Health Insurance is Hard to Find*, WASH. POST, June 11, 1991, at A10.

<sup>65</sup> Bodenheimer, *supra* note 7, at 275.

<sup>66</sup> Wendy K. Mariner, *Problems with Employer-Provided Health Insurance — The Employee Retirement Income Security Act and Health Care Reform*, 327 NEW ENG. J. MED. 1682, 1683 (1992).

<sup>67</sup> NATIONAL HEALTH L. PROGRAM, *Health Benefits: How the System is Responding to AIDS*, 3 CLEARINGHOUSE REV. 724, 736 (1988) [hereinafter NHELP]; DAVIS ET AL., *supra* note 23, at 17.

<sup>68</sup> One mammoth HMO in southern California serves every zip code in Los Angeles County except the one covering West Hollywood, a heavily gay enclave. CALIFORNIA HIV TASK FORCE, *supra* note 61, at 5. Insurers often refuse to sell insurance to businesses thought to employ large numbers of gay men, such as hair salons, florists, interior design firms, and restaurants. DAVIS ET AL., *supra* note 23, at 14; CALIFORNIA HIV TASK FORCE, *supra* note

Most insurers in the individual market routinely screen applicants for HIV antibodies and exclude from coverage those testing positive.<sup>69</sup> More than 90 percent of insurers surveyed in 1987 considered HIV-positive applicants uninsurable, while all carriers questioned refused to write policies for persons diagnosed with full-blown AIDS.<sup>70</sup> Although numerous states enacted laws against HIV antibody testing by insurers during the 1980s,<sup>71</sup> these laws generally have been overturned in the courts<sup>72</sup> or repealed by state legislatures.<sup>73</sup> California still bars insurers from testing applicants for HIV antibodies, but numerous carriers reportedly use the CD+4 test as a surrogate for HIV screening.<sup>74</sup>

Insurers routinely require applicants for individual coverage to disclose information on medical questionnaires about past diagnoses or symptoms.<sup>75</sup> Carriers also often demand access to medical records that may confirm or lead one to suspect HIV infection.<sup>76</sup> Some carriers deny coverage to applicants with a history of sexually transmitted diseases.<sup>77</sup>

An insurance applicant's failure to disclose material information — such as facts that would prompt the insurer not to issue the policy or to issue a materially different policy — may provide the insurer grounds to rescind coverage

61, at 20. Tellingly, these occupations are generically distinct from other intrinsically hazardous endeavors that insurers frequently exclude from coverage, such as construction work, diving, oil exploration, fire fighting, asbestos work, foundry work, and law enforcement. See John F. Wasik, *The Crisis in Health Insurance*, CONSUMERS DIG. 49, 50 (1991).

<sup>69</sup> EDEN, *supra* note 43, at 30; Greely, *supra* note 59, at 123; Tonery, *supra* note 48, at 136.

<sup>70</sup> INTERGOVERNMENTAL HEALTH POLICY PROJECT, INTERGOVERNMENTAL AIDS REPORTS 6 (Mar./Apr. 1990) [hereinafter IHPP I].

<sup>71</sup> See NHELP, *supra* note 67, at 738; Tonery, *supra* note 48, at 137.

<sup>72</sup> *E.g.*, Health Ins. Ass'n of America v. Corcoran, 565 N.E.2d 1264 (N.Y. 1990); Life Ins. Ass'n v. Commissioner of Ins., 530 N.E.2d 168 (Mass. 1988).

<sup>73</sup> Mark Scherzer, *Insurance and Employee Benefits*, in AIDS PRACTICE MANUAL: A LEGAL AND EDUCATIONAL GUIDE § 8, at 25 (Nat'l Lawyers Guild, 1992).

<sup>74</sup> EDEN, *supra* note 43, at 32. See also Nichols, *supra* note 62, at 66.

<sup>75</sup> Greely, *supra* note 59, at 123.

<sup>76</sup> Thomas S. Mulligan, *Magic's Revelation Spotlights Insurance*, L.A. TIMES, Nov. 9, 1991, at D1.

<sup>77</sup> Nichols, *supra* note 62, at 57.

once the person submits medical claims.<sup>78</sup> California's official Task Force on HIV/AIDS Insurance Issues reports that submission of an HIV-related claim during the contestability period often triggers an intensive, time-consuming, and occasionally harassing investigation of the insured's medical history.<sup>79</sup>

Carriers often discontinue coverage of small groups after receiving a group member's HIV-related claim.<sup>80</sup> Small group premiums frequently skyrocket when the group includes one or more HIV-positive individuals.<sup>81</sup> The entire group's coverage is jeopardized when the cost of coverage rises beyond the means of small employers.<sup>82</sup> Upon loss of coverage, small companies often are unable to find any replacement coverage.<sup>83</sup>

Recently, states have passed a variety of laws addressing discriminatory underwriting practices in the small group market. Several states now have "no gain, no loss" laws requiring insurers to cover all workers in the company. Numerous states now require carriers in the small group market to set standard premium rates applicable to all groups,

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<sup>78</sup> Scherzer, *supra* note 73, at 22; CALIFORNIA HIV TASK FORCE, *supra* note 61, at 24.

<sup>79</sup> CALIFORNIA HIV TASK FORCE, *supra* note 61, at 24-25. Some investigations take as long as two years, during which the integrity of the insured's medical coverage is constantly in doubt. Although the insured's goal in these circumstances is to avoid the bill for HIV-related care, carriers often latch on to *any* undisclosed prior health problem, even the most minor. California's task force reports that some insurers have rescinded coverage on the grounds that the HIV-infected individual failed to disclose minor medical treatment that occurred more than a decade prior to completion of the application. *Id.*

Insurers often effectively delay adjudication of groundless claims of material misrepresentation. In California, for example, when insurers unilaterally rescind coverage on grounds of material misrepresentation, they must demonstrate the validity of their decision. Rather than follow this procedure, however, at least one insurance company has repeatedly filed lawsuits for rescission in distant forums against insured individuals who were too sick to defend. *Id.* Some states fail to provide for a private right of action for unfair insurance practices and vest sole investigative authority in the insurance department, without providing officials with sufficient resources to investigate and adjudicate such claims swiftly. *Id.*

<sup>80</sup> *Id.* at 20.

<sup>81</sup> DAVIS ET AL., *supra* note 23, at 14.

<sup>82</sup> *Id.* at 15.

<sup>83</sup> Carl J. Schramm, *Health Care Financing for All Americans*, 265 JAMA 3296, 3297 (1991).

regardless of the employee medical profile of a particular company.<sup>84</sup> Such laws help equalize access to small group coverage but have not significantly increased overall access.<sup>85</sup>

Assuming that some coverage is better than none, many states have attempted to provide for the uninsured by granting waivers which allow insurers to issue scaled-down health plans.<sup>86</sup> The resulting "bare-bones" plans typically include enormous deductibles and strictly limit certain basic benefits, such as prescription drugs or hospital coverage.<sup>87</sup> One leading health care analyst refers to the plans as "health insurance that doesn't insure," because the plans leave HIV-infected patients without coverage for key services and in risk of financial catastrophe.<sup>88</sup>

## B. LARGE GROUP PLANS AND SELF-INSURANCE

Historically, insurance offered by large employers has been the preferred form of health coverage in the United States. Large corporations can spread costs over a broad base and offer more comprehensive coverage at a lower cost per worker than small employers. Due to a serious regulatory gap in the health care financing system, however, a few large companies have recently adopted many of the discriminatory underwriting practices previously confined to small groups.<sup>89</sup>

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<sup>84</sup> See Milt Freudenheim, *States Press U.S. on Insurance Plan*, N.Y. TIMES, Mar. 31, 1992, at D2; Sarah Lyall, *Bill to Overhaul Health Insurance Passes in Albany*, N.Y. TIMES, July 2, 1992, at A1.

<sup>85</sup> Greg Steinmetz, *Health Insurers Aren't Expected to End Business in New York Despite New Law*, WALL ST. J., July 7, 1992, at A4 (noting that community rating laws lead to general increases in premium rates and that Vermont's law prompted insurers to leave the state).

<sup>86</sup> Philip J. Hiltz, *Bare-Bones Health Plans Are Found to Attract Few*, N.Y. TIMES, July 23, 1993, at A10. Due to escalating costs, many small employers fail to provide their workers with health benefits, and even fewer cover employees' dependents. See Mariner, *supra* note 66, at 1683; Rockefeller, *supra* note 58, at 2507.

<sup>87</sup> Hilary Stout, *Insurance Firms Are Criticized on Health Plans*, WALL ST. J., June 4, 1991, at B4. Hiltz calls bare-bones policies "a disastrous market failure." Hiltz, *supra* note 86, at A10.

<sup>88</sup> Spencer Rich, *"Bare-Bones" Medical Insurance Assailed*, WASH. POST, June 4, 1991, at A6.

<sup>89</sup> See Mariner, *supra* note 66, at 1683.

Perhaps more significant is the recent trend toward self-insurance.<sup>90</sup> Judicial interpretation of the Employment Retirement Income Security Act ("ERISA")<sup>91</sup> allows companies to escape state regulation of health benefit plans by self-insuring, i.e., directly paying for health benefits from company funds rather than from an outside insurance plan.<sup>92</sup> Self-insurance limits company medical costs by shifting various health expenses to the workers.<sup>93</sup> By 1990, an estimated 80 percent of the nation's larger companies were self-insured,<sup>94</sup> and an increasing number of smaller employers are also funding their own benefit plans.<sup>95</sup> Approximately seventy million Americans are now covered by self-insured plans.<sup>96</sup>

Federal law has been similarly ineffective in regulating discriminatory insurance practices. ERISA<sup>97</sup> challenges to discriminatory insurance plans have been largely unsuccessful.

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<sup>90</sup> Analysts agree that AIDS coverage problems greatly accelerated the trend toward self-insurance. See Greely, *supra* note 59, at 101.

<sup>91</sup> 29 U.S.C. §§ 1001-1461 (1988).

<sup>92</sup> See *FMC Corp. v. Holliday*, 498 U.S. 52 (1990).

<sup>93</sup> *Mariner*, *supra* note 66, at 1682. Numerous businesses, including some of the most prestigious in U.S. commerce, have even discontinued health coverage for retirees. *Id.* at 1683.

<sup>94</sup> John K. Iglehart, *The American Health Care System: Private Insurance*, 326 NEW ENG. J. MED. 1715, 1718 (1992). Self-insurance limits are significantly lower than state regulated limits. See *Kadinger v. IBEW Local 110*, No. 3-93-159 (N.D. Minn. filed Mar. 17, 1993) (\$50,000 limit); *Owens v. Storehouse*, 773 F. Supp. 416 (N.D. Ga. 1991), *aff'd*, 984 F.2d 394 (11th Cir. 1993) (\$25,000 limit); *Equal Employment Opportunity Comm'n v. Allied Servs. Div. Welfare Fund*, No. 93-5076 (C.D. Cal. filed Aug. 23, 1993) (\$5,000 limit); *McGann v. H&H Music Co.*, 946 F.2d 401 (5th Cir. 1991), *cert. denied sub nom.* *Greenberg v. H&H Music Co.*, 113 S. Ct. 482 (1992) (\$5,000 limit). Some self-insurance plans exclude AIDS-related coverage altogether. See *Donaghey v. Mason Tenders Dist. Council Trust Fund*, EEOC Charge No. 160-93-1419 (Jan. 28, 1993).

<sup>95</sup> Milt Freudenheim, *Employers Winning Right to Cut Back Medical Insurance*, N.Y. TIMES, Mar. 29, 1992, at A1.

<sup>96</sup> David G. Savage, *Court Lets Firms Cut Health Care*, L.A. TIMES, Nov. 10, 1992, at A1.

<sup>97</sup> Section 510 of ERISA makes it unlawful for any person to . . . discriminate against a participant or beneficiary for exercising any right to which he is entitled under the provisions of an employee benefit plan . . . or for the purpose of interfering with the attainment of any right to which such participant may become entitled under the plan . . . .  
29 U.S.C. § 1140 (1988).



Courts have held that Congress, in enacting ERISA, did not intend to limit employers' freedom to structure their health care plans.<sup>98</sup> Because employers do not have a fiduciary duty to employees regarding modification of health benefits, employees cannot insist under ERISA that benefit plans be structured in a particular way.<sup>99</sup>

The employment provisions of the Americans With Disabilities Act ("ADA")<sup>100</sup> substantially improve the likelihood that courts will strike down AIDS-specific benefit caps or exclusions. The ADA prohibits discrimination against HIV-infected workers with respect to hiring, firing, compensation, and "the terms, conditions, and privileges of employment."<sup>101</sup> Although the ADA generally immunizes bona fide insurance plans from its anti-discrimination provisions, it provides that plans cannot be a "subterfuge to evade the purposes [of the Act]."<sup>102</sup>

Moreover, the Equal Employment Opportunity Commission ("EEOC") may deem these provisions of the ADA applicable to fringe benefits such as medical coverage.<sup>103</sup> The criteria in the EEOC's interim enforcement guidance would probably regard most plans targeting HIV care for limitation or exclusion as subterfuge. HIV-related costs may occasionally present fiscal challenges to particular health plans, but this normally can be addressed non-discriminatorily by spreading expenses over the whole plan.

Unfortunately, the first reported case involving a self-insured plan under the ADA suggests that it is far from certain that the law will eradicate discriminatory practices against individuals infected with HIV. In that case,<sup>104</sup> a wholesalers' association in New England successfully asserted that their self-

<sup>98</sup> See, e.g., *McGann v. H&H Music Co.*, 946 F.2d 401 (5th Cir. 1991), cert. denied sub nom. *Greenberg v. H&H Music Co.*, 113 S. Ct. 482 (1992); *Owens v. Storehouse*, 773 F. Supp. 416 (N.D. Ga. 1991), *aff'd*, 984 F.2d 394 (11th Cir. 1993).

<sup>99</sup> See *id.*

<sup>100</sup> 42 U.S.C. §§ 12101-12213 (Supp. 1991). The Act's protections became effective in July 1992.

<sup>101</sup> 42 U.S.C. § 12112(a) (1988).

<sup>102</sup> 42 U.S.C. § 12201(c) (1988).

<sup>103</sup> See 29 C.F.R. § 1630.4(f) (1993).

<sup>104</sup> *Carparts Distrib. Ctr., Inc. v. Automotive Wholesalers Ass'n*, 826 F. Supp. 583 (D.N.H. 1993).

insured plan was not a "covered entity" under the employment provisions of the ADA.

### C. MANAGED CARE

Managed care involves access controls and limits on medical services through a system of review and financial incentives. Managed care arrangements include: the staff-model HMO, which employs salaried physicians and limits plan members to services provided by the HMO; preferred-provider organizations ("PPOs"), which provide patients with financial incentives to select particular providers or facilities; and utilization review, which seeks to reduce the volume of unnecessary services through administrative intervention.

More Americans than ever, including many people with HIV, are obtaining medical services through some form of managed care. By 1992, more than forty-one million Americans had enrolled in an HMO,<sup>105</sup> a four-fold increase since 1980.<sup>106</sup> Millions more belong to PPOs,<sup>107</sup> and nearly nine out of ten employer group plans employ administrative practices designed to restrain health care spending.<sup>108</sup>

Managed care proponents contend that the approach reduces health care spending and promotes good health. Traditional fee-for-service coverage compensates providers for each *service* delivered, regardless of its benefit. In contrast, HMOs rely on capitated compensation, which pays for each *patient* enrolled in the plan. Proponents contend that the strategy encourages providers to withhold unnecessary services and provides recipients with the preventive care needed to keep patients healthy.

Limited empirical information exists regarding the quality of care provided within managed care plans. One study notes that "[a]pproximately 30% of Medicare HMO patients disenroll within 2 years, an indication of serious dissatisfaction with the

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<sup>105</sup> Alain C. Enthoven & Sara J. Singer, *Health Care Is Healing Itself*, N.Y. TIMES, Aug. 17, 1993, at A17.

<sup>106</sup> John K. Iglehart, *The American Health Care System — Managed Care*, 327 NEW ENG. J. MED. 742, 744 (1992).

<sup>107</sup> Alain C. Enthoven & Richard Kronick, *A Consumer-Choice Health Plan for the 1990s: Universal Health Insurance in a System Designed to Promote Quality and Economy* (pt.1), 320 NEW ENG. J. MED. 29 (1989).

<sup>108</sup> Mariner, *supra* note 66, at 1682.

plan."<sup>109</sup> For patients with HIV disease and other chronic illnesses, the drawbacks of managed care are more pronounced.

### 1. *Selective Treatment*

The ability of managed care to restrain medical spending is the subject of considerable dispute among health care economists. While some studies suggest that employers have reduced health care costs by moving to managed care,<sup>110</sup> other reports document the lack of significant cost savings.<sup>111</sup> To the extent that HMOs have successfully reduced health care spending, critics cite the tendency of HMOs to avoid poor medical risks.<sup>112</sup> Indeed, the Congressional Office of Technology Assessment concludes that private HMOs reject applicants at higher rates than commercial insurers.<sup>113</sup>

Selective treatment by HMOs reflects the most dangerous feature of managed care for patients with chronic diseases such as HIV. For those HIV patients who receive some coverage, "the incentives of a capitation payment system may encourage the inappropriate reduction of necessary services."<sup>114</sup> Patients requiring intensive (and expensive) medical care represent the greatest threat to profitability under a capitated compensation system.

HMOs sometimes inappropriately infringe on physicians' treatment of HIV-infected persons. The HMO may restrict services by limiting payments for care and by refusing to refer patients who require specialists.<sup>115</sup> HMOs may withhold

<sup>109</sup> Ronald S. Bronow et al., *The Physicians Who Care Plan: Preserving Quality and Equitability in American Medicine*, 265 JAMA 2511, 2514 (1991).

<sup>110</sup> *Health Plans Savings Cited*, N.Y. TIMES, Apr. 8, 1992, at D11; see Willard G. Manning et al., *A Controlled Trial of the Effect of a Prepaid Group Practice on Use of Services*, 310 NEW ENG. J. MED. 1505 (1984).

<sup>111</sup> Jon R. Gabel & Thomas Rice, *Is Managed Competition a Field of Dreams?*, J. AM. HEALTH POL'Y 19, 21 (1993) (citing studies conducted by KMPG Peat Marwick and by the Health Insurance Association of America); Dena Bunis, *No Cure for Soaring Health Costs*, N.Y. NEWSDAY, Apr. 7, 1992, at 41 (citing study by benefits consulting firm showing mixed results from managed care).

<sup>112</sup> See Katherine Hiduchenko, *Do Health Maintenance Organizations Control Costs or Shift Costs?*, 328 NEW ENG. J. MED. 971 (1993).

<sup>113</sup> EDEN, *supra* note 43, at 19-22.

<sup>114</sup> Bronow et al., *supra* note 109, at 2514.

<sup>115</sup> Jean Hopfensberger, *Move to HMOs has Cut Some Services to Poor*

compensation to primary care physicians, thereby deterring some doctors from treating HIV-infected patients.<sup>116</sup> In litigation recently filed in a Texas state court, a physician with a significant AIDS practice asserted that he was wrongfully terminated by an HMO due to his insistence that his patients receive appropriate care.<sup>117</sup> In another case, AIDS patients filed a class action suit against an HMO, alleging that the health plan denied HIV-positive patients access to vital medications and to the doctor of their choice.<sup>118</sup> The complaint further alleged that the HMO unreasonably limited AIDS-related hospital stays by badgering physicians who hospitalized their HIV-positive patients.<sup>119</sup>

## 2. Lack of Expertise

HMOs also use more subtle tools to avoid the medical costs of chronically ill patients.<sup>120</sup> They may fail to include in their list of providers physicians with recognized expertise in treating HIV disease; they may not employ the full range of subspecialists required in the treatment of HIV disease.<sup>121</sup> Even when plans arrange referrals to out-of-plan specialists, patients often experience needless delays in care.<sup>122</sup>

Many HMOs require patients to choose a primary care provider to serve as a "gatekeeper" to additional services, without ensuring that chronically ill patients have access to primary care doctors with expertise in the patient's particular

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*People, Critics of System Claim*, STAR TRIBUNE, Nov. 11, 1991, at A1.

<sup>116</sup> Hiduchenko, *supra* note 112.

<sup>117</sup> *Gathe v. CIGNA Health Plan of Texas, Inc.*, No. 93-40135 (Tex. Dist. Ct. filed Aug. 4, 1993).

<sup>118</sup> *San Francisco HMO Is Target of Lawsuit, Union Protest*, AIDS POL'Y & L., Aug. 21, 1992, at 2-3 [hereinafter *San Francisco HMO*].

<sup>119</sup> *Id.* at 3.

<sup>120</sup> See Arnold S. Relman, *Controlling Costs by "Managed Competition" — Would It Work?*, 328 NEW ENG. J. MED. 133, 134 (1993).

<sup>121</sup> Studies indicate that health care facilities with limited AIDS care experience have notably higher AIDS-related mortality rates than centers with a high level of AIDS experience. Charles L. Bennett et al., *The Relation Between Hospital Experience and In-Hospital Mortality for Patients with AIDS-Related PCP*, 261 JAMA 2975 (1989); Valerie E. Stone et al., *The Relation Between Hospital Experience and Mortality for Patients with AIDS*, 268 JAMA 2655 (1992).

<sup>122</sup> Hiduchenko, *supra* note 112.

condition.<sup>123</sup> Thus, even if a managed care plan offers the expertise to deal with an HIV patient's symptoms, the patients are unlikely to benefit. Studies suggest that general practitioners consistently undertreat patients with chronic illnesses.<sup>124</sup>

#### D. OUT-OF-POCKET COSTS

American consumers pay nearly one out of three health care dollars from personal funds.<sup>125</sup> Out-of-pocket medical expenditures doubled between 1980 and 1991,<sup>126</sup> and observers expect this trend to continue in the future, as employers seek to control medical outlays by shifting additional costs to workers.<sup>127</sup> Increasing out-of-pocket expenses frequently discourage consumers from obtaining preventive services.<sup>128</sup> Even modest levels of co-payments have negative health outcomes among the poor and chronically ill.<sup>129</sup>

Employer health plans typically transfer health care costs to workers in three ways. First, health care plans usually require consumers to pay substantial out-of-pocket costs in the form of deductibles and co-payments. The percentage of companies offering health plans with deductibles higher than \$200 increased from 29 percent in 1987 to 75 percent in 1991.<sup>130</sup>

<sup>123</sup> See Hopfensberger, *supra* note 115, at A1.

<sup>124</sup> Hiduchenko, *supra* note 112. Reportedly, some managed care plans have sought to remedy their lack of AIDS expertise by establishing "centers of excellence" for AIDS care. *San Francisco HMO*, *supra* note 118, at 3. Critics, however, question the wisdom of segregating patients who require a wide range of mainstream services. One medical ethicist has noted that segregating socially-marginalized patients will probably lead to inferior care. John D. Arras, *The Fragile Web of Responsibility: AIDS and the Duty to Treat*, HASTINGS CENTER REP., Apr./May 1988, Supp. at 10, 12.

<sup>125</sup> Kevin Grumbach et al., *Liberal Benefits, Conservative Spending: The Physicians for a National Health Program Proposal*, 265 JAMA 2549, 2552 (1991).

<sup>126</sup> Hilary Stout, *Average U.S. Family Is Spending 11.7% Of Income on Health Care, Study Finds*, WALL ST. J., Dec. 11, 1991, at A2.

<sup>127</sup> Bodenheimer, *supra* note 7, at 275.

<sup>128</sup> Susan Marquis & Stephen H. Long, *Uninsured Children and National Health Reform*, 268 JAMA 3473 (1992).

<sup>129</sup> See Robert H. Brook, *Health, Health Insurance, and the Uninsured*, 265 JAMA 2998, 2998-99 (1991).

<sup>130</sup> *Fewer Medical-Insurance Free Rides for Employees*, PHYSICIAN'S

Second, health care plans often severely limit allowable lifetime benefits. Fourteen percent of insurance plans limit lifetime benefits to \$250,000, while two out of three cap benefits at \$1 million or less.<sup>131</sup> A 1989 survey found that more than 6 percent of working-age Americans had exceeded their coverage limits.<sup>132</sup>

Finally, private health care plans routinely shift medical expenses to individuals by imposing waiting periods or outright exclusions on health conditions that were pre-existing at the time of the individual's enrollment in the plan. Although waiting periods typically apply to conditions requiring treatment or producing symptoms within three months to two years prior to the policy's commencement,<sup>133</sup> the National Association of Insurance Commissioners would permit insurers to look back as many as five years to locate evidence of a pre-existing condition.<sup>134</sup> Some plans delay coverage for any conditions for which symptoms have *ever* appeared.<sup>135</sup> On average, the waiting time for coverage of a pre-existing condition is nine months, but waiting periods can last several years.<sup>136</sup>

Most observers agree that HIV infection alone — as opposed to full-blown AIDS — does not satisfy the standard definition of a pre-existing condition. Asymptomatic infection with HIV does not invariably require treatment and does not produce medical symptoms normally associated with a pre-existing condition.<sup>137</sup> Nonetheless, insurers frequently deny coverage to persons who submit HIV-related claims during the pre-existing condition waiting period.<sup>138</sup>

In light of the strategies used to transfer health expenses directly to workers, it is not surprising that medical costs have financially devastated many people with HIV in the United

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WKLY., May 18, 1992.

<sup>131</sup> Bodenheimer, *supra* note 7, at 274.

<sup>132</sup> *Id.* at 275.

<sup>133</sup> DAVIS ET AL., *supra* note 23, at 17.

<sup>134</sup> Greely, *supra* note 59, at 125.

<sup>135</sup> DAVIS ET AL., *supra* note 23, at 17.

<sup>136</sup> Bodenheimer, *supra* note 7, at 275.

<sup>137</sup> EDEN, *supra* note 43, at 34; Tonery, *supra* note 48, at 141. As Mark Scherzer observes, "In order for a condition to be pre-existing . . . the general rule is that it must be manifest, not latent, at the time of inception of the policy." Scherzer, *supra* note 73, at 18.

<sup>138</sup> EDEN, *supra* note 43, at 34; Tonery, *supra* note 48, at 141.

States.<sup>139</sup> Indeed, serious illness in the contemporary United States routinely leads to poverty.<sup>140</sup>

### E. BENEFIT PACKAGES

Even if a private plan offers health coverage to persons with HIV disease, many plans exclude important HIV-related medical services. For example, most private health plans do not reimburse for prescription drugs<sup>141</sup> — the single most important service for HIV-infected patients. As a result of these exclusions, Americans pay out-of-pocket three out of every four dollars for prescription drugs.<sup>142</sup> People with HIV pay an even greater share of the costs of prescription drugs.<sup>143</sup>

Many of the leading AIDS drugs are extremely costly as a result of their protection under the Federal Orphan Drug Act of 1983.<sup>144</sup> A standard drug bill for a person with AIDS exceeds

<sup>139</sup> See Nancy Kass et al., *Change in Employment, Insurance, and Income in Relation to HIV Status and Disease Progression*, Abstract No. PO-D5579, VIII Int'l Conference on AIDS, July 19-24, 1992.

<sup>140</sup> Marsha F. Goldsmith, *Cost in Dollars and Lives Continues to Rise*, 266 JAMA 1055 (1991) (observing that deterioration of health coverage among HIV-infected individuals "appear[s] to reflect the impoverishment that often accompanies worsening illness in the United States").

<sup>141</sup> Peter S. Arno et al., *Economic and Policy Implications of Early Intervention in HIV Disease*, 262 JAMA 1493, 1497 (1989).

<sup>142</sup> *Id.* at 1496.

<sup>143</sup> DAVIS ET AL., *supra* note 23, at 31.

<sup>144</sup> Orphan Drug Act of 1983, Pub. L. No. 97-414, 96 Stat. 2049 (codified as amended in scattered sections of Titles 15, 21, 26, and 42 U.S.C.). The Orphan Drug Act was enacted to provide financial incentives for the development of "orphan" drugs, defined under the act as drugs for the treatment of diseases for which the sale of the drug would not be profitable enough to cover development costs. Mary T. Griffin, *AIDS Drugs & the Pharmaceutical Industry: A Need for Reform*, 17 AM. J.L. & MED. 363, 396 (1991). The Act's regulations have led to high costs for many AIDS-related drugs. For example, AZT typically costs about \$2,200 per year. Marlene Cimons, *Judge Upholds Burroughs' Claim to AZT Patent*, L.A. TIMES, July 23, 1993, at D1. Nevertheless, that is a substantial reduction from the original yearly price of \$10,000, which ignited a fire storm of protest. *The Cost of AIDS: A Stitch in Time*, THE ECONOMIST, Aug. 18, 1990, at 21. Aerosolized pentamidine, which until recently was the primary drug used in the treatment of HIV-related PCP, cost \$25 per vial when it was first introduced as an orphan drug in 1984, only to increase in price four-fold within two years. NEW YORK CITY DEPT OF CONSUMER AFF., MAKING A KILLING ON AIDS: HOME HEALTH CARE & PENTAMIDINE 1-2 (May 1991). After years of seeking

\$10,000 annually.<sup>145</sup> Patients relying on private coverage must pay out-of-pocket much, if not all, of that figure.<sup>146</sup> Numerous drug companies subsidize drug costs for indigent patients, but few patients benefit from the subsidies.<sup>147</sup>

Private health plans generally exclude coverage for experimental drugs.<sup>148</sup> These exclusions disproportionately affect patients with HIV disease, since they must rely heavily on non-approved therapies — particularly for conditions for which standard treatments do not exist. Although both the Health Insurance Association of America<sup>149</sup> and a federal blue ribbon panel of medical experts<sup>150</sup> have recommended that private insurers adopt flexible reimbursement practices for experimental drugs used in the treatment of life-threatening conditions, the insurance industry has generally ignored the advice, even with regard to "off-label" uses of drugs approved for other conditions.<sup>151</sup>

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meaningful therapies for HIV-related cytomegalovirus disease, a condition frequently leading to blindness, activists initially rejoiced following the approval of the drug foscarnet only to learn that the yearly price of the compound exceeded \$20,000. Malcolm Gladwell, *High Price of Latest Drugs for AIDS Patients Decried*, WASH. POST, Nov. 12, 1991, at A1, A5. Rifabutin, approved in 1993 for the treatment of a principal cause of HIV-related death, costs roughly \$2,000 per year, and clarithromycin, a standard antibiotic used to treat numerous HIV-related conditions, can cost \$3,000 per year. See DAVIS ET AL., *supra* note 23, at 32.

<sup>145</sup> Green & Arno, *supra* note 44, at 1265. This figure includes anti-retroviral therapy, requisite prophylaxis, and treatments for various opportunistic infections. *Id.*

<sup>146</sup> Griffin, *supra* note 144, at 403.

<sup>147</sup> Susan Moffat, *Drug Aid Not Getting to Indigents*, L.A. TIMES, Oct. 30, 1992, at D1.

<sup>148</sup> HCFA GUIDE, *supra* note 53, at 15; Nichols, *supra* note 62, at 53-54; Julia F. Costich, Note, *Denial of Coverage for "Experimental" Medical Procedures: The Problem of De Novo Review Under ERISA*, 79 KY. L.J. 801, 807 (1990-91).

<sup>149</sup> Nichols, *supra* note 62, at 56. The Health Insurance Association of America represents about 85% of all commercial health insurance companies in the United States. *Id.*

<sup>150</sup> FINAL REPORT OF THE NATIONAL COMMITTEE TO REVIEW CURRENT PROCEDURES FOR APPROVAL OF NEW DRUGS FOR CANCER AND AIDS vii (1990).

<sup>151</sup> Nichols, *supra* note 62, at 54; U.S. GEN. ACCT. OFF., OFF-LABEL DRUGS: REIMBURSEMENT POLICIES CONSTRAIN PHYSICIANS IN THEIR CHOICE OF CANCER THERAPIES 2 (Sept. 27, 1991).



Finally, private plans routinely exclude coverage of other important services, such as long-term care,<sup>152</sup> standard preventive services such as vaccinations,<sup>153</sup> and home health care.<sup>154</sup> Even though patients with severe HIV disease frequently experience rapid and potentially life-threatening weight loss, private plans vary widely in their coverage of nutritional supplements.<sup>155</sup>

#### F. CONTINUATION AND CONVERSION

The federal Consolidated Omnibus Budget Reconciliation Act of 1985 ("COBRA")<sup>156</sup> requires employers of twenty or more workers to continue health coverage for eighteen months for workers who leave their jobs. COBRA limits the cost of continuation premiums to the full group premium price plus 2 percent, which the former employee must pay out-of-pocket.<sup>157</sup> For workers who leave employment due to a disability which qualifies them for Social Security Disability Insurance, continuation coverage lasts twenty-nine months (when Medicare eligibility begins), provided the insured pays 150 percent of the premium after the eighteenth month.<sup>158</sup>

Unfortunately, COBRA has limited utility for many people with HIV. Many people with HIV work for small companies, which are not covered by COBRA.<sup>159</sup> Moreover, the cost of COBRA premiums, although limited by law, is often beyond the means of an unemployed person with HIV.<sup>160</sup>

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<sup>152</sup> HCFA GUIDE, *supra* note 53, at 15; Tonery, *supra* note 48, at 143.

<sup>153</sup> Bodenheimer, *supra* note 7, at 275.

<sup>154</sup> Scherzer, *supra* note 73, at 15.

<sup>155</sup> PHYSICIANS ASS'N FOR AIDS CARE, PAAC NOTES (May/June 1992).

<sup>156</sup> Consolidation Omnibus Budget Reconciliation Act of 1985, 26 U.S.C. § 4980 (1988). See DAVIS ET AL., *supra* note 23, at 15.

<sup>157</sup> DAVIS ET AL., *supra* note 23, at 15.

<sup>158</sup> *Id.* at 15-16.

<sup>159</sup> CALIFORNIA HIV TASK FORCE, *supra* note 61, at 29. Some states, however, have "mini-COBRA" laws that essentially extend COBRA's continuation coverage provisions to the small group market. See Scherzer, *supra* note 73, at 8-9.

<sup>160</sup> DAVIS ET AL., *supra* note 23, at 13; Green & Arno, *supra* note 44, at 1265.

## G. REGULATORY GAPS

Gaps in the regulatory scheme for medical services frequently lead to price gouging. Recently, for example, a home infusion industry has blossomed in response to the need of HIV-positive patients for home-based medical services.<sup>161</sup> Unfortunately, this salutary development has a dark side, as a lack of government oversight has permitted many home care companies to charge exorbitant rates for the simplest services.<sup>162</sup> These abuses may negate the natural cost-effectiveness of home health care.<sup>163</sup>

## H. RISK POOLS

By 1991, nearly half the states had created risk pools to improve insurance coverage for individuals with HIV disease and other chronic diseases.<sup>164</sup> Despite this trend, however, not all risk pools cover individuals with HIV. South Carolina's risk pool, for example, expressly excludes persons with HIV.<sup>165</sup>

Premiums under such plans are quite high, usually 150-200 percent higher than commercial insurance rates.<sup>166</sup> Although

<sup>161</sup> NEW YORK CITY DEP'T OF CONSUMER AFF., *supra* note 144, at 1-2.

<sup>162</sup> An investigation by the New York City Department of Consumer Affairs found that home health care companies frequently engage in "highway robbery" by overcharging patients. *Id.* at 2. The New York City investigation discovered that "[h]igh-tech home care companies that provide infusion treatment charge patients \$9.84 for 10 ml. of sterile water that can be purchased at any pharmacy for \$2.00; they charge \$22.22 for a dextrose solution that pharmacies sell for \$4.00; and they charge up to \$10,000 a month for [total parenteral nutrition] (a life-extending nutritional supplement) that actually costs \$1,300." *Id.* "Without the drug cytovene, AIDS sufferers go blind; yet while it retails for less than \$40 per 500 mgs., some home infusion companies charge more than \$200. An AIDS patient can pay up to \$100,000 a year for this one drug." *Id.* The investigation found that home health care companies often charge markups of 2,000 to 3,000% on inexpensive equipment. "People with AIDS often administer intravenous treatments themselves, but home infusion companies bill as if their nurses had performed the treatments." *Id.*

<sup>163</sup> *Id.*

<sup>164</sup> Sally Squires, *State-Sponsored Health Plans Attract Uninsured*, WASH. POST, Mar. 26, 1991, (Health Supplement), at 5.

<sup>165</sup> S.C. CODE ANN. § 38-74-30(d)(8) (Law. Co-op. 1992).

<sup>166</sup> NHELP, *supra* note 67, at 735. "[I]n some states (such as Florida) the premiums may go as high as 300% of standard average premiums for high

these risk pools improve insurance availability, they are accessible only to the fraction of people with HIV capable of affording premiums over \$8,000 per year.<sup>167</sup> According to analysts, risk pools are much less effective in reducing the number of uninsured than are state laws that prohibit medical underwriting.<sup>168</sup>

### III. PUBLIC COVERAGE FOR HIV CARE

As popular myth would have it, there is a clear and permanent divide between those in the United States who are poor and those who are not. The AIDS epidemic, however, has exposed the fallacies inherent in the myth. Thousands of working Americans have fallen into poverty as a direct result of their HIV infection. Dependent on Medicaid, public hospitals, and community clinics for their medical care, these individuals have experienced first-hand this nation's neglect of the health care needs of the indigent.

This section describes the experience of HIV-infected individuals with public health care. It begins by analyzing the barriers HIV-positive people face in obtaining Medicaid, then discusses the experience of HIV-positive people who receive medical care through Medicaid. It closes with a discussion of public hospitals and other public medical care programs.

#### A. MEDICAID

##### 1. *Eligibility Barriers*

Most adults with HIV infection obtain Medicaid through Supplemental Security Income, which provides benefits to applicants who have satisfied the Social Security Administration's rigorous disability rules.<sup>169</sup> A person with HIV satisfies these rules only after a doctor diagnoses him or her with full-blown AIDS.<sup>170</sup> Medicaid eligibility is thus normally

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risk individuals." NEW YORKERS FOR ACCESSIBLE HEALTH COVERAGE, WHY HIGH RISK POOLS WON'T WORK (Feb. 15, 1992). [hereinafter NEW YORKERS FOR ACCESSIBLE HEALTH COVERAGE].

<sup>167</sup> IHPP I, *supra* note 70, at 8.

<sup>168</sup> NEW YORKERS FOR ACCESSIBLE HEALTH COVERAGE, *supra* note 166.

<sup>169</sup> 20 C.F.R. § 404.1505 (1993).

<sup>170</sup> *See id.* In 1993, the Social Security Administration decoupled its

impossible until a person with HIV exhibits an official AIDS indicator disease.

The restrictive requirements for Medicaid eligibility harm persons with HIV by eliminating their ability to receive early care. According to the Centers for Disease Control, an estimated 60 percent of people infected with HIV could benefit from early intervention.<sup>171</sup> Medicaid's rules, however, require poor people with HIV to experience needless illness, have a poorer quality of life, and die sooner than more affluent HIV-positive patients.<sup>172</sup> Deprived of access to the most rudimentary services, many poor people at high risk of HIV infection never seek testing for antibodies to the virus.<sup>173</sup> Moreover, poor, uninsured patients who learn that they are HIV-positive are unlikely to be offered AZT or other early-intervention services.<sup>174</sup>

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eligibility guidelines from the CDC's epidemiologic standard, effectively expanding access to SSI benefits. See 58 Fed. Reg. 36008.01 & 36065.01 (1993) (to be codified at 20 C.F.R. part 404).

<sup>171</sup> *Revised Classification*, *supra* note 12 (examining the progression of HIV and noting that it is characterized by manifesting illnesses that would not threaten the health of uninfected persons, but that lead to severe complications and prolonged illness in infected persons).

<sup>172</sup> See Richard D. Moore et al., *Zidovudine and the Natural History of the Acquired Immunodeficiency Syndrome*, 324 NEW ENG. J. MED. 1412 (1991); Michael P. Stein et al., *Differences in Access to Zidovudine (AZT) Among Symptomatic HIV-Infected Persons*, 6 J. GEN. INTERN. MED. 35 (1991); Stephen Crystal et al., *Impact of Zidovudine Treatment on Survival and Health Services Utilization*, Abstract No. PO-D5702, VIII Int'l Conf. on AIDS, July 19-24, 1992; Osamah Hamouda et al., *Knowledge of HIV Serostatus Is Related to Changes in the Spectrum of AIDS Defining Disease*, Abstract No. PO-C4117, VIII Int'l Conf. on AIDS, July 19-24, 1992; Ira Longini et al., *The Effect of Routine Clinical Use of Therapy on the Progression of HIV Disease in a Population-Based Cohort*, Abstract No. PO-B3894, VIII Int'l Conf. on AIDS, July 19-24, 1992; David A. Cooper, *The Efficacy and Safety of Zidovudine Therapy in Early Asymptomatic HIV Infection*, Abstract No. PO-B3718, VIII Int'l Conf. on AIDS, July 19-24, 1992.

<sup>173</sup> For example, in 1993, years after the development and approval of a battery of treatments which have effectively rendered PCP preventable, poor Americans who are unaware of their HIV infection continue to obtain their AIDS diagnoses by appearing with PCP in the emergency rooms of public hospitals. See DAVIS ET AL., *supra* note 23, at 29-30.

<sup>174</sup> Barbara J. Turner et al., *Does Having a Primary Provider Influence the Likelihood of Receiving Zidovudine (AZT)?*, Abstract No. PO-B3418, VIII Int'l Conf. on AIDS, July 19-24, 1992 ("HIV infected persons with a primary care provider are twice as likely to have been prescribed AZT than those with more fragmented care").

Acknowledging both the depth of the AIDS crisis and the deficiencies in existing health care delivery mechanisms, Congress enacted the Ryan White Comprehensive AIDS Resource Emergency Act ("CARE").<sup>175</sup> CARE provides emergency assistance to the hardest-hit cities, early intervention services to persons lacking health coverage, and support for a variety of community-based initiatives.<sup>176</sup> Appropriations for CARE services, however, have amounted to only a fraction of the funding levels authorized in the original legislation.<sup>177</sup> While CARE funding remains meager, caseloads continue to increase.

Failure to offer people with HIV meaningful, timely access to health care also impedes efforts to control the future spread of the epidemic. Without access to rudimentary services such as testing, people who do not know they are HIV positive may continue to engage in risky activities. Patients are more likely to adhere to recommended behavior norms for preventing HIV transmission if they have an ongoing relationship with a primary care physician. Not only does this relationship promote clinically beneficial care, but it also allows the physician to reinforce prevention messages.<sup>178</sup>

## 2. Reimbursement Levels

Medicaid fails to cover the cost of AIDS care.<sup>179</sup> Moreover, because Medicaid compensates physicians at only 64 percent of Medicare rates, the number of physicians willing to treat Medicaid patients is limited. People with HIV are particularly vulnerable under this system because of Medicaid's prominence in the delivery of AIDS care. It is possible to alleviate this problem. To encourage more private HIV specialists to participate in Medicaid, for example, New York State compensates providers of HIV care at "super-reimbursement" rates.<sup>180</sup>

<sup>175</sup> Pub. L. No. 101-381, §§ 1-422, 104 Stat. 576 (1990).

<sup>176</sup> *See id.*

<sup>177</sup> *See* NCOA, *AMERICA LIVING WITH AIDS*, *supra* note 19, at 82.

<sup>178</sup> *See* Donald P. Francis et al., *Early Intervention: Effect on Sexual Behavior Change*, Abstract No. PO-D5319, VIII Int'l Conf. on AIDS, July 19-24, 1992.

<sup>179</sup> IHPP I, *supra* note 70, at 6.

<sup>180</sup> Mireya Navarro, *New York Will Raise Fees to Doctors for AIDS*

### 3. Coverage Limitations

Although prescription drug coverage is technically an optional service under the Medicaid Act, all fifty states and the District of Columbia include prescription drug coverage in their Medicaid plans.<sup>181</sup> Unfortunately, most states limit the number of refills, the total quantity of each prescription, and the total cost of prescription drugs.<sup>182</sup> Washington State, for example, limits Medicaid recipients to two prescriptions per month, and Texas and Oklahoma permit only three.<sup>183</sup>

These reimbursement policies interfere with clinicians' ability to deliver adequate HIV care. The monthly bill for prescription drugs for the typical HIV patient substantially exceeds typical state limits. In states with the most severe limits, Medicaid assists the patient in covering the costs of fewer than one in three of the medically necessary drugs.<sup>184</sup>

With early treatment, 60 percent of persons with HIV infection could avoid needless illness and enjoy an improved and prolonged life.<sup>185</sup> Ironically, numerical restrictions on prescription drugs — which are intended to keep Medicaid costs low — may cost more in the long run by producing unnecessary illness. After New Hampshire limited Medicaid coverage to three prescriptions per month, researchers found that the policy placed "frail, low-income, elderly patients at increased risk of institutionalization in nursing homes and may increase Medicaid costs."<sup>186</sup>

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*Patients*, N.Y. TIMES, Aug. 20, 1991, at B1. See also NCOA, AMERICA LIVING WITH AIDS, *supra* note 19, at 78 (discussing Medicaid expansion efforts that would offer 100% reimbursement rates to providers at community facilities meeting minimum federal standards and receiving federal funding).

<sup>181</sup> INTERGOVERNMENTAL HEALTH POL'Y PROJECT, U.S. DEPT. OF HEALTH AND HUM. SERVS., SURVEY OF STATE MEDICAID COVERAGE OF AIDS-RELATED DRUGS I (1990) [hereinafter IHPP I].

<sup>182</sup> IHPP I, *supra* note 70, at 5.

<sup>183</sup> IHPP II, *supra* note 181, at 14.

<sup>184</sup> See IHPP II, *supra* note 181.

<sup>185</sup> See DAVIS ET AL., *supra* note 23, at 33.

<sup>186</sup> Stephen B. Soumerai et al., *Effects of Medicaid Drug-Payment Limits on Admission to Hospitals and Nursing Homes*, 325 NEW ENG. J. MED. 1072, 1072 (1991).

Nearly every state Medicaid program refuses to pay for unapproved drugs.<sup>187</sup> In addition, a survey undertaken for the Health Care Financing Administration revealed that twenty-one states exclude coverage for ancillary medical services associated with the administration of an unapproved compound.<sup>188</sup> Failure to cover such ancillary costs may effectively exclude poor persons from clinical trials, which sometimes do not cover the costs of diagnostic tests or other forms of medical monitoring required by the protocol.<sup>189</sup>

Medicaid beneficiaries with HIV infection frequently confront additional coverage restrictions which impede effective medical management of the disease. Numerous states, for example, place arbitrary limits on the number of hospital days for which Medicaid recipients may be reimbursed in any given year.<sup>190</sup> Depending on the state in which the person with HIV resides, Medicaid rules may limit access to dental care,<sup>191</sup> drug treatment,<sup>192</sup> long-term care,<sup>193</sup> home health care,<sup>194</sup> preventive medical services,<sup>195</sup> and other alternative therapies.

<sup>187</sup> IHPP II, *supra* note 181, at 17.

<sup>188</sup> *Id.*

<sup>189</sup> Nichols, *supra* note 62, at 59-60.

<sup>190</sup> NHELP, *supra* note 67, at 730-31.

<sup>191</sup> ASSOCIATION OF STATE & TERRITORIAL HEALTH OFFICIALS AND ASS'N OF STATE & TERRITORIAL DENTAL DIRECTORS, GUIDE TO PUBLIC HEALTH PRACTICE: HIV AND THE DENTAL COMMUNITY 9 (1989) [hereinafter ASTHO, DENTAL REPORT].

<sup>192</sup> Medicaid is institutionally biased toward "medical" models of drug and alcohol treatment, frequently refusing to cover drug-free addiction treatment delivered in non-hospital settings. Moreover, even when coverage is available, meaningful access to drug treatment is impeded by the acute shortage of available treatment slots. NATIONAL COMM'N ON AIDS, THE TWIN EPIDEMICS OF SUBSTANCE USE AND HIV 1 (1991) [hereinafter NCOA, TWIN EPIDEMICS].

<sup>193</sup> Although Medicaid outperforms Medicare and most private insurance plans in coverage of long-term care, such Medicaid services are limited to persons who are destitute or who have depleted personal resources to the point of impoverishment. Charlene Harrington et al., *A National Long-Term Care Program for the United States*, 266 JAMA 3023 (1991). In addition, Medicaid has an institutional bias in favor of nursing home care, to the exclusion of other long-term care options that may be more appropriate for many people with HIV. *See id.*

<sup>194</sup> While the Medicaid Act requires states to cover services provided in a patient's home by a certified medical professional, states are not required to pay for private duty nursing and personal care services. *See id.*

<sup>195</sup> *See* NCOA, AMERICA LIVING WITH AIDS, *supra* note 19, at 73.

#### 4. *Managed Care*

Observers report an explosive growth in the enrollment of Medicaid beneficiaries in managed care.<sup>196</sup> Early expectations that managed care would result in substantial financial savings, however, have not been met.<sup>197</sup> Studies suggest that low income patients in managed care do not perform as well as managed care patients with private coverage. While one study found that higher income patients had health care expenditures roughly equivalent to similar individuals in fee-for-service plans, the study concluded that the "health status [of low income participants receiving care in HMOs] was significantly poorer than that of comparable persons in the fee-for-service program."<sup>198</sup> Moreover, perhaps as a result of difficulties related to the administrative bureaucracy of managed care, studies suggest that managed care actually reduces health care access for many poor people.<sup>199</sup>

With respect to people with HIV or other chronic conditions, Medicaid managed care incorporates the same incentives to undertreat that inhere in HMOs serving the privately insured.<sup>200</sup> These incentives are particularly pronounced

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<sup>196</sup> Thirty-six states enroll at least a portion of their Medicaid recipients in managed care. U.S. DEP'T OF HEALTH AND HUM. SERVS., NEWS RELEASE, Nov. 30, 1992 [hereinafter HHS NEWS RELEASE]. This is an increase of five states since 1991. CONGRESSIONAL RESEARCH SERV., MEDICAID SOURCE BOOK: BACKGROUND DATA AND ANALYSIS (1992) [hereinafter MEDICAID SOURCE BOOK]. Between 1991 and 1992, the number of Medicaid beneficiaries enrolled in managed care grew by 35%. By November 1992, an estimated 12% of Medicaid beneficiaries nationwide had enrolled in managed care. HHS NEWS RELEASE, *supra*. Federal officials believe that this figure could soar as high as 20% by the end of 1993. Comments of Michael Fiore, HEALTH CARE FINANCING ADMIN., CONFERENCE ON HEALTH CARE STRATEGIES FOR LOW INCOME PEOPLE IN 1993, sponsored by NAT'L HEALTH LAW PROG., Feb. 5-7, 1993. Because mandatory managed care violates Medicaid regulations protecting the freedom of Medicaid recipients to choose their own providers, states must receive a federal waiver in order to require Medicaid recipients to enroll in managed care. See MEDICAID SOURCE BOOK, *supra*.

<sup>197</sup> See MEDICAID SOURCE BOOK, *supra* note 196.

<sup>198</sup> John E. Ware, Jr. et al., *Comparison of Health Outcomes at a Health Maintenance Organization with Those of Fee-For-Service Care*, LANCET 1017 (1986).

<sup>199</sup> Cf. U.S. GOV'T ACCOUNTING OFFICE, MEDICAID: OVERSIGHT OF HEALTH MAINTENANCE ORGANIZATIONS IN THE CHICAGO AREA (1990) (cited in MEDICAID SOURCE BOOK, *supra* note 196).

<sup>200</sup> See *infra* notes 123-124 and accompanying text.



because Medicaid reimburses only a portion of medical expenditures.

### 5. *Medicaid and Puerto Rico*

Puerto Rico has the second highest per capita prevalence of AIDS cases in the United States, following only the District of Columbia.<sup>201</sup> Puerto Rico leads the nation in the rate of new AIDS cases and in AIDS incidence among women.<sup>202</sup> The National Commission on AIDS reports that "[a]lthough Puerto Rico as a territory ranks ahead of 45 states in numbers of AIDS cases it ranks 20th in funding for AIDS-related programs per capita and ranks 55th among 57 states and territories in total funding per reported case."<sup>203</sup> This funding inequity is primarily caused by discriminatory Medicaid rules, which arbitrarily limit federal Medicaid contributions to Puerto Rico to \$79 million each year.<sup>204</sup>

As a result of such fiscal restrictions, Puerto Rico must ration health care for its poor. Although the Commonwealth's federally approved Medicaid plan states that it covers prescription drugs,<sup>205</sup> Puerto Rico reportedly uses no Medicaid funds to reimburse for HIV-related pharmaceutical products.<sup>206</sup> With federal disbursements under the Ryan White CARE Act, Puerto Rico can provide AZT, PCP prophylaxis, and other AIDS-related drugs to only a small fraction of HIV-infected patients who could benefit from the therapy.<sup>207</sup>

<sup>201</sup> CENTERS FOR DISEASE CONTROL, *supra* note 17, at 15.

<sup>202</sup> NATIONAL COMM'N ON AIDS, *THE HIV/AIDS EPIDEMIC IN PUERTO RICO* 10 (1992) [hereinafter NCOA, PUERTO RICO].

<sup>203</sup> *Id.* at 2.

<sup>204</sup> 42 U.S.C. § 1308 (1988). Federal law further penalizes indigent Puerto Ricans by treating the Commonwealth as an affluent state for purposes of determining the federal government's share of Medicaid costs. Medicaid recipients are prohibited from obtaining care from any provider not employed by a health care facility operated by the Commonwealth. Further, Puerto Rico must adhere to income eligibility rules stricter than those applicable to the fifty states. NCOA, PUERTO RICO, *supra* note 202.

<sup>205</sup> See Puerto Rico State Plan Under Title XIX of the Social Security Administration Act Medical Assistance Program (approved by the Health Care Financing Administration, Oct. 20, 1989).

<sup>206</sup> NCOA, PUERTO RICO, *supra* note 202, at 14.

<sup>207</sup> *Id.*

If Puerto Rico were to comply with the prescription drug provisions in its Medicaid plan, it would spend its entire federal allotment only on the delivery of HIV-related drugs to eligible beneficiaries.<sup>208</sup> According to the National Commission on AIDS, "[i]f the current trend of utilization continues, by the year 2000 more than 50% of the budget for public hospitals [in Puerto Rico] will be devoted to the care of persons with HIV disease."<sup>209</sup> The Commission has called on Congress to raise the cap on federal Medicaid spending to ensure adequate access to HIV-related care in Puerto Rico.<sup>210</sup>

## B. PUBLIC HOSPITALS

Public hospitals bear much of the burden associated with caring for people with AIDS.<sup>211</sup> In 1987, 82 percent of all outpatient visits by AIDS patients occurred in public hospitals.<sup>212</sup> Since Medicaid rules limit coverage to patients with full-blown AIDS, patients who do not yet display an official AIDS indicator condition frequently require care in public facilities.<sup>213</sup> As the HIV disease progresses, these patients must rely on public hospitals because third-party payment practices render an ongoing relationship with a private physician difficult to maintain.<sup>214</sup>

Third-party payers seldom compensate public institutions for the full cost of AIDS care. Indeed, the AIDS crisis has driven many of the country's public hospitals to the brink of insolvency.<sup>215</sup> In 1988, public hospitals lost an average of \$8,000

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<sup>208</sup> See *id.* at 12, 14.

<sup>209</sup> *Id.* at 12.

<sup>210</sup> *Id.* at 2.

<sup>211</sup> See generally NEW YORK CITY HEALTH AND HOSPITALS CORP., AIDS: THE CHALLENGE FACING THE HHC SYSTEM (1989) (examining hospital care for AIDS patients in New York City; finding that some hospitals have taken in a disproportionate numbers of AIDS patients).

<sup>212</sup> DAVIS ET AL., *supra* note 23, at 38.

<sup>213</sup> Warren E. Leary, *Surprising Costs Found for H.I.V.*, N.Y. TIMES, May 13, 1992, at A18.

<sup>214</sup> Thirty-seven percent of patients with HIV infection rely on hospital outpatient clinics as their primary source of medical care. Seventy-nine percent of people with AIDS principally receive their care in hospital clinics. Goldsmith, *supra* note 140.

<sup>215</sup> See Fox, *supra* note 33, at 230-31; Green & Arno, *supra* note 44, at 1261; Spencer Rich, *AIDS, Uninsured Swamp Nation's Public Hospitals*,

on each AIDS patient treated on an inpatient basis.<sup>216</sup> AIDS patients reportedly account for "28% of the costs and 36% of the financial losses of public hospitals."<sup>217</sup>

While public health care centers deserve gratitude for shouldering the primary burden of AIDS care in the United States, questions persist regarding the ability of financially burdened public facilities to deliver adequate care to patients with HIV. As one study concluded:

[P]ublic hospital [AIDS] patients were not receiving the care private patients can demand. Fewer were receiving [AZT], for example, and even when they began therapy with the antiviral drug, many dropped out of treatment because there was no way they could have their cell counts monitored or adverse effects treated.<sup>218</sup>

### C. ADDITIONAL PUBLIC PROGRAMS

In addition to Medicaid and the services available through public hospitals, many people with HIV look to a variety of other publicly funded health care programs. Although these programs often provide important services unavailable elsewhere, they normally cannot deliver the full continuum of medical services needed by people with AIDS.

Medicare accounts for only 2 percent of AIDS-related medical spending.<sup>219</sup> Medicare is of limited utility primarily because of its twenty-nine month waiting period between onset of disability and eligibility for services. Since the average person with AIDS usually does not survive more than twenty-nine months following diagnosis of AIDS, few gain access to the program.<sup>220</sup> Medicare also largely excludes coverage for

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WASH. POST, Jan. 30, 1991, at A3.

<sup>216</sup> *Public Hospitals Report Losses of \$8,000 for each AIDS Patient Treated in 1988*, AIDS POL'Y & L., Feb. 6, 1991, at 1.

<sup>217</sup> Goldsmith, *supra* note 140.

<sup>218</sup> *Id.*

<sup>219</sup> See NCOA, AMERICA LIVING WITH AIDS, *supra* note 19, at 73.

<sup>220</sup> See NCOA, AMERICA LIVING WITH AIDS, *supra* note 19, at 74; Fox, *supra* note 33, at 228.

outpatient prescription drugs, long-term care, and routine dental care.<sup>221</sup>

In 1990, medical programs administered by the Veterans Administration ("VA") served 7 percent of all people with AIDS.<sup>222</sup> Although VA medical programs retain strong political support in Congress, one might question the quality of care delivered in some VA facilities. Moreover, the limited number of VA facilities restricts meaningful access for many veterans, particularly those in rural areas.<sup>223</sup>

The Indian Health Service ("IHS"), an arm of the United States Public Health Service, has primary responsibility for addressing the growing problem of HIV infection among Native Americans.<sup>224</sup> However, the ability of IHS to serve Native Americans at risk of HIV infection is hampered by limited funding and inadequate staffing.<sup>225</sup> AIDS-related funding for IHS facilities remains meager, notwithstanding escalating infection rates among Native Americans.<sup>226</sup>

Job Corps is a federally sponsored program which provides vocational training to tens of thousands of economically deprived teenagers.<sup>227</sup> The young people involved with Job Corps are at high risk of contracting HIV.<sup>228</sup> Although Job Corps mandatorily tests incoming corps members for HIV

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<sup>221</sup> See CALIFORNIA HIV TASK FORCE, *supra* note 61, at 37.

<sup>222</sup> HCFA GUIDE, *supra* note 53, at 10. The U.S. Department of Defense administers the Civilian Health and Medical Program of the Uniformed Services ("CHAMPUS"), which provides medical care to military personnel and their dependents. *Id.* The bulk of AIDS patients served by CHAMPUS are civilian spouses or dependents of active duty personnel, since active duty personnel typically receive medical discharges upon receiving an AIDS diagnosis and are thereafter served in VA facilities. *Id.*

<sup>223</sup> Eli Ginzberg & Miriam Ostow, *Beyond Universal Health Insurance to Effective Health Care*, 265 JAMA 2559, 2559 (1991).

<sup>224</sup> NATIONAL MINORITY AIDS COUNCIL, *THE IMPACT OF HIV ON COMMUNITIES OF COLOR: A BLUEPRINT FOR THE NINETIES* (1992) [hereinafter NMAC].

<sup>225</sup> *Id.*

<sup>226</sup> See Joyce Lombardi, *Trail of Tears: AIDS and Native Americans*, VILLAGE VOICE, Dec. 31, 1991, at 14.

<sup>227</sup> U.S. DEP'T OF LABOR, *JOB CORPS IN BRIEF* 1 (1989).

<sup>228</sup> Michael E. St. Louis et al., *Human Immunodeficiency Virus Infection in Disadvantaged Adolescents*, 266 JAMA 2387 (1991).

antibodies,<sup>229</sup> observers question the quality of medical care delivered to Job Corps members who tested HIV-positive.<sup>230</sup>

Demand for HIV-related services provided by public clinics substantially outstrips the capacity of such facilities.<sup>231</sup> In Nashville, Tennessee, for example, increasing caseloads in late 1992 forced the city's HIV clinics to begin turning away patients unless they were diagnosed with full-blown AIDS.<sup>232</sup> Similarly, staffing shortages forced Los Angeles to curtail its acceptance of new patients at its publicly financed HIV clinic.<sup>233</sup> As a result of inadequate funding, the wait for an appointment in Washington, D.C.'s public AIDS center is three months for patients who are not bedridden.<sup>234</sup>

Due to high rates of HIV infection in the nation's prisons, correctional officials must frequently provide HIV-related medical care to inmates.<sup>235</sup> Unfortunately, HIV-infected inmates are often forced to obtain care from providers who have little or

<sup>229</sup> Public health professionals and medical experts have excoriated the Job Corps' mandatory HIV testing policy, contending that no public health or medical basis exists on which to require mandatory HIV antibody testing of U.S. teenagers. See Ronald Bayer, *Private Acts, Social Consequences: AIDS and the Politics of Public Health* 162 (1989).

<sup>230</sup> See Karen Hein, *Mandatory HIV Testing of Youth: A Lose-Lose Proposition*, 266 JAMA 2430 (1991).

<sup>231</sup> See Catherine Hutchinson et al., *CD+4 Lymphocyte Concentrations in Patients with Newly Identified HIV Infection Attending STD Clinics*, 266 JAMA 253 (1991).

<sup>232</sup> *Asymptomatic Patients Turned Away From Nashville's AIDS Program*, AIDS POL'Y & L., Oct. 2, 1992, at 4.

<sup>233</sup> Bruce Mirken, *AIDS Groups Press County to Restore Clinic Services*, L.A. READER, Sept. 18, 1992, at 5.

<sup>234</sup> Wendy Melillo, *An Overwhelmed AIDS Center: At D.C. General, More Patients Arrive With Other Intractable Problems*, WASH. POST, Nov. 10, 1992, at 9.

<sup>235</sup> By 1990, nearly 7,000 AIDS cases had been reported among prison inmates. CENTERS FOR DISEASE CONTROL, *HIV Prevention in the U.S. Correctional System, 1991*, 41 MORBIDITY & MORTALITY WKLY. REP. 389 (1992). For example, AIDS is now the leading cause of death among inmates and parolees in the District of Columbia. Stephanie Mencimer, *D.C.'s New Death Row: AIDS Is Devastating the District's Prisons and Busting Its Budget*, WASH. POST, Jan. 31, 1993, at C1. According to the National Institute of Justice, "A blind epidemiologic study among incoming [New York State] prisoners in late 1987 and early 1988 found an HIV seroprevalence rate of 17 percent." NATIONAL INST. OF JUST., AIDS BULLETIN 4 (Sept. 1990) [hereinafter NATIONAL INST. OF JUST.]. Twenty percent of Washington, D.C. inmates are infected with the virus. Mencimer, *supra*.

no experience in treating HIV disease.<sup>236</sup> Some prison health care providers refuse to serve inmates infected with the virus.<sup>237</sup> Prison systems vary in their policies regarding the provision of AZT or other HIV-related drugs.<sup>238</sup> Some systems withhold care until inmates progress to an advanced stage of disease.<sup>239</sup> Prison officials frequently fail to ensure that HIV-positive inmates obtain proper nutrition,<sup>240</sup> dental care,<sup>241</sup> or access to clinical research programs.<sup>242</sup> Due to the poor quality of health care in correctional facilities, HIV-infected inmates suffer needless illness and premature death.<sup>243</sup>

#### IV. ADDITIONAL BARRIERS TO HEALTH CARE

Health coverage alone cannot ensure meaningful access to care. Too many infected patients face additional barriers that often have little to do with health care financing. Unless reform proposals address structural barriers as well, financing reform could be a hollow victory for many people living with HIV. This section discusses these additional barriers.

##### A. DISCRIMINATION

AIDS first received national attention when gay men, an already stigmatized group, began dying from the disease. This early stigma, coupled with the inevitable medical consequences of HIV infection, has amplified discrimination.<sup>244</sup> According to

<sup>236</sup> See *Harris v. Thigpen*, 941 F.2d 1495 (11th Cir. 1991) (requiring "deliberate indifference" to inmates' medical needs to establish 8th Amendment violations).

<sup>237</sup> NATIONAL COMM'N ON AIDS, *HIV DISEASE IN CORRECTIONAL FACILITIES 2* (1991) [hereinafter NCOA, *CORRECTIONAL FACILITIES*].

<sup>238</sup> NATIONAL INST. OF JUST., *supra* note 235, at 8.

<sup>239</sup> Bruce Lambert, *Prisons Criticized on AIDS Programs*, N.Y. TIMES, Aug. 19, 1990, at 16.

<sup>240</sup> NCOA, *CORRECTIONAL FACILITIES*, *supra* note 237, at 3.

<sup>241</sup> Grace Lopes & Ruth Eisenberg, *Caring for Prisoners With AIDS*, WASH. POST, Mar. 10, 1991, at D8.

<sup>242</sup> NCOA, *CORRECTIONAL FACILITIES*, *supra* note 237, at 2.

<sup>243</sup> *Id.* at 2 ("A 1987 study by the Correctional Association of New York suggests that prisoners with AIDS may be dying at twice the rate of nonprisoners with AIDS").

<sup>244</sup> Gregory M. Herek & Eric K. Glunt, *An Epidemic of Stigma: Public*

the National Commission on AIDS, denial of medical services to HIV-positive patients is fast replacing more overt forms of prejudice.<sup>245</sup> Studies suggest that "[a] considerable number of physicians are refusing to treat persons with AIDS or HIV infection, or threatening to refuse."<sup>246</sup>

Discriminatory attitudes within the health care profession inevitably limit HIV-positive patients' access to medical care.<sup>247</sup> Many medical professionals report that they are uncomfortable employing or treating gay men in their practices.<sup>248</sup> Lesbians also frequently lack access to targeted HIV-related information<sup>249</sup> and to sensitive medical care. Ironically, denials

*Reactions to AIDS*, 43 AM. PSYCHOL. 886, 887 (1988).

<sup>245</sup> NCOA, AMERICA LIVING WITH AIDS, *supra* note 19, at 113.

<sup>246</sup> Daniel M. Fox, *The Politics of Physicians' Responsibility in Epidemics: A Note on History*, HASTINGS CENTER REP., Apr./May 1988, Supp. at 5, 9. Nearly one half of primary care physicians surveyed in Los Angeles County revealed that they do not treat patients with HIV infection. *Medical Briefs*, AIDS POL'Y & L., Mar. 19, 1992, at 5. Nationwide, nearly one third of primary care physicians do not believe they have a responsibility to treat infected patients. Fifty percent of doctors would not treat people with HIV, if given a choice. Barbara Gerbert et al., *Primary Care Physicians and AIDS: Attitudinal and Structural Barriers to Care*, 266 JAMA 2837, 2839 (1991).

Paramedics and ambulance attendants often refuse to answer the emergency calls of patients with HIV disease. Joseph Reiner, Comment, *AIDS Discrimination by Medical Care Providers: Is Washington Law an Adequate Remedy?*, 63 WASH. L. REV. 701, 707 (1988); Jessie Mangaliman, *Family Gets \$15,000 in AIDS Case*, N.Y. NEWSDAY, Sept. 10, 1991, at 8 (describing incident where ambulance driver refused to help AIDS patient down flight of stairs). Nursing homes routinely refuse to admit HIV-positive patients who require long-term care. Reiner, *supra*, at 707. See Lacrishia Butler, *State Cites AIDS Discrimination*, NASHVILLE TENNESSEAN, Dec. 10, 1990, at 1B; NEW YORK STATE DEP'T OF SOCIAL SERVS., AIDS UPDATE 3 (Winter 1992).

Similarly, a sizable proportion of dentists avoid caring for patients infected with HIV. According to the American Dental Association, only 31% of dentists surveyed said they were willing to treat HIV-positive patients. ASTHO, DENTAL REPORT, *supra* note 191, at 3 (citing Carl A. Verussio et al., *The Dentists and Infectious Diseases: A National Survey of Attitudes and Behaviors*, 118 JADA 560 (1989)). Another survey found that almost three quarters of dentists questioned routinely refer HIV-positive patients to other providers. ASTHO, DENTAL REPORT, *supra* note 191, at 2 (citing Gerbert, *AIDS and Infection Control in Dental Practice: Dentists' Attitudes, Knowledge, and Behavior*, 114 JADA 312 (1987)).

<sup>247</sup> See John D. Arras, *The Fragile Web of Responsibility: AIDS and the Duty to Treat*, HASTINGS CENTER REP., Apr./May 1988, Supp. at 10, 12.

<sup>248</sup> Gerbert et al., *supra* note 246.

<sup>249</sup> Rebecca Cole & Sally Cooper, *Lesbian Exclusion from HIV Education:*

of care to patients with HIV violate universally recognized rules of medical ethics,<sup>250</sup> as well as some federal, state, and local anti-discrimination laws.<sup>251</sup> The frequency of HIV-related discrimination in the health care setting demonstrates the ineffectiveness of ethical canons or legal prohibitions in overcoming the stigma associated with HIV infection.

To offset this phenomenon, aggressive federal enforcement of the ADA's prohibitions on health care discrimination against HIV-infected individuals can help the Act achieve its objective of eradicating disability-based discrimination. In addition, the federal government's authority to terminate federal funding, including Medicaid and Medicare reimbursement, to providers who fail to adhere to anti-discrimination laws can be used to prevent discrimination.<sup>252</sup>

Unfounded fears of contracting HIV through casual contact also discourage health care providers from caring for people with the virus. In reality, providing health care to a patient infected with HIV presents only minimal risks of HIV transmission if the worker adheres to recommended infection control procedures.<sup>253</sup> Federal law requires that all health care workers — including those working in private medical and

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*Ten Years of Low-Risk Identity and High-Risk Behavior*, SIECUS REP., Dec./Jan. 1991.

<sup>250</sup> See Oscar W. Clarke & Robert B. Conley, *The Duty to "Attend Upon the Sick"*, 266 JAMA 2876 (1991).

<sup>251</sup> See 42 U.S.C. §§ 12182(a), 12181(7)(F) (Supp. III 1991) (public accommodations provisions of Americans With Disabilities Act); *State v. Clausen*, 491 N.W.2d 662 (Minn. Ct. App. 1992) (holding that dentist's denial of care to HIV-infected patient violated Minnesota human rights law); NAN D. HUNTER, ACLU AIDS PROJECT, EPIDEMIC OF FEAR: A SURVEY OF AIDS DISCRIMINATION IN THE 1980S AND POLICY RECOMMENDATIONS FOR THE 1990S 83-133 app. (1990) (state-by-state survey of anti-discrimination laws applicable to HIV).

<sup>252</sup> In one widely publicized case, the U.S. Department of Health and Human Services ordered the termination of federal funding to a major New York City area medical center that had improperly refused to hire an HIV-infected pharmacist. See *In re Westchester County Medical Center*, No. 91-504-2 (U.S. Dep't of Health and Human Servs., Civ. Rts. Rev. Auth., Sept. 25, 1992).

<sup>253</sup> See NEW YORK STATE DEPT OF HEALTH, POLICY STATEMENT AND GUIDELINES TO PREVENT TRANSMISSION OF HIV AND HEPATITIS B THROUGH MEDICAL/DENTAL PROCEDURES 1 (May 1992); Centers for Disease Control, *Recommendations for Prevention of HIV Transmission in Health-Care Settings*, 36 MORBIDITY AND MORTALITY WKLY. REP. 2S, at 3S (Aug. 27, 1987).



dental offices — follow standard infection control practices.<sup>254</sup> Public health authorities strongly support strategies to improve workers' compliance with recommended infection control procedures.<sup>255</sup>

## B. DISREGARD FOR CONFIDENTIALITY

In order to access medical care, many HIV-infected persons must risk a breach of confidentiality regarding their HIV status. According to the Association of State and Territorial Health Officers, "[e]nsuring confidentiality of HIV-related information is critical to maintaining and promoting public confidence in the health care delivery system."<sup>256</sup> Unfortunately, reported cases reveal that health care providers sometimes disclose HIV-related information without the patient's consent.<sup>257</sup>

## C. PUBLIC HEALTH OFFICIALS

Public health authorities are responsible for controlling infectious diseases, educating the public regarding health threats, monitoring health trends, and urging leadership to promote good health. Many public health officials deserve gratitude for their enlightened response to the HIV epidemic, but some — particularly those in leadership positions at the federal level — have failed in their response. According to the House Committee on Government Operations, federal authorities often base HIV prevention strategies "on 'political dogma' rather than [on] rational public health principles."<sup>258</sup> For example, the CDC's prevention efforts consist mainly of

<sup>254</sup> 29 C.F.R. § 1910.1030 (1993).

<sup>255</sup> NATIONAL COMM'N ON AIDS, PREVENTING HIV TRANSMISSION IN THE HEALTH CARE SETTING 2-3 (1992); OFFICE OF TECHNOLOGY ASSESSMENT, HIV IN THE HEALTH CARE WORKPLACE 3 Nov., 1991); Testimony of the Amer. Hospital Ass'n at the Open Meeting on the Risks of Transmission of Bloodborne Pathogens to Patients During Invasive Procedures 105 (Feb. 21-22, 1991) (transcript available from the Centers for Disease Control).

<sup>256</sup> ASTHO, DENTAL REPORT, *supra* note 191 at 13.

<sup>257</sup> *See, e.g.*, Estate of Behringer v. Medical Center, 592 A.2d 1251 (N.J. Super. Law Div. 1991); Doe v. Roe, 155 Misc.2d 392 (N.Y. Sup. Ct. 1992).

<sup>258</sup> COMMITTEE ON GOV'T OPERATIONS, U.S. HOUSE OF REPS., THE POLITICS OF AIDS PREVENTION: SCIENCE TAKES A TIME OUT 4 (192d Cong. 1992) (summarizing testimony of Dr. Donald C. Francis, a retired senior CDC official) [hereinafter HOUSE PREVENTION REPORT].

testing and counseling, despite evidence suggesting that this approach is ineffective.<sup>259</sup> Moreover, the CDC imposes stringent restrictions on the content of HIV prevention materials.<sup>260</sup>

Few federal officials have demonstrated the courage to confront the American public with crucial AIDS information. While C. Everett Koop, Surgeon General under President Reagan, insisted that Americans have access to frank HIV-related information,<sup>261</sup> health officials in the Bush Administration spent millions of dollars on a national public service announcement campaign that provided few facts regarding HIV, failed to mention the word "condom," and merely advised viewers to call a toll-free telephone number if they desired additional information.<sup>262</sup>

According to Dr. Donald P. Francis, a retired senior CDC official, federal public health officials "lost sight [during the AIDS epidemic] of their role as advocates of the public's health and inadvertently became servants of politicians who were uninhibited by either knowledge, experience, or wisdom."<sup>263</sup> Health insurance reform is essential, but reform alone will not provide a solution if efforts in related areas are based on politics rather than science.

#### D. SPECIAL SEGMENTS OF THE POPULATION

In many ways, the health care system incorporates the racism, sexism, homophobia, and neglect of the unfortunate that typifies American society. For example, doctors offer AZT more frequently to their white patients than to HIV-positive people of color.<sup>264</sup> One Rhode Island study found that while 97 percent of

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<sup>259</sup> See HOUSE PREVENTION REPORT, *supra* note 258, at 3. For years the CDC monitored the AIDS epidemic through a case definition that ignored life-threatening disease manifestations common to women, injection drug users, and the poor. After finally acquiescing to political pressure, the CDC expanded its case surveillance definition in 1993, broadening its surveillance of serious HIV-related disease. *Revised Classification*, *supra* note 12, at 4, 6.

<sup>260</sup> See *Gay Men's Health Crisis v. Sullivan*, 792 F. Supp. 278 (S.D.N.Y. 1992) (striking down CDC's content restrictions as unconstitutionally vague).

<sup>261</sup> See generally C. EVERETT KOOP, SURGEON GENERAL'S REPORT ON ACQUIRED IMMUNE DEFICIENCY SYNDROME (1986) (suggesting that efforts be made to improve access to health-related information).

<sup>262</sup> HOUSE PREVENTION REPORT, *supra* note 258, at 7-10.

<sup>263</sup> HOUSE PREVENTION REPORT, *supra* note 258, at 4.

<sup>264</sup> Stein et al., *supra* note 172, at 38.

gay white men with a history of PCP were offered AZT by their physicians, doctors of non-white, female intravenous drug users made the drug available only 58.8 percent of the time.<sup>265</sup> Researchers contend that these differences in access to AZT cannot be explained by variations in health coverage.<sup>266</sup>

Many health care providers ignore HIV's unique impact on women.<sup>267</sup> Even when women have adequate health coverage, they often lack access to necessary transportation or child care. As society's primary care-givers, women often have personal responsibilities that interfere with their own health care.<sup>268</sup>

Children born infected with HIV have higher mortality rates than HIV-positive adults.<sup>269</sup> Recently, important breakthroughs in the treatment of pediatric HIV infection have emerged,<sup>270</sup> yet financial barriers inhibit the delivery of medical care to many children.<sup>271</sup> Teenagers evince startling rates of AIDS, HIV infection, and risky behavior,<sup>272</sup> yet nearly one in seven adolescents in the United States has no health insurance.<sup>273</sup> Moreover, many state laws presume that minors

<sup>265</sup> *Id.* at 38.

<sup>266</sup> Moore et al., *supra* note 172, at 1416.

<sup>267</sup> Kathryn Anastos & Carola Marte, *Women — The Missing Persons in the AIDS Epidemic*, in *THE AIDS READER* 190 (Nancy McKenzie ed., 1991).

<sup>268</sup> NCOA, *AMERICA LIVING WITH AIDS*, *supra* note 19, at 12.

<sup>269</sup> Carol Levine, *The Special Needs of Women, Children, and Adolescents*, in *THE AIDS READER* 205 (Nancy McKenzie ed., 1991).

<sup>270</sup> National Inst. of Child Health and Human Dev. IVIG Study Group, *Intravenous Immunoglobulin for the Prevention of Bacterial Infections in Children with Symptomatic Human Immunodeficiency Virus Infection*, 325 *NEW ENG. J. MED.* 74 (1991); Centers for Disease Control, *Guidelines for Prophylaxis against Pneumocystis Carinii Pneumonia for Children Infected with Human Immunodeficiency Virus*, 40 *MORBIDITY & MORTALITY WKLY. REP.* RR-2 (Mar. 15, 1991); Ross McKinney et al., *A Multicenter Trial of Oral Zidovudine in Children with Advanced Human Immunodeficiency Virus Disease*, 324 *NEW ENG. J. MED.* 1018 (1991).

<sup>271</sup> Emily Friedman, *The Uninsured: From Dilemma to Crisis*, 265 *JAMA* 2491 (1991). Nationwide, children and adolescents are second only to young adults in lacking health coverage. *Id.* at 2491-2492.

<sup>272</sup> See Karen Hein, *Lessons from New York City on HIV/AIDS in Adolescents*, 90 *N.Y. ST. J. MED.* 143 (1990); Centers for Disease Control, *Selected Behaviors that Increase Risk for HIV Infection Among High School Students — United States, 1990*, 41 *MORBIDITY & MORTALITY WKLY. REP.* 231 (1992).

<sup>273</sup> Ross Newacheck et al., *Financing Health Care for Adolescents: Problems, Prospects, and Proposals*, 265 *JAMA* 2474 (1991).

lack the capacity to consent to medical care,<sup>274</sup> a policy that potentially discourages adolescents from undergoing HIV antibody testing or otherwise receiving appropriate medical care.

HIV-infected intravenous drug users ("IDUs") have difficulty obtaining treatment for their drug problem when doctors become aware of their HIV infection.<sup>275</sup> Although drug and alcohol treatment are effective in reducing drug and alcohol use,<sup>276</sup> and generally enable patients to obtain meaningful medical care for other conditions,<sup>277</sup> physicians frequently avoid treating HIV-infected IDUs for their drug problems because of the short supply of slots in drug treatment programs.<sup>278</sup>

Newly-arrived foreigners also suffer because of inherent barriers to medical care and information. Experts observe that "[t]he United States has been admitting approximately a million immigrants, refugees, and illegal aliens every year for the last decade."<sup>279</sup> Language barriers and fear of deportation discourage many such persons from obtaining needed medical care.<sup>280</sup> Many recent immigrants remain alarmingly ignorant of basic facts related to HIV transmission.<sup>281</sup>

<sup>274</sup> JAMES MORRISSEY & BILL THROPE, RIGHTS AND RESPONSIBILITIES OF YOUNG PEOPLE IN NEW YORK: A LEGAL GUIDE FOR HUMAN SERVICE PROVIDERS 86 (N.Y. ST. B.A. 1990).

<sup>275</sup> Carol Levine & David Novick, *Expanding the Role of Physicians in Drug Abuse Treatment: Problems, Perspectives*, 1 J. CLINICAL ETHICS 152 (1990).

<sup>276</sup> Glen Hubbard, National Inst. of Drug Abuse, *Treatment Outcome Prospective Survey (TOPS): Client Characteristics Before, During, and After Treatment Evaluation: Strategies, Programs and Prospects*, in BLUEPRINT FOR A NEW AND EFFECTIVE NATIONAL DRUG AND ALCOHOL STRATEGY (1992).

<sup>277</sup> NCOA, AMERICA LIVING WITH AIDS, *supra* note 19, at 48.

<sup>278</sup> New York City has only 38,000 treatment slots for an estimated injection drug-using population of 200,000 people. NCOA, TWIN EPIDEMICS, *supra* note 192, at 1. Nationwide, approximately 107,000 people are currently on waiting lists for drug treatment, according to estimates by the National Institute on Drug Abuse. *Id.*

<sup>279</sup> Ginzberg & Ostow, *supra* note 223, at 2560.

<sup>280</sup> *Id.*

<sup>281</sup> NMAC, *supra* note 224; Tim Russell, *Asian Groups Fare Poorly in AIDS Study*, SAN FRAN. CHRON., Sept. 4, 1991, at A14.

Finally, HIV disease frequently leads to homelessness.<sup>282</sup> The National Commission on AIDS estimates that as many as one half of all people with AIDS are either homeless or in danger of becoming homeless.<sup>283</sup> The shortage of appropriate housing for people with AIDS remains "acute."<sup>284</sup> Clinics serving the homeless find it difficult to recruit and retain qualified physicians and support personnel who understand the unique medical needs of homeless patients.<sup>285</sup>

#### E. RESOURCE SHORTAGES

Since the beginning of the AIDS epidemic, care for people with HIV has been provided principally by a relatively small cadre of primary care providers who tend to practice in a few large metropolitan areas. Experts agree, however, that "[t]he capacity of AIDS or infectious disease specialists to meet the needs of the epidemic has been surpassed."<sup>286</sup> The epidemic can be effectively managed only if additional primary care providers develop necessary AIDS-related expertise.<sup>287</sup>

There are numerous barriers to the development of an adequate supply of HIV-competent primary care doctors. First, the nationwide shortage of primary care providers for all diseases limits the number of physicians available for AIDS care.<sup>288</sup> Second, inadequate reimbursement for AIDS care by third-party payers discourages providers from treating patients infected with HIV.<sup>289</sup> Third, some providers avoid HIV care due to discriminatory attitudes toward the communities most affected by the epidemic or because of fear of becoming infected.<sup>290</sup> Fourth, most primary care providers believe they

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<sup>282</sup> NATIONAL COMM'N ON AIDS, HOUSING AND THE HIV/AIDS EPIDEMIC: RECOMMENDATIONS FOR ACTION 7 (1992).

<sup>283</sup> *Id.*

<sup>284</sup> *Id.* at 8.

<sup>285</sup> Bruce Doblin et al., *Patient Care and Professional Staffing Patterns in McKinney Act Clinics Providing Primary Care to the Homeless*, 267 JAMA 698 (1992).

<sup>286</sup> Smith, *supra* note 20, at S56.

<sup>287</sup> *Id.* at S59.

<sup>288</sup> *Id.*

<sup>289</sup> Smith, *supra* note 20, at S59.

<sup>290</sup> One survey of general internists, family physicians and general practitioners found that 35% said they would "feel nervous among a group of

lack the knowledge and expertise necessary to provide high-quality care to patients with HIV infection.<sup>291</sup> This fourth factor requires energetic government intervention to encourage medical schools to better prepare graduates for HIV care and to disseminate HIV-related clinical information rapidly and widely. The anticipated issuance of HIV-related care guidelines by the federal Agency for Health Care Policy and Research will likely close gaps in physicians' knowledge regarding basic HIV care,<sup>292</sup> but such guidelines must be updated regularly.

HIV-related medical technology, like physicians, is often poorly distributed throughout the country. In many parts of the country, few laboratories are capable of performing the CD+4 test,<sup>293</sup> even though the test is an important diagnostic tool for patients with HIV infection.

### CONCLUSION: PRINCIPLES FOR HEALTH CARE REFORM

Reform of the nation's health care system must be premised on the maxim that meaningful access to health care is a basic human right. The above-described experience of people living with HIV suggests six principles for ensuring each person's enjoyment of this fundamental right.

- (1) *The federal government must ensure universal access in the United States and its territories to non-discriminatory medical coverage in a single-tier health care system.*

The gap in access to health care has been an obvious problem in this country for several years. Fortunately, the recently proposed health care plan may alleviate some of the problems created by the lack of universal access to non-discriminatory health care.

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homosexuals," while more than one half said they would be uncomfortable having injection drug users in their practice. Gerbert et al., *supra* note 246, at 2839.

<sup>291</sup> See Gerbert et al., *supra* note 246, at 2837; Mark D. Smith, *supra* note 18, at S59; Hayward et al., *Program Directors' Attitudes Towards Residents' Care of Patients Who Have AIDS*, 6 J. GEN. INTERN. MED. 18 (1991).

<sup>292</sup> See Warren Leary, *More Advice for Doctors: U.S. Guides on Treatments*, N.Y. TIMES, Apr. 15, 1992, at C14.

<sup>293</sup> Ronald Valdiserri et al., *Capacity of US Labs to Provide TLI in Support of Early HIV-1 Intervention*, 81 AM. J. PUB. H. 491 (1991).

- (2) *The federal government must guarantee a comprehensive package of benefits that promotes good health, emphasizes primary care, and leads to the most efficient use of health care expenditures.*

The United States must transcend the present system's failed efforts to cut costs through short-sighted, counterproductive, and arbitrary limitations on services. The benefits package should include the medical services which Americans need, including but not limited to: (1) prescription drug coverage; (2) inpatient and outpatient services with flexible rules for coverage of unapproved treatments in patients with life-threatening conditions; (3) physician, nursing, clinical, and dental services; (4) laboratory, x-ray, and physical therapy services, as well as coverage of medical devices or substances required in the administration of other medical services; (5) broad coverage for nutritional supports; (6) coverage on demand for a range of alcohol and drug treatment options; (7) a variety of long-term care options, including both home and community-based care; (8) private duty nursing services; (9) case management, where appropriate; (10) services provided or prescribed by licensed practitioners in the healing arts; (11) mental health services; and (12) all other services set forth in the Medicaid Act.

- (3) *Health care must be progressively financed.*

Out-of-pocket costs must be diminished based on each patient's ability to pay, required only for less necessary medical services, or eliminated entirely. Wealthier Americans should pay their fair share to ensure universal enjoyment of the fundamental right to health care.

- (4) *The federal government must retain central authority to control costs, to correct imbalances in resource allocation, and to ensure meaningful access to medical care.*

The government must establish and enforce national health care budgets by: (1) rebuilding the nation's public health infrastructure; (2) overseeing and improving data collection, technology assessment, and resource allocation; (3) ensuring that the medical work-force is properly educated; (4) providing an adequate supply of primary care providers; and (5) eliminating discrimination in the provision of medical care.

In addition, the United States must improve health care access by addressing related issues, such as medical fraud, biomedical research, and access to family planning and reproductive health services. Further, facilities serving special populations (such as homeless, community, and school-based clinics, as well as facilities serving recent immigrants or undocumented persons) must receive attention. In recognition of the social supports required for meaningful health care access, the United States must develop national housing, child care, and transportation policies.

*(5) The health care system must be efficient.*

Health care financing must be drastically simplified. Reforms should include substantial reduction in third-party payers, standardization of claim forms, and mandatory electronic billing. Medical underwriting should be prohibited, and providers found to discriminate against perceived poor risks should be subject to severe penalties.

Physicians must be free to do what they were meant to do — practice medicine. Administrative paperwork should be curtailed accordingly. This concept includes limiting time-consuming review of physicians' decisions by non-medical personnel.

*(6) The health care system must maximize the freedom of providers and consumers and be accountable to consumers.*

The health care system must preserve to the greatest extent possible the consumer's freedom to choose providers. This right is especially important for patients with chronic diseases, such as AIDS. Within enforceable health care budgets, physicians need maximum freedom to practice medicine. Collaborative decisions of individual patients and their physicians should be the touchstone for "medical necessity."

Health care providers must be accountable to consumers. Having collected comprehensive empirical data, the government must implement effective quality assurance protocols. Patients, particularly those subject to managed care, should have ready access to swift and fair due process review of medical decisions.



