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# EMPLOYERS AND AIDS: MEETING THE HEALTH BENEFIT NEEDS OF PEOPLE WITH HIV DISEASE

# Judith K. Barr<sup>†</sup> and Robert A. Padgug<sup>††</sup>

#### INTRODUCTION

Well into its second decade in the United States, the HIV epidemic<sup>1</sup> continues to intrude into all spheres of American society.<sup>2</sup> In particular, the epidemic has exerted extraordinary pressure on the financing and provision of health care.<sup>3</sup> By creating additional health burdens, AIDS has magnified the many problems inherent in our health care system.<sup>4</sup> Because employer-sponsored health insurance is a central feature of the American health care financing system, the HIV epidemic has

The views expressed in this Article do not necessarily reflect the opinions of the institutions at which the authors are employed.

<sup>1</sup> An estimated 1.5 million people in the United States are infected with the Human Immunodeficiency Virus. MICHAEL T. ISBELL, HEALTH CARE REFORM: LESSONS FROM THE HIV EPIDEMIC 1, i (1993).

<sup>2</sup> See generally AIDS LAW TODAY: A NEW GUIDE FOR THE PUBLIC (Scott Burris et al. eds., 1993) (discussing responses of the private and public sectors to the AIDS epidemic); AIDS: THE MAKING OF A CHRONIC DISEASE (Elizabeth Fee & Daniel M. Fox eds., 1992) (describing the impact of AIDS on women, homosexuals and intravenous drug users); NATIONAL RESEARCH COUNCIL, THE SOCIAL IMPACT OF AIDS IN THE UNITED STATES: PANEL ON MONITORING THE SOCIAL IMPACT OF THE AIDS EPIDEMIC (Albert R. Jonsen & Jeff Stryker eds., 1993) (discussing the social impact of AIDS on the public health system, the health care finance and delivery system, clinical research, drug regulation and the correctional system).

<sup>3</sup> See ISBELL, supra note 1, at ii-v.

<sup>4</sup> *Id*. at i.

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had a major impact on employers and has threatened the financial stability of their plans.<sup>5</sup>

This Article examines employer responses to the health care challenge presented by the AIDS epidemic and suggests more appropriate, cost-effective options than those offered under traditional coverage plans. Part I of the Article sets forth the difficulties HIV disease presents to employer sponsored health plans. Part II analyzes the evolution of the epidemic and why it now demands a new response from employers. Part III examines the medical and legal costs of HIV and discusses employer responses to these costs. Part IV suggests a coverage option that meets the needs of both employers and employees with HIV.

#### I. THE NEED FOR EMPLOYER-SPONSORED HEALTH BENEFITS

Employer-sponsored health insurance was created for a predominantly young and active work force,<sup>6</sup> whose major need for health care involved a variety of acute conditions and treatments.<sup>7</sup> Generally, the expected outcome for an employee with an acute condition was either recovery and a return to work with largely unimpeded capacity, or a complete withdrawal from the work force due to disability or death.<sup>8</sup> Accordingly, employers perceived chronic illness and disability as problems that existed outside the work place. The fact that elderly and retired persons have always had the highest rates of chronic conditions and disability reinforced that perception.<sup>9</sup>

HIV disease, however, is unusual among major lifethreatening illnesses in that it largely affects the relatively

<sup>&</sup>lt;sup>5</sup> Gerald M. Oppenheimer & Robert A. Padgug, *AIDS and the Crisis of Health Insurance, in AIDS & ETHICS 105, 114-16 (Frederick G. Reamer ed., 1991).* 

<sup>&</sup>lt;sup>6</sup> PAUL STARR, THE SOCIAL TRANSFORMATION OF AMERICAN MEDICINE 294 (1982).

<sup>&</sup>lt;sup>7</sup> Oppenheimer & Padgug, *supra* note 5, at 115-16.

<sup>&</sup>lt;sup>8</sup> DANIEL M. FOX, POWER AND ILLNESS: THE FAILURE AND FUTURE OF AMERICAN HEALTH POLICY 106 (1993).

young during their most productive working years.<sup>10</sup> Over 54 percent of all U.S. workers,<sup>11</sup> and 77 percent of all persons diagnosed with AIDS through December 1992 were between the ages of twenty-five and forty-four.<sup>12</sup> While the number of HIVinfected persons who continue to work is uncertain, it is clear that AIDS disproportionately affects people during their prime working years. Since it takes years before HIV infection progresses to the point where an affected employee can no longer work, many persons infected with HIV - and some who have even developed AIDS -- continue to work for employers of all sizes throughout the United States. A recent study of persons with AIDS living in California found that eighty-six percent were employed at the time they were diagnosed with the disease.<sup>13</sup> Moreover, half of those with at least one symptom of HIV-related illness remained in the work force for over two vears.<sup>14</sup> Data on health insurance coverage suggests that a large minority of persons with HIV are insured through employers and, thus, have an incentive to remain in the work force.<sup>15</sup> Others have retired from active work but remain covered under the insurance plans of their former employers through eligibility for disability benefits, continuation of benefits under the Consolidated Omnibus Budget Reconciliation Act

<sup>11</sup> UNITED STATES DEP'T OF COMMERCE, STATISTICAL ABSTRACT OF THE UNITED STATES 385 (112th ed. 1992).

<sup>12</sup> CENTERS FOR DISEASE CONTROL, U.S. DEP'T OF HEALTH & HUM. SERVS., HIV/AIDS SURVEILLANCE: U.S. AIDS CASES REPORTED THROUGH DECEMBER 1992, at 13 t.7 (Feb. 1993) [hereinafter CDC].

<sup>13</sup> Edward H. Yelin et al., *The Impact of HIV-Related Illness on Employment*, 81 AM. J. PUB. HEALTH 79, 81, 83 (1991).

<sup>14</sup> Id.

<sup>15</sup> See Judy K. Ball et al., Third-Party Financing for AIDS Hospitalizations in New York, 5 AIDS & PUB. POL'Y J. 51, 51 (1990); Daniel Fife & James McAnaney, Private Medical Insurance Among Philadelphia Residents Diagnosed with AIDS, 6 J. AIDS 512, 516 (1993); Jesse Green & Peter S. Arno, The 'Medicaidization' of AIDS: Trends in the Financing of HIV-Related Medical Care, 264 JAMA 1261, 1265 (1990); Nancy E. Kass et al., Loss of Private Health Insurance Among Homosexual Men with AIDS, 28 INQUIRY 249, 253 (1991).

<sup>&</sup>lt;sup>10</sup> Id.

("COBRA")<sup>16</sup> and analogous state statutes,<sup>17</sup> or eligibility as spouses or dependents of employees with family coverage.

AIDS is both a "catastrophic"<sup>18</sup> and a "chronic"<sup>19</sup> illness that presents financial, coverage, and benefit problems. Since many persons with HIV disease are eligible for employer-sponsored health insurance, employers have a strong incentive to examine their health insurance plans to ensure that these plans meet their own fiscal needs and the health care coverage requirements of HIV-infected employees. HIV disease poses a compound problem for employer-sponsored health plans: concern over rising health care costs and the need for increasing benefits. The two sides of the problem do not necessarily contradict each other because an appropriate mix of benefits could help reduce, rather than raise, the costs of HIV treatment and care.<sup>20</sup> At the same time, such a mix could provide more of the services that persons with HIV disease require. Employers who pay attention to the needs of all parties may, therefore, obtain better results in terms of both cost-effectiveness and coverage than employers who attempt to ignore the epidemic.

Overall, employers in the United States have yet to address the need for adequate employer-sponsored health care for

<sup>18</sup> See generally EMPLOYEE BENEFIT RESEARCH INSTITUTE, WHERE COVERAGE ENDS: CATASTROPHIC ILLNESS AND LONG-TERM CARE COSTS (1988) (discussing the definition and consequences of catastrophic illness).

<sup>19</sup> A chronic disease is "of long duration; denoting a disease of slow progress and long continuance." STEDMAN'S MED. DICTIONARY 305 (25th ed. 1990). See generally PHILIP W. BRICKNER ET AL., LONG-TERM HEALTH CARE (1987) (describing long-term health care for the elderly); ANSELM STRAUSS & JULIET M. CORBIN, SHAPING A NEW HEALTH CARE SYSTEM (1988) (discussing the impact of chronic illness on the health care system); Thomas J. Burns, et al., The Health Insurance Coverage of Working-Age Persons with Physical Disabilities, 28 INQUIRY 187 (1991) (examining the health insurance status of working-age, physically-disabled persons); Sara D. Watson, Reality Ignored: Health Reform and People with Disabilities, 3 J. AM. HEALTH POL'Y 49 (1993) (suggesting that current discussions of health care reform continue to ignore chronic illness and disability issues).

<sup>20</sup> See Michael T. Isbell, AIDS and Access to Care: Lessons for Health Care Reformers, 3 CORNELL J.L. & PUB. POL'Y 7 (1993).

<sup>&</sup>lt;sup>16</sup> 29 U.S.C. §§ 1161-1168 (1988). COBRA requires employers with 20 or more employees to offer workers who leave their jobs the opportunity to continue coverage for up to 18 months. *Id.* 

<sup>&</sup>lt;sup>17</sup> See, e.g., GA. CODE ANN. § 33-24-21.2 (1993); R. I. GEN. LAWS § 27-20.4-5 (1992); WIS. STAT. § 146.88 (1991-1992).

HIV/AIDS,<sup>21</sup> apparently believing that the HIV problem will scarcely affect them. Some employers have begun to examine their health coverage plans and compare coverage options.<sup>22</sup> Other employers, however, seem to believe that they can avoid the problem simply by reducing or eliminating coverage for HIV disease, leaving affected employees to fend for themselves or seek Medicaid assistance.<sup>23</sup> Unfortunately, the epidemic is increasing in magnitude in all areas of the nation and in every type of work place.<sup>24</sup>

# II. THE CHANGING NATURE OF THE EPIDEMIC

The evolution of HIV disease and its treatment has affected the demographic structure of the epidemic, the length of time persons with the virus survive after diagnosis, the types of care required by those persons, the sites at which care is provided, and the array of treatments available.<sup>25</sup> A brief review of these trends will point out areas of health coverage employers must examine in order to meet their employees' health needs and prevent financial damage to their health insurance plans.

#### A. DEMOGRAPHICS

In the early years of the HIV epidemic, medical researchers thought that the virus mainly affected homosexual men in large urban areas.<sup>26</sup> It was, of course, incorrect to view AIDS

<sup>&</sup>lt;sup>21</sup> WILLIAM F. BANTA, AIDS IN THE WORKPLACE 28 (1993); Barr, Organizational Response to AIDS in the Workplace, 3 ADVANCES IN MED. SOC. 143, 160 (1993). See generally NATIONAL COMM'N ON AIDS, HIV/AIDS: A CHALLENGE FOR THE WORKPLACE (1993) (discussing employer responses to AIDS) [hereinafter NATIONAL COMM'N ON AIDS]; Paul A. Landsbergis, et al., AIDS and Employment Policies: The Role of Labor Unions, 6 AIDS & PUB. POL'Y J. 76 (1991) (examining labor union activities taken in response to AIDS); Arthur Leonard, AIDS, Employment, and Unemployment, 49 OHIO ST. L.J. 929 (1989) (describing the development of employment law in response to AIDS).

<sup>&</sup>lt;sup>22</sup> BANTA, supra note 21, at 28; Barr, supra note 21, at 160.

<sup>&</sup>lt;sup>23</sup> Barr, *supra* note 21, at 146.

<sup>&</sup>lt;sup>24</sup> BANTA, *supra* note 21, at 208.

<sup>&</sup>lt;sup>25</sup> ISBELL, *supra* note 1, at 54-65.

<sup>&</sup>lt;sup>26</sup> See Robert A. Padgug & Gerald M. Oppenheimer, *Riding the Tiger:* AIDS and the Gay Community, in AIDS: THE MAKING OF A CHRONIC DISEASE 253, 254 (Elizabeth Fee and Daniel M. Fox eds., 1992).

exclusively as a gay disease, since other high-risk groups carried the virus from the very earliest period of its public emergence.<sup>27</sup> Nevertheless, the majority of reported HIV cases involved homosexual men, and a large proportion of those men were employed members of the middle class who were residing in a few large urban areas, most notably San Francisco, New York, and Los Angeles.<sup>28</sup>

As the epidemic has spread, it has spared no one. Newly reported cases among gay men now represent a steadily declining proportion of the total number of new cases, while members of other risk groups represent a continually increasing proportion. New cases of HIV are increasing rapidly among intravenous drug users,<sup>29</sup> African-Americans,<sup>30</sup> and Hispanics.<sup>31</sup> The greatest increase in the rate of new cases, though, is to be found among women, the majority of whom acquire the infection through heterosexual activity.<sup>32</sup> Because women, African-Americans, and Hispanics have higher rates of poverty,

<sup>27</sup> See Gerald M. Oppenheimer, Causes, Cases, and Cohorts: The Role of Epidemiology in the Historical Construction of AIDS, in AIDS: THE MAKING OF A CHRONIC DISEASE 49, 55 (Elizabeth Fee and Daniel M. Fox eds., 1992).

<sup>28</sup> See The Second 100,000 Cases of Acquired Immunodeficiency Syndrome: United States, June 1981-December 1991, 41 MORBIDITY & MORTALITY WKLY. REP. 28, 28 (1992). Recently, HIV disease has been increasing in other areas of the country. See CDC, supra note 12 (describing the current state of the AIDS epidemic in terms of geographic spread and risk category); NATIONAL COMM'N ON AIDS, AMERICA LIVING WITH AIDS 11 (1991) (discussing the spread of HIV/AIDS into rural areas); Pauline A. Thomas et al., Trends in the First Ten Years of AIDS in New York City, 137 AM. J. EPIDEMIOLOGY 121, 129 (1993).

<sup>29</sup> See generally NATIONAL RESEARCH COUNCIL, AIDS: SEXUAL BEHAVIOR AND INTRAVENOUS DRUG USE (Charles F. Turner et al. eds., 1989) (discussing the unique role of intravenous drug users in the transmission chain of HIV).

<sup>30</sup> See generally SAMUEL V. DUH, BLACKS AND AIDS: CAUSES AND ORIGINS (1991) (examining the reasons behind the disproportionately high rates of AIDS in black populations); DAVID MCBRIDE, FROM TB TO AIDS: EPIDEMICS AMONG URBAN BLACKS SINCE 1900 (1991) (noting the persistently higher mortality and morbidity levels for black Americans in many major disease categories when the levels for the general American population have been declining significantly).

<sup>31</sup> See generally Theresa Diaz et al., AIDS Trends Among Hispanics in the United States, 83 AM. J. PUB. HEALTH 504 (1993) (noting that from 1989 to 1990, Hispanics had a larger proportionate increase in AIDS cases than any other racial or ethnic group in the United States and examining trends in the incidence of AIDS among Hispanics by region of residence).

<sup>32</sup> See CDC, supra note 12.

unemployment, and low-wage employment at jobs that do not offer health coverage,<sup>33</sup> the shifting demographics of the HIV epidemic have probably worked to reduce the percentage of persons with HIV disease covered by employer-sponsored private health insurance. There are exceptions. Recent studies indicate that a large proportion of intravenous drug users are employed and eligible for coverage under employer-sponsored plans.<sup>34</sup>

The demographic shifts in the HIV epidemic have resulted in the emergence of new illness patterns and health needs because the opportunistic infections associated with HIV tend to vary between different risk groups.<sup>35</sup> Women, for example, have very different health requirements than men, and new-born children with HIV have special needs of their own.<sup>36</sup> Moreover, many members of the more recently afflicted risk groups have limited social support services available in their communities. They often belong to less sympathetic communities that are less able to meet their emotional needs, as compared to the support network provided by the gay community.<sup>37</sup> The wide range of

<sup>34</sup> See generally Jon Eisenhandler & Ernest Drucker, Opiate Dependency Among the Subscribers of a New York Area Private Insurance Plan, 269 JAMA 2890 (1993) (suggesting that current estimates of the number of opiate users and their social characteristics should be reconsidered to take into account the fact that there is a large population of insured opiate users).

<sup>35</sup> See Karen M. Farizo et al., Spectrum of Disease in Persons with Human Immunodeficiency Virus Infection in the United States, 267 JAMA 1798, 1802-04 (1992); Joyce V. Kelly et al., Duration and Costs of AIDS Hospitalizations in New York: Variations by Patient Severity of Illness and Hospital Type, 27 MED. CARE 1085, 1086 (1989); Peter Selwyn et al., Clinical Manifestations and Predictors of Disease Progression in Drug Users with Human Immunodeficiency Virus Infection, 327 NEW ENG. J. MED. 1697, 1700 (1992). Cf. Vincent Mor et al., Variation in Health Service Use Among HIV-Infected Patients, 30 MED. CARE 17, 17 (1992) (discussing the considerable variations in medical utilization among risk groups).

<sup>36</sup> See generally ACT-UP/NY WOMEN AND AIDS BOOK GROUP, WOMEN, AIDS & ACTIVISM 31-43 (1990) (discussing women and their medical needs when infected with HIV); Ann Meredith, Until That Last Breath: Women with AIDS, in AIDS: THE MAKING OF A CHRONIC DISEASE 229 (Elizabeth Fee and Daniel M. Fox eds., 1992) (discussing the impact of AIDS on women); James D. Hegarty et al., The Medical Care Costs of the Human Immunodeficiency Virus: Infected Children in Harlem, 260 JAMA 1901, 1903-05 (1988) (examining the impact of HIV on children).

<sup>37</sup> See generally Harlan Dalton, AIDS in Blackface, 118 DAEDALUS 205, 205-18 (1989) (discussing the black community's reactions to the AIDS

<sup>&</sup>lt;sup>33</sup> UNITED STATES DEP'T OF COMMERCE, supra note 11, at 399.

problems encountered by those afflicted with HIV makes it imperative that employers be more attentive to the needs of the increasingly varied population of persons infected with HIV when offering coverage options.<sup>38</sup>

## B. AIDS AS A CHRONIC DISEASE

Employers and health insurance providers hoping to cope with HIV disease must acknowledge that HIV-infection has become a chronic disease. In the early years of the epidemic, persons with AIDS died relatively quickly following diagnosis. concentrating medical costs into a short period of time.<sup>39</sup> The largest proportion of treatment costs went to hospitals and physicians providing acute care treatment for the opportunistic infections associated with HIV and AIDS.<sup>40</sup> In recent years, this pattern has changed dramatically.<sup>41</sup> Earlier diagnosis and treatment. a more substantial array of treatments and opportunistic pharmaceuticals for infections. and the development of relatively effective drugs aimed at HIV itself have combined to increase the average life expectancy of persons with AIDS from twelve months following initial diagnosis to twenty-four months.<sup>42</sup>

The increasing life expectancy of persons with HIV and the improved range of treatments for both the underlying infection and the opportunistic infections that accompany HIV have

epidemic).

<sup>38</sup> See Isbell, supra note 20, at 43-46.

<sup>39</sup> See generally John Piette et al., *Patterns of Survival with AIDS in the United States*, 26 HEALTH SERVICES RES. 75, 75 (1991) (finding that persons diagnosed with AIDS in 1981 lived significantly longer than those diagnosed earlier).

<sup>40</sup> Most insurance companies provide broader coverage for in-patient hospital care. Ann M. Hardy et al., *The Economic Impact of the First 10,000 Cases of Acquired Immunodeficiency Syndrome in the United States*, 255 JAMA 209, 210 (1986).

<sup>41</sup> Ernestine S. Pantel, The Health-Care Needs of AIDS Patients: Parallels with the Elderly, 6 AIDS & PUB. POL'Y J. 83, 83 (1991); George R. Seage III et al., Effect of Changing Patterns of Care and Duration of Survival on the Cost of Treating the Acquired Immunodeficiency Syndrome (AIDS), 80 AM. J. PUB. HEALTH 835, 838 (1990).

<sup>42</sup> Fred J. Hellinger, *The Lifetime Cost of Treating a Person with HIV*, 270 JAMA 474, 474 (1993); Jon Eisenhandler, *AIDS: Update and Reserving*, 18 REC. SOC'Y ACTUARIES 673, 676 (1993) [hereinafter ACTUARIES]. combined to make AIDS a "chronic" disease.<sup>43</sup> Indeed, persons with HIV typically experience relatively long periods of freedom from opportunistic infections.<sup>44</sup> Still, they also experience relatively short periods that demand acute care intervention.<sup>45</sup> Some situations may also require sub-acute and custodial care<sup>46</sup> and a variety of pharmaceuticals for treatment of both opportunistic infections and the virus itself.<sup>47</sup> Persons with HIV require a wide continuum of care, ranging from the most intensive care to the least intensive, purely custodial care. Within this continuum, care focuses on restoration and maintenance of functional capacity to the greatest degree possible, rather than curing the disease itself.<sup>48</sup>

The needs of persons with HIV vary depending on the stage of infection, the specific opportunistic infections and the complications present in each given case.<sup>49</sup> Because there is no "typical" person with AIDS, an employer-sponsored health plan must cover a wide range of treatment modalities and situations to effectively meet the varying needs of HIV-infected persons.

C. TYPES AND SITES OF CARE

Treating HIV as a chronic condition requires considerable expansion of both the types of treatment and the sites where treatments are available. In recent years, treatment modalities have expanded beyond the acute care provided in hospitals and physicians' offices.<sup>50</sup> Drug therapy represents the most notable advance for stemming the progression of illness and preventing the onset of opportunistic infections.<sup>51</sup>

<sup>45</sup> Levine, supra note 44, at 48; Seage, supra note 41, at 838.

<sup>46</sup> Custodial care includes assistance with activities of daily living ("ADLs") such as bathing, dressing, or preparing meals; custodial care at home or in nursing homes for persons with mental problems caused by the infection; and assistance in meeting other social needs. Pantel, *supra* note 41, at 83.

<sup>47</sup> ISBELL, *supra* note 1, at 87.

<sup>48</sup> Id. at 54-63; Levine, supra note 44, at 45-50.

<sup>49</sup> Levine, *supra* note 44, at 48.

<sup>50</sup> Id. at 57-60.

<sup>51</sup> Kenneth H. Mayer, The Natural History of HIV Infection and Current

<sup>&</sup>lt;sup>43</sup> Pantel, *supra* note 41.

<sup>&</sup>lt;sup>44</sup> Carol Levine, In and Out of the Hospital, in AIDS AND THE HEALTH CARE SYSTEM 45, 48 (Lawrence O. Gostin ed., 1990); Seage, supra note 41, at 838-39.

Pharmaceuticals account for a large and growing proportion of medical costs associated with HIV. In fact, some health plans report that twenty-five percent of their total HIV-related costs accrue from pharmaceutical costs.<sup>52</sup> Intravenous nutritional and antibiotic infusion therapies administered in the patient's home now represent a significant subcategory of pharmaceuticals.<sup>53</sup> An entire industry has developed around home infusion for AIDS patients, with costs per case frequently reaching \$100,000 per year.<sup>54</sup>

As medical technology progressed during the late 1980s and early 1990s, an increasingly large number of high-tech procedures previously performed only in hospitals have become available for use at other sites, including physician's offices, day-treatment centers, hospice settings, and the home.<sup>55</sup> Patients can now receive home care for a multitude of opportunistic infections, nutritional problems, and other problems with relative ease.<sup>56</sup> Indeed, in the last few years, outpatient utilization and costs for persons with AIDS appear to have outstripped hospital utilization and costs in most plans and regions.<sup>57</sup> While technological progress of this sort has improved the quality of life of persons with HIV, it raises a host of new problems related to coverage, costs and cost containment for health plans.

#### D. ADEQUACY OF EMPLOYER-SPONSORED COVERAGE FOR HIV DISEASE

In light of the trends outlined above, employers must ensure that their health plans provide adequate coverage for a

<sup>53</sup> Frank E. Samuel, Jr., *High Technology Home Care: An Overview, in* DELIVERING HIGH TECHNOLOGY HOME CARE 1, 9 (Maxwell J. Mehlman & Stuart J. Youngner eds., 1991).

<sup>54</sup> Id.

Therapeutic Strategies, in AIDS AND THE HEALTH CARE SYSTEM 21, 23-25 (Lawrence O. Gostin ed., 1990). For example, the widely prescribed drug zidovudine ("AZT") which appeared on the market in the late 1980s has been shown to have a therapeutic effect on HIV-infected persons. *Id.* 

<sup>&</sup>lt;sup>52</sup> See ACTUARIES, supra note 42, at 675-76.

<sup>&</sup>lt;sup>55</sup> Office of Technology Assessment, U.S. Congress, Home Drug Infusion Therapy Under Medicare 3 (1992).

<sup>&</sup>lt;sup>56</sup> Id. at 4-7.

<sup>&</sup>lt;sup>57</sup> See ACTUARIES, supra note 42, at 676-78.

demographically varied population of persons with HIV infection. Unfortunately, traditional plans are insufficient to meet the health care requirements of persons with HIV. Health insurance plans were created to deal with the acute care needs of a generally healthy population; it thus follows that these plans are often ill-suited to deal with chronic illness.<sup>58</sup> Traditional health plans are particularly deficient in that they fail to cover most aspects of long-term care, especially those basically custodial in nature.<sup>59</sup> They also generally fail to provide the *coordination of care* (or "case management") that persons with long-term and chronic illnesses require for optimal access to care.<sup>60</sup> Current health plans rarely integrate acute care, long-term care coverage and case management.<sup>61</sup> Even those companies that have begun to move towards integrated plans have not achieved satisfactory results.<sup>62</sup>

Many health care plans provide inadequate coverage, even for generally covered acute care services. In particular, many plans lack sufficient coverage for pharmaceuticals.<sup>63</sup> This presents a major problem for persons with HIV, who depend on an array of drugs to deal with both opportunistic infections and the underlying HIV infection.<sup>64</sup> This lack of coverage often applies to both therapeutically useful and safe drugs, as well as to drugs still considered experimental.<sup>65</sup> Most plans also lack sufficient coverage for preventive and primary care<sup>66</sup> and

<sup>60</sup> KARYL THORN, APPLYING MEDICAL CASE MANAGEMENT: AIDS 22-23 (1990).

<sup>61</sup> Cf. Thomas P. Burke, Alternatives to Hospital Care Under Employee Benefit Plans, MONTHLY LAB. REV., Dec. 1991, at 9 (noting limits on alternative care benefits); Rita Shoor, Looking to Manage Care More Closely, BUS. AND HEALTH, Sept. 1993, at 46-53 (questioning the cost effectiveness of home care).

<sup>62</sup> Id.

<sup>63</sup> Peter Arno et al., *Economic and Policy Implications of Early Intervention in HIV Disease*, JAMA 1493, 1498 (1989).

<sup>64</sup> See ISBELL, supra note 1, at 87.

<sup>65</sup> Id. at 88, 91-95; Mark H. Jackson, *Health Insurance: The Battle Over Limits in Coverage, in AIDS AGENDA: EMERGING ISSUES IN CIVIL RIGHTS 147, 154-55 (Nan D. Hunter & William B. Rubenstein, eds. 1992).* 

<sup>66</sup> Thomas Bodenheimer, *Underinsurance in America*, 327 NEW ENG. J. MED. 274, 275 (1992).

<sup>&</sup>lt;sup>58</sup> See Oppenheimer & Padgug, supra note 5; Yelin, supra note 13.

<sup>&</sup>lt;sup>59</sup> See ISBELL, supra note 1, at 15.

contain a bewildering array of co-payments, deductibles and lifetime coverage limits.<sup>67</sup> Numerous internal rules and regulations including requirements that certain procedures be performed at specified sites further impede access to care.<sup>68</sup>

Finally, health care plans have traditionally focused on inpatient hospital care, covering it more broadly than other services.<sup>69</sup> Even today, services like home care often receive only narrow coverage, if they receive any at all.<sup>70</sup> Attempting to deal with the massive cost increases that affected their health plans during the late 1970s and the 1980s, many employers tried to reverse their traditional focus on in-patient care.<sup>71</sup> These efforts, however, mainly involved reducing the utilization and costs of hospital care.<sup>72</sup> While this reduction entailed some expansion of coverage for out-patient care, the scope of covered services remains relatively limited.<sup>73</sup>

Even when employers pursued cost containment strategies and managed care techniques, they focused primarily on hospital in-patient care.<sup>74</sup> Few employer-sponsored health plans have effectively managed or fully covered the costs of the outpatient services needed by persons with HIV disease, such as home care and nursing home care.<sup>75</sup> Employers have begun to comprehend the challenges of HIV disease; unfortunately, some

<sup>69</sup> BARBARA M. ALTMAN & DANIEL C. WALDEN, U.S. DEP'T OF HEALTH AND HUM. SERV., NATIONAL MEDICAL EXPENDITURES SURVEY RESEARCH FINDINGS 8, 12-13 (1993); ISBELL, *supra* note 1, at 100. *Cf.* THORN, *supra* note 60, at 22 (stating that the health insurance industry is geared to short-term in-hospital care).

<sup>70</sup> ISBELL, *supra* note 1, at 100.

<sup>71</sup> See Burke, supra note 68, at 9.

<sup>72</sup> INSTITUTE OF MEDICINE, CONTROLLING COSTS AND CHANGING PATIENT CARE 59 (Bradford H. Gray & Marilyn J. Field, eds. 1989).

<sup>73</sup> See Burke, supra note 68, at 11.

<sup>74</sup> Oppenheimer & Padgug, *supra* note 5, at 115-16.

<sup>75</sup> See id. at 116.

<sup>&</sup>lt;sup>67</sup> See ISBELL, supra note 1, at 15-16; Oppenheimer & Padgug, supra note 5, at 115; Thomas Rice, Containing Health Care Costs in the United States, 49 MED. CARE REV., 19, 25-28 (1992).

<sup>&</sup>lt;sup>68</sup> Thomas P. Burke, Alternatives to Hospital Care Under Employee Benefit Plans, MONTHLY LAB. REV., Dec. 1991, at 9, 11. Cf. ISBELL, supra note 1, at 88 (noting that some insurers only pay for drugs administered in a hospital setting).

have responded to pressure on their health care plans by restricting coverage rather than by expanding it.<sup>76</sup>

#### III. EFFECTS OF HIV DISEASE ON EMPLOYERS' HEALTH PLANS

HIV disease affects a predominantly working-age population.<sup>77</sup> Thus, in an employer-based system of health care, the medical costs of HIV infection fall disproportionately on employers.<sup>78</sup> Strategies for insuring HIV-infected persons become more complicated in light of the costs of treating HIV disease and the legal situation confronting employers with respect to coverage. Indeed, the substantial costs of treating HIV infection and AIDS have frightened many employers.<sup>79</sup> Some persons with HIV lose benefits when they can no longer work, and others fear losing their jobs if they submit HIVrelated claims.<sup>80</sup> Healthy employees worry that HIV-related expenses will drive up the health care premiums for all employees.<sup>81</sup>

#### A. COSTS OF HIV DISEASE

Several studies have compiled information on the costs of treating HIV disease.<sup>82</sup> Convincing evidence indicates that

<sup>78</sup> Cf. Oppenheimer & Padgug, supra note 5, at 115 (noting that most health insurance has been based on employment).

<sup>79</sup> NEW YORK BUSINESS GROUP ON HEALTH, HIV/AIDS AND THE WORKPLACE: WHAT EMPLOYERS NEED TO KNOW AND DO! 14 (1993) [hereinafter NYBGH].

<sup>80</sup> See id. at 23-24.

<sup>81</sup> NATIONAL LEADERSHIP COALITION ON AIDS, supra note 77, at 14.

 $<sup>^{76}</sup>$  Cf. ISBELL, supra note 1, at 73-75 (discussing benefit caps and exclusions for HIV-related illness).

<sup>&</sup>lt;sup>77</sup> See CDC, supra note 12 (table of AIDS cases by age at diagnosis and exposure category); NATIONAL LEADERSHIP COALITION ON AIDS, EMPLOYEE ATTITUDES ABOUT AIDS: WHAT WORKING AMERICANS THINK 2 (1993).

<sup>&</sup>lt;sup>82</sup> See, e.g., BANTA, supra note 21, at 125-27; Fox, supra note 8, at 105-06; Green & Arno, supra note 15, at 1261; Joel W. Hay et al., Projecting the Medical Costs of AIDS and ARC in the United States, 1 J. AIDS 466 (1990); NATIONAL COMM'N ON AIDS, supra note 21, at 68; NYBGH, supra note 80, at 15.

AIDS is no more costly overall than many other catastrophic diseases requiring intensive and invasive procedures.<sup>83</sup>

## 1. HIV/AIDS-Related Claims

In 1992, the American Council of Life Insurance and the Health Insurance Association of America surveyed member companies about both accident and health insurance policies for groups and individuals.<sup>84</sup> The study shows that claims have risen steadily since 1988, when HIV-related individual accident and health claims totalled \$50.3 million, and group claims were \$248.6 million.<sup>85</sup> HIV-related claims represented 1.5 percent of total group accident and health claims, and 1.4 percent of total individual accident and health claims.<sup>86</sup> Medical expenses totaling \$46.4 million for individual claims and \$235.7 million for group claims accounted for the largest proportion of these costs.<sup>87</sup> HIV-related claims accounted for 1.7 percent of group claims.<sup>88</sup> Disability expenses, while a much smaller proportion of the total, accounted for 2 percent of all claims paid under both individual and group accident and health plans.<sup>89</sup> These amounts and proportions represent increases over the last five years.<sup>90</sup> Moreover, the Association's report warns that the survey results "may significantly understate the number and amount of AIDS-related claims ... paid by the reporting companies."91 Reasons for the under-reporting of HIV-related claims include: (1) HIV diagnosis not made at the time the claim was submitted; (2) opportunistic disease not indicated in reported diagnosis; and (3) diagnosis imprecisely stated (e.g.,

<sup>87</sup> Id. at A-2 (Appendix-Claims Reported in 1992).

<sup>89</sup> Id.

<sup>&</sup>lt;sup>83</sup> See ISBELL, supra note 1, at 67-68.

<sup>&</sup>lt;sup>84</sup> AMERICAN COUNCIL OF LIFE INSURANCE AND HEALTH INSURANCE ASSOCIATION OF AMERICA, AIDS RELATED CLAIMS SURVEY: CLAIMS PAID IN 1992 at 1, 1 (1993).

<sup>&</sup>lt;sup>85</sup> Id.

<sup>&</sup>lt;sup>86</sup> Id. at 1, 8 t.5.

<sup>&</sup>lt;sup>88</sup> Id.

 $<sup>^{90}</sup>$  Id. (comparing the claims reported in 1992 with the claims reported in 1987).

<sup>&</sup>lt;sup>91</sup> Id. at 2, B-1.

cancer rather than Kaposi's sarcoma), or intentionally misstated to avoid identification.<sup>92</sup>

The approximate lifetime cost of treating a person with HIV from the time of infection to death is \$119,000.<sup>93</sup> The cost of treatment from AIDS diagnosis until death is estimated at \$69,100.<sup>94</sup> Similar estimates from 1991 indicate a higher cost of \$102,000 per case from AIDS diagnosis to death.<sup>95</sup> The apparent decline in costs is attributed to shorter lengths of stay and less frequent hospitalizations.<sup>96</sup>

A different cost picture emerges from data and analysis based on the claims experience of Empire Blue Cross and Blue Shield ("EBCBS") in New York, the largest private payor for HIV care in the United States.<sup>97</sup> EBCBS data also indicates a decline in in-patient expenditures but suggest that a concurrent increase in out-patient expenditures causes a continuing increase in overall costs.<sup>98</sup> EBCBS found that projected lifetime costs, from HIV infection to death, or from infection to loss of insurance, increased from \$60,000 per case in 1986 to \$200,000 per case in 1993.<sup>99</sup> These costs reflect three trends: medical inflation, increased life expectancy of HIV-infected individuals,<sup>100</sup> and more aggressive out-patient treatment.

# 2. Employers and Health Benefit Costs for AIDS

Employers bear much of the cost for treating HIV disease through health insurance benefits to employees.<sup>101</sup> Analyses

<sup>97</sup> Jon Eisenhandler, AIDS Update, Address Before the New York Business Group on Health 1, 1 (Mar. 23, 1993) (unpublished speech on file with author).

<sup>101</sup> Cf. ISBELL, supra note 1, at 10 (noting that two of three Americans

<sup>&</sup>lt;sup>92</sup> Id. at B-1.

<sup>&</sup>lt;sup>93</sup> This figure is based on 1992 national estimates from data obtained through interviews with 1,164 HIV-infected individuals, 784 of whom had been diagnosed with AIDS. Hellinger, *supra* note 42, at 477.

<sup>&</sup>lt;sup>94</sup> Id.

<sup>&</sup>lt;sup>95</sup> Id.

<sup>&</sup>lt;sup>96</sup> Id. at 477-78.

<sup>&</sup>lt;sup>98</sup> Id. at 10-12.

<sup>&</sup>lt;sup>99</sup> Id. at 8-9.

 $<sup>^{100}</sup>$  Id. at 10 (stating that the average survival time after diagnosis increased from 540 days in 1986 to a projected 725 days in 1990 and 900 days in 1993).

indicate that private, largely employer-sponsored insurance coverage pays for approximately 40 percent of hospital costs for persons with AIDS in New York.<sup>102</sup> An analysis by Paul Farnham at the Centers for Disease Control and Prevention ("CDC") found that the total direct costs of HIV disease equal 60 percent of all cancer treatment costs, 26 percent of mental illness costs, and 24 percent of physical injury costs in the United States.<sup>103</sup>

As these findings indicate, HIV disease is less costly than other chronic conditions such as heart disease requiring invasive procedures, breast cancer, and kidney cancer treatments.<sup>104</sup> Some employers, however, have attempted to set limits on payments for HIV disease, and some exclude coverage for specific treatments needed by people with HIV.<sup>105</sup> Attempts to avoid the costs of covering persons with HIV are increasingly the subject of court challenges under existing and recently enacted laws.<sup>106</sup>

# B. THE AMERICANS WITH DISABILITIES ACT AND THE WORKPLACE

The Americans with Disabilities Act ("ADA" or "the Act")<sup>107</sup> is the strongest means for enforcing the legal rights of those who have HIV disease. The ADA applies to employers with twenty-five or more employees,<sup>108</sup> and it applies to health insurance plans.<sup>109</sup> More importantly, persons with AIDS may be "qualified individual[s] with disabilities" under the ADA.<sup>110</sup>

have employer-sponsored health coverage).

<sup>102</sup> Ball et al., *supra* note 15, at 53.

<sup>103</sup> NYBGH, supra note 80, at 16.

<sup>104</sup> ISBELL, *supra* note 1, at 67-68.

<sup>105</sup> See e.g., Jackson, *supra* note 65, at 149-55.

<sup>106</sup> See discussion infra part III(B)(1).

 $^{107}$  42 U.S.C. \$ 12101-12213 (Supp. 1991). The Act's protections became effective in July 1992.

<sup>108</sup> Id. § 12111(5).

 $^{109}\,See\,\,id.$  § 12201(c) (delineating the range of acceptable insurance practices under the ADA).

<sup>110</sup> The ADA provides that "qualified individual with a disability' means an individual with a disability who, with or without reasonable accomodation, can perform the essential functions of the employment position that such individual holds or desires." *Id.* § 12111(8); Lawrence O. Gostin, *Update I*: In its June 1993 interim ruling, the Equal Employment Opportunity Commission ("EEOC") construed the ADA to require that employees with disabilities be given access to the same health insurance benefits as non-disabled employees.<sup>111</sup> Under the EEOC guidelines, employers, including the selfinsured, bear the burden of proving that plan designs and changes are actuarially based and not subterfuge for discrimination against people with specific illnesses.<sup>112</sup> The ruling does not interpret the ADA to require health plans to address the special needs of any persons.

#### 1. Capping AIDS Costs

The much publicized case of McGann v. H&H Music Co.<sup>113</sup> involved an employer placing limits on coverage for HIV-related treatments. Seven months after employee John McGann submitted his first HIV-related health claim in 1988, H&H Music, a self-insurer, changed its benefits package by cutting the maximum benefit for HIV-related claims from one million dollars to five thousand dollars.<sup>114</sup> In response to the employer's efforts to cap benefits for HIV cases, McGann sued the company for discrimination under the Employment Retirement Income Security Act ("ERISA").<sup>115</sup> The Fifth Circuit decided in favor of the company, ruling that ERISA does not mandate that employers provide any particular level of benefits.<sup>116</sup> The court further ruled that, absent a showing of discriminatory retaliation. ERISA permits an employer to deny or drop coverage for HIV, even if it provides coverage for other catastrophic illnesses.<sup>117</sup> In petitioning the Supreme Court to grant a writ of certiorari, the Lambda Legal Defense and Education Fund argued that by permitting employers to

Legislative Report: The Americans with Disabilities Act and the U.S. Health System, 61 HEALTH AFF. 248, 249 (1992).

<sup>111</sup> 29 C.F.R. §§ 1630.4(f) (1993).

<sup>112</sup> EEOC POLICY GUIDELINES, REPORT NO. N-915.002, at 9-11 (June 8, 1993).

<sup>113</sup> 946 F.2d 401 (5th Cir. 1991), cert. denied sub nom. Greenberg v. H&H Music Co., 113 S. Ct. 482 (1992).

<sup>114</sup> Id. at 403.

<sup>115</sup> 29 U.S.C. §§ 1001-1461 (1988 & Supp. 1992).

<sup>116</sup> McGann, 946 F.2d at 406.

<sup>117</sup> Id. at 408.

discriminate against employees with specific diseases, the *McGann* court's ruling would have the effect of denying health coverage to those who need it most.<sup>118</sup> In November 1992, the Supreme Court denied certiorari, leaving intact the rule that ERISA allows employers with self-insured plans to modify or cut benefits to preserve a plan's financial integrity.<sup>119</sup>

Two cases involving self-insured unions reveal an unresolved tension between the McGann court's holding that an employer may limit coverage of specific diseases and the ADA's mandate that employers not discriminate on the basis of disability. These cases raise the issue of whether an employer who caps benefits for AIDS while maintaining higher benefit levels for other catastrophic illnesses violates the ADA. In New York, the Mason Tenders District Council Welfare Fund decided to exclude HIV from its health insurance coverage but continue coverage for other costly illnesses.<sup>120</sup> Mason Tenders contended that the decision to withdraw coverage for HIV was motivated by non-discriminatory economic considerations and asserted that it had cut other benefits as well, including dental care and organ transplants.<sup>121</sup> The EEOC disagreed, ruling that the Fund's actions constituted discrimination under the ADA.<sup>122</sup> Mason Tenders responded in July 1993 by filing suit and moving for summary judgment against the EEOC.<sup>123</sup>

In another case, Local 110 of the International Brotherhood of Electrical Workers and its health insurance plan capped AIDS benefits at a lower level than benefits for other illnesses.<sup>124</sup> The estate of a worker who died of AIDS sued both the union and the plan under the ADA, alleging that the union plan, which capped coverage at \$500,000 for non-HIV-related

<sup>&</sup>lt;sup>118</sup> Supreme Court Refuses to Hear Employer's Reduction of Benefits for AIDS Treatment, DAILY REP. FOR EXECS (BNA) No. 218, at D-5 (Nov. 10, 1992).

<sup>&</sup>lt;sup>119</sup> Greenberg v. H&H Music Co., 113 S. Ct. 482 (1992).

<sup>&</sup>lt;sup>120</sup> Mason Tenders District Council Welfare Fund v. Donaghey, 93-ev-1154 (S.D.N.Y. July 19, 1993). See also In Brief, AIDS POL'Y & L., July 23, 1993, at 7.

<sup>&</sup>lt;sup>121</sup> Id.

<sup>&</sup>lt;sup>122</sup> Milt Freudenheim, Patients Cite Bias in AIDS Coverage by Health Plans, N.Y. TIMES, Jun 1, 1993, at A1, D2.

<sup>&</sup>lt;sup>123</sup> In Brief, supra note 120.

<sup>&</sup>lt;sup>124</sup> Freudenheim, *supra* note 122, at D2.

claims, set a 50,000 limit on HIV coverage and discriminatorily refused to pay the worker's HIV-related bills of over 100,000.<sup>125</sup>

Another unresolved issue is whether ERISA preempts state civil rights laws that otherwise prevent employers from placing lower caps on health insurance coverage for HIV than on other diseases. In Westhoven v. Lincoln Foodservices Products.<sup>126</sup> the Indiana Court of Appeals held that ERISA preempts state handicap discrimination laws.<sup>127</sup> The state Civil Rights Commission ruled that Lincoln Foodservice Products violated state anti-discrimination laws by capping health insurance benefits at \$25,000 per year and \$50,000 lifetime on HIV claims but retained a one million dollar cap for most other conditions.<sup>128</sup> The trial court reversed, ruling that the Commission did not have jurisdiction over the health plan.<sup>129</sup> The Indiana Court of Appeals affirmed, holding that neither the Rehabilitation Act<sup>130</sup> nor the ADA displaces ERISA's provisions, which preempt state law.<sup>131</sup> The decision was based in part on the fact that the employer's actions occurred prior to the enactment of the ADA.<sup>132</sup> In other cases, however, employers' decisions to restrict AIDS benefits have been reversed under state civil rights law or rescinded after public pressure or threats of legal action.<sup>133</sup>

#### 2. Coverage for Specific Treatments

Employers and insurers sometimes restrict health plan coverage by refusing to pay for certain drugs or treatments. For example, after denying payment and arguing that a bone

<sup>127</sup> Id. at 779. See also Indiana Court Upholds Decision that ERISA Pre-Empts State Law, 8 AIDS POL'Y & L., July 23, 1993, at 2-3 (discussing Westhoven) [hereinafter Indiana Court Upholds Decision].

<sup>128</sup> Westhoven, 616 N.E.2d at 780.

<sup>129</sup> Indiana Court Upholds Decision, supra note 127, at 3.

<sup>130</sup> Rehabilitation Act of 1973, 29 U.S.C. §§ 706, 791, 793, 794a (1993).

<sup>131</sup> Westhoven, 616 N.E.2d at 782-84.

<sup>132</sup> Id. at 784.

<sup>133</sup> Jackson, *supra* note 65, at 150-51; Doe v. Beaverton Nissan, No. ST-EM-HP-870108-1353 (Or. Bul. Lab. & Indus. 1986) (finding against an employer that revised an insurance plan to exclude reimbursement for HIVrelated costs).

<sup>&</sup>lt;sup>125</sup> Id.

<sup>&</sup>lt;sup>126</sup> 616 N.E.2d 778 (Ind. Ct. App. 1993).

marrow transplant for an individual with AIDS was investigational and experimental, New York-based Empire Blue Cross and Blue Shield was forced to pay the claim.<sup>134</sup> Other large insurers have refused to pay for prescription drugs or drug therapy prescribed for conditions other than those explicitly listed by the Food and Drug Administration, arguing that the use of such drugs is experimental.<sup>135</sup>

Employers and insurers often severely restrict coverage for drugs and drug treatments by capping the dollar amount of coverage for specific benefits at a much lower level than the actual costs of HIV therapy.<sup>136</sup> For example, the *New York Times* reports that a California computer engineer is pressing his employer to continue payments of \$10,000 a month for intravenous treatments of ganciclovir for AIDS-related retinitis.<sup>137</sup> The payments were stopped early in 1993 after they reached \$186,000; the company had limited payments to \$100,000 several months prior to the discontinuation.<sup>138</sup> The ADA allows employers to limit coverage for general procedures and specific treatments such as X-rays, blood transfusions and experimental drugs, but only if such restrictions apply equally to individuals with and without disabilities.<sup>139</sup> Such coverage limitations would have a greater impact on those with HIV disease than on those with other chronic illnesses.

# 3. Implications for Employers

As the EEOC responds to employee complaints of discriminatory denial of health insurance coverage and litigation over these claims ensues, it is apparent that paying for the care of HIV-infected employees may prove less costly to employers than paying for lawsuits. Employers must also consider the damage to their public images that denial of benefits may

<sup>&</sup>lt;sup>134</sup> Bradley v. Empire Blue Cross and Blue Shield, 149 Misc.2d 20 (N.Y. Sup. Ct. 1990). See also Empire Blue Cross Ordered to Pay For Man's Bone Marrow Transplant, 5 AIDS POL'Y AND L., Aug. 8, 1990, at 7.

<sup>&</sup>lt;sup>135</sup> Jackson, *supra* note 65, at 154-55; ISBELL, *supra* note 1, at 91-95.

<sup>&</sup>lt;sup>136</sup> Jackson, *supra* note 65, at 152-54.

<sup>&</sup>lt;sup>137</sup> Freudenheim, *supra* note 122, at D2.

<sup>&</sup>lt;sup>138</sup> Id.

<sup>&</sup>lt;sup>139</sup> The purpose of the ADA is to eliminate discrimination against persons with disabilities. 42 U.S.C. § 12101(b). *See* Gostin, *supra* note 110, at 2.

cause.<sup>140</sup> For example, the New York City-based advocacy group ACT-UP successfully induced two companies to rescind AIDS benefits limitations by both threatening and carrying out mass protest call-ins on toll-free lines.<sup>141</sup> One company had imposed a \$50,000 lifetime limit on HIV claims while maintaining a \$1 million maximum for other illnesses; the other had placed a \$10,000 limit on AIDS claims.<sup>142</sup>

#### 4. Health Reform and AIDS Benefits

The precise impact the ADA will have on HIV coverage under employer-sponsored health insurance plans is unclear. The ADA's statutory purpose of eliminating discrimination against individuals with disabilities is best served by ensuring equal health insurance coverage and preventing health insurance plans from reducing coverage for people with HIV infection and AIDS.<sup>143</sup> It has been argued, however, that the EEOC's rulings on the insurance provisions of the ADA will have a greater impact on small businesses and union welfare funds with small budgets than on larger employers who can spread the costs of treating HIV and other expensive illnesses over a larger risk pool.<sup>144</sup> If troubled plans fail or small insurers drop coverage, many employees will lose insurance benefits. exacerbating the problem of the uninsured and enlarging the pool of people who may need to be covered by a governmental health reform plan.<sup>145</sup>

It is unclear whether the ADA will affect rulings that relieve self-insured employers from maintaining equal access to coverage under ERISA.<sup>146</sup> The ADA prohibits employee benefit plans from excluding persons with HIV when other coworkers are covered, but it allows risk underwriting to the extent it is

<sup>&</sup>lt;sup>140</sup> See Jackson, supra note 65, at 151, 153 (listing examples of situations in which companies have altered policies due to public pressure).

<sup>&</sup>lt;sup>141</sup> NEW YORK BUSINESS GROUP ON HEALTH, CHANGES IN AIDS BENEFITS 8 (1990).

<sup>&</sup>lt;sup>142</sup> Id.

<sup>&</sup>lt;sup>143</sup> Milt Freudenheim, *Health Insurance Ruling to Hit Small Employers*, N.Y. TIMES, June 10, 1993, at D2.

<sup>&</sup>lt;sup>144</sup> Id.

<sup>&</sup>lt;sup>145</sup> See Oppenheimer & Padgug, supra note 5, at 110.

<sup>&</sup>lt;sup>146</sup> See discussion supra part III(B)(1).

consistent with state law.<sup>147</sup> Cases like *McGann* may thus be upheld on the basis that the employer engaged in "sound underwriting" principles.<sup>148</sup> With evidence suggesting that AIDS may be no more costly than certain other specific diseases and conditions,<sup>149</sup> the rationale of *McGann* could be applied to limit benefits even further by excluding coverage or capping benefits for diseases other than HIV infection.<sup>150</sup>

#### C. OTHER ISSUES FOR EMPLOYERS

Costs to employers from the AIDS epidemic include not only directly incurred health insurance costs, but also ancillary costs related to sick leave and long term disability, recruitment and hiring, training, preventive education, reduced productivity, litigation, and adverse publicity.<sup>151</sup> In making benefits design decisions about insurance coverage for HIV disease, employers need to consider both the direct and indirect costs of HIV.

A related work place issue for employers involves HIV testing. A 1993 American Management Association annual survey of 630 companies found that 5.7 percent require compulsory HIV testing for selected employees or new hires.<sup>152</sup> Only 3.3 percent require HIV testing for new hires as part of a pre-employment physical.<sup>153</sup> Of the companies with previous experience with HIV, 7.5 percent require testing for employees or new hires.<sup>154</sup> Companies that have not faced HIV in their work places are less likely to test for HIV, with only 2.7 percent requiring tests for employees and new hires.<sup>155</sup> The actions taken by companies with respect to employees who test positive for HIV are especially relevant to health insurance and benefits issues. Fifty percent of the companies surveyed reported that

<sup>150</sup> Id.

 $^{152}$  American Management Association, The 1993 AMA Survey on HIV- and AIDS-Related Policies 1-2 (1993).

- <sup>153</sup> *Id*. at 1. <sup>154</sup> *Id*.
- <sup>155</sup> Id.

<sup>&</sup>lt;sup>147</sup> 42 U.S.C. § 12201(c)(1)-(2).

<sup>&</sup>lt;sup>148</sup> Id.

<sup>&</sup>lt;sup>149</sup> See ISBELL, supra note 1, at 67-68.

<sup>&</sup>lt;sup>151</sup> Id. at 16.

they refer such employees for appropriate treatment and care.<sup>156</sup> HIV testing also raises other issues of confidentiality and liability for employers.<sup>157</sup>

Employers must also deal with employees' reluctance to report their HIV status. Even in an AIDS service organization such as Gay Men's Health Crisis, many staff persons are reluctant to say they are infected.<sup>158</sup> In a recent national survey, 15 percent of working Americans surveyed believed that their employer would restrict the health insurance coverage of an HIV-positive employee, and 7 percent asserted that the employer *should* restrict such coverage.<sup>159</sup> Yet concern about coverage and the failure to report infection with HIV in its early stages can lead to more costly treatment in the future and loss of productivity.

#### IV. WHAT CAN EMPLOYERS DO?

Given the dilemma posed by increasing health insurance costs for employers and the legal and other implications of eliminating or capping benefits for HIV, employers should consider other means of addressing the needs of HIV-infected employees. A promising alternative to traditional health plans is case management. The character of HIV disease — a chronic condition that often does not fit the acute care treatment model upon which the American health care system is based<sup>160</sup> — further emphasizes the need to seek new ways of providing and structuring appropriate health care coverage.

#### A. THE CASE MANAGEMENT APPROACH

Case management is a method of managing high-cost chronic illness cases by coordinating care and identifying and providing the most appropriate types of care and care providers.<sup>161</sup> A professionally trained case manager, usually a registered nurse or licensed social worker, oversees the needed

<sup>161</sup> Id. at 7.

<sup>&</sup>lt;sup>156</sup> Id. at 3.

<sup>&</sup>lt;sup>157</sup> NEW YORK BUSINESS GROUP ON HEALTH, AIDS AND THE WORKPLACE: A LEGAL/REGULATORY UPDATE 8-9 (1993).

<sup>&</sup>lt;sup>158</sup> NYBGH, *supra* note 80, at 27.

<sup>&</sup>lt;sup>159</sup> NATIONAL LEADERSHIP COALITION ON AIDS, *supra* note 77, at 14.

<sup>&</sup>lt;sup>160</sup> THORN, supra note 60, at 22.

care.<sup>162</sup> Because of the uncertainty of treatment and the difficulty of managing many of the physical and psychological effects of HIV, the case manager may have to handle a wide range of care problems and consider alternate treatment modalities.<sup>163</sup>

An important aspect of case management is the identification and referral of patients.<sup>164</sup> Once identified, the employee's condition and situation is assessed to determine whether case management would be appropriate.<sup>165</sup> A major focus of case management is home health care, which aims to enable patients to remain in their own homes rather than enter the hospital.<sup>166</sup> Case management has been credited not only with reducing care costs, but also with improving the caliber of care and quality of life for seriously ill people.<sup>167</sup> It helps persons with HIV disease obtain needed health care and has been evaluated positively by them.<sup>168</sup> Case management can take different forms.<sup>169</sup> For example, one approach emphasizes patient service needs, while another focuses on system costs and emphasizes justification of costly services.<sup>170</sup> Its emphasis on appropriate individualized care makes it an attractive alternative to most current health care plans.

#### B. AT HOME OPTIONS PROGRAM

Many services required by AIDS patients are not reimbursed under typical health insurance policies.<sup>171</sup> The At Home Options Program ("AHOP") is a cooperative effort between Empire Blue Cross and Blue Shield ("EBCBS") and

<sup>166</sup> See THORN, supra note 60, at 250.

<sup>&</sup>lt;sup>162</sup> SIERRA HEALTH FOUNDATION, CHALLENGES FOR THE FUTURE: COORDINATING HIV/AIDS CARE AND SERVICES IN THE NEXT DECADE 12 (1991) [hereinafter SIERRA].

<sup>&</sup>lt;sup>163</sup> See THORN, supra note 60, at 79-81.

<sup>&</sup>lt;sup>164</sup> Id. at 7-11.

<sup>&</sup>lt;sup>165</sup> See SIERRA, supra note 162, at 22.

<sup>&</sup>lt;sup>167</sup> Peter Kemper, The Evaluation of the National Long Term Care Demonstrations, 23 HSR: HEALTH SERVICES RES. 161, 166-67 (1988).

<sup>&</sup>lt;sup>163</sup> John Fleishman et al., AIDS Case Management: The Client's Perspective, 26 HSR: HEALTH SERVICES RES. 447, 447, 460 (1991).

<sup>&</sup>lt;sup>169</sup> SIERRA, *supra* note 162, at 21-23.

<sup>&</sup>lt;sup>170</sup> Id. at 22.

<sup>&</sup>lt;sup>171</sup> Jackson, *supra*, note 65, at 147-48.

VNS Home Care, a non-profit subsidiary of the Visiting Nurse Service of New York ("VNS") that seeks to expand the range of services available to HIV-infected individuals.<sup>172</sup> AHOP is a three-year experimental program that endeavors to enhance the quality of care and reduce costs by substituting home care for hospital care and combining case management with capitation payment.<sup>173</sup> For this experimental program, EBCBS has agreed to expand covered benefits to include a comprehensive array of services and expanded benefits.<sup>174</sup> VNS has agreed to accept part of the risk under a modified capitation rate in lieu of its traditional fee-for-service arrangement.<sup>175</sup>

AHOP is open to people with AIDS or symptomatic HIV disease who reside in Brooklyn, the Bronx, Manhattan, or Queens, and whose health insurance includes both major medical and hospital coverage under a community rated EBCBS policy.<sup>176</sup> Participation in AHOP is voluntary, with recruitment for persons infected with HIV occurring through hospitals, physicians, and voluntary community groups.<sup>177</sup> Thus far, the vast majority of AHOP participants have been males from Manhattan.<sup>178</sup>

A cohort comparison of AHOP participants with a matched group of non-participants at a comparable stage of illness found a cost savings under AHOP.<sup>179</sup> While enrolled in AHOP, participants incurred an average of \$5,102 less for in-patient admissions, \$754 less in out-patient institutional claims, and \$355 less in hospital-related home care costs.<sup>180</sup> The study also revealed that AHOP participants spent an average of 6.4 fewer days in the hospital.<sup>181</sup> The cohort comparison results are

<sup>173</sup> Id. at 1-4.
<sup>174</sup> Id. at 4.
<sup>175</sup> Id. at 3.
<sup>176</sup> Id. at 4.

- <sup>177</sup> Id. at 7.
- <sup>178</sup> Id.
- <sup>179</sup> Id. at 9.
- <sup>180</sup> Id.
- <sup>181</sup> Id.

<sup>&</sup>lt;sup>172</sup> Jon Eisenhandler et al., The At Home Options Program 1-2, Address at the 1992 Annual Symposium on Health Service Research (Nov. 18, 1992) (transcript on file with author).

preliminary, but they suggest that the AHOP program does yield savings.

#### CONCLUSION

In a recent survey of employees, half of those responding stated that AIDS was their most important health concern.<sup>182</sup> The weight of public opinion and the increasing incidence of AIDS in the work place may combine to encourage employers to take a more proactive role in responding to the needs of their HIV-infected employees. Certainly, many employers are making good-faith efforts to take care of their employees. The HIV epidemic may serve as a testing ground, allowing them to adjust their health insurance plans to meet the needs their employees will have in the future. This Article argues that employers can best respond to HIV in the work place by ensuring that AIDS is treated like any other disease.

Employers seeking well-designed health insurance plans that will meet the needs of employees with HIV disease and moderate employer costs must integrate selected features of long-term care into their traditional acute care plans. They can do so by designing benefits packages that treat home care as an independent type of care, rather than as a mere addendum to in-patient acute care procedures. These benefits packages would attend to the varied needs of persons with HIV-related illnesses and provide case management to both restrain costs and to better coordinate care for HIV-infected persons. The types of benefits needed by HIV-infected employees continually change as new medications and therapies are developed and as home care and out-patient services expand. Nevertheless. providing effective benefits for HIV-infected employees should result in long run savings to employers.