PROFESSIONAL LIABILITY

AND

HEALTH CARE REFORM

prepared as a discussion draft

for the

AMERICAN BAR ASSOCIATION

WORKING GROUP ON HEALTH CARE REFORM

by the

ABA Special Committee

on Medical Professional Liability

June 1993

In addressing access to health care proposals that contain provisions on medical professional liability, four questions need to be asked. First, what is the cost saving that can be achieved? Second, have such provisions, when enacted, lowered health care costs in states which have adopted their essential elements? Third, what are the consequences to the traditional American legal system and to the rights of the injured persons? Fourth, does the proposal merely result in a cost shifting from the medical professional who caused the injuries to the person who was injured or to a governmental agency?

WHAT IS THE COST OF THE MEDICAL-LEGAL SYSTEM?

The American Bar Association does not purport to possess the expertise to analyze all of the reasons for escalating medical costs. We do, however, have the ability to analyze the interrelationship of the legal system and those costs. Moreover, we are able to determine the consequences of proposed legislation upon the American legal system and those seeking compensation for injuries.

The major components that have been cited as contributing to the rising cost of health care are:

* Reliance on modern, sophisticated and expensive treatment and technology.
* Innovative treatment of illnesses, such as heart disease, AIDS and cancer;
* An aging population, which adds to Medicare and Medicaid expenditures;

* High administrative costs of the health care system; and

* The medical-legal system.

Studies concerning the medical-legal system show that its impact on the national expenditures is not only questionable but also insignificant.[1] The Congressional Budget Office stated in 1992 that medical-legal costs, as measured by medical malpractice insurance premiums, account for 0.74 percent of the national health expenditures.[2] We understand that these insurance premiums account for a lower percentage of national health expenditures at this point in time. The other component of cost attributed to the legal system is that of so-called "defensive medicine." Varying figures for the cost of "defensive medicine" have been estimated. However, no one has reliably measured what, if anything, defensive medicine costs.

An October 1992 study of the Congressional Budget Office concluded that health care spending is propelled upward by high-cost technological and medical breakthroughs. The study finds that rising incomes, demographic changes, and medical

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1 According to the 1992 U.S. Industrial Outlook prepared by the U.S. Department of Commerce, in 1991 national health care outlays accounted for approximately 13 percent of the GNP, totaling $738 billion up about 11 percent from $666 billion in 1990. The medical-legal component in the same period, however, appears to have decreased since health care costs greatly increased during this period and malpractice premiums decreased.

2 Testimony, Robert D. Reischauer, Director, Congressional Budget Office, Statement before the Committee on Ways and Means, U.S. House of Representatives, March 4, 1992.

malpractice costs do not appear to account for much of the increase in the nation's health care bill. The report states that malpractice insurance premiums account for less than one penny of each dollar spent annually on the nation's health care.

The report also concluded that "much of the care that is commonly dubbed 'defensive medicine' would probably still be provided for reasons other than concerns about medical malpractice. Physicians have always sought to provide patients with the best possible medical care at the lowest risks and would continue to do so even without the threat of lawsuits. Because much of this 'defensive care' helps to reduce the uncertainty of medical diagnosis, it seems unlikely that physicians would change their practice patterns dramatically in response to malpractice reform."[3]

To address the subject of "defensive medicine," there must be agreement upon the meaning of the phrase. However, there is no agreement upon the definition.[4] That uncertainty has resulted

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[3] Congressional Budget Office, Economic Implications of Rising Health Care Costs (October 1992) page 27.

[4] The American Medical Association has estimated the cost of defensive medicine based upon a survey of physicians who were asked, for example, whether they ordered more tests because of the perceived risk of a medical malpractice claim. The AMA, moreover, recognized other reasons contributed to an affirmative response, stating, "like other defensive measures, all defensive medicine cannot be characterized necessarily as overuse but can reflect necessary improvements in patient care." Statement on behalf of the American Medical Association to the Senate Finance Subcommittee on Medicare and Long Term Care Regarding Medical Liability Reform, October 16, 1991, page 4.

in the inability to statistically measure the cost.[5] In published studies, "defensive medicine" has included erroneously the cost of the consequence of physicians' financial incentive to direct patients for tests and examinations in facilities in which physicians have a proprietary interest.[6] Some have

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5 The Physician Payment Review Commission (PPRC) has questioned such figures, noting that "Studies that use physicians' estimates of the amount of defensive medicine they practice are not sufficiently reliable to make quantitative estimates." Physician Payment Review Commission 1991 Annual Report to Congress, page 374.

6 Mark N. Cooper, "Physician Self-Dealing for Diagnostic Tests in the 1980s: Defensive Medicine vs. Offensive Profits," Consumer Federation of America, October 3, 1991, reported that the rapid spread of physician ownership of diagnostic testing facilities is a much more likely cause of rising diagnostic costs than fear of malpractice liability.

A January 1991 study by the State of Florida's Health Care Cost Containment Board looked into physician ownership of health care facilities. It found that joint ventures among health care providers resulted in higher health care costs due primarily to the over-utilization of services.

A study of radiation centers in Florida found that doctor-owned centers appeared to result in a substantial increase in use and cost of the services. See Mitchell, Jean M.; Sunshine, Jonathan H.; "Consequences of Physicians' Ownership of Health Care Facilities - Joint Ventures in Radiation Therapy, The New England Journal of Medicine, Vol.327, No.21, Nov. 19, 1992, pages 1497-1501.

Another study examined workers' compensation claims in California and found that self-referral increases the cost of medical care covered by workers' compensation for physical therapy, psychiatric evaluation services and MRI Scans. Swedlow, Alex; Johnson, Gregory; Smithline, Neil; and Milstein, Arnold, "Increased Costs and Rates of Use in the California Workers' Compensation System as a Result of Self-Referral by Physicians," The New England Journal of Medicine, Vol.327, No.21 Nov. 19, 1992, pages 1502-1506.

considered the cost of new technology and advancements in medical knowledge, care and treatment. In that regard, patients expect the use of very modern, sophisticated and expensive technology to refine diagnosis and eliminate uncertainties.

Therefore, to examine the impact of the medical-legal system, the necessary inquiry is to what extent physicians direct medical expenses that are unwarranted for the treatment or diagnosis of patients, and are not motivated by personal financial interests. In other words, an expense is only attributable to the medical-legal system when a physician does not consider certain tests or medical treatment to be good medical practice but orders them solely out of concern about liability. There has been no study to measure that cost, and there appears to be no basis for assuming that competent and reputable physicians impose expenses upon their patients without a justifiable medical reason.

To the extent that physicians' concern about liability results in more conscientious medical care, then "defensive medicine" is certainly desirable.[7] When the fear of tort liability deters medical injuries, then health care costs are lowered by avoiding the costs associated with medical injury.[8]

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[7] Patricia M. Danzon, "Liability for Medical Malpractice," Journal of Economic Perspectives, Vol.5, No.3, Summer 1991, pages 51-69. Ms. Danzon concludes that liability concerns have brought about some efficient changes in practice.

[8] Testimony, Robert D. Reischauer, Director, Congressional Budget Office, Statement before the Committee on Ways and Means, U.S. House of Representatives, March 4, 1992, Appendix F, page 32.

Thus, if liability concerns are a deterrent, provisions that relieve physicians of concern regarding negligent practices can actually result in an increase of health care costs.

Because no reliable studies have been done to estimate the cost of so-called defensive medicine, the Office of Technology Assessment has been asked to study the issue and is expected to complete its study before 1994.

HAVE TORT PROPOSALS, WHEN ENACTED, LOWERED OVERALL HEALTH CARE COSTS?

It is often asserted that caps on noneconomic damages and elimination of the collateral source rule result in lower health care costs for everyone. In general, these types of proposals have been enacted only within the last ten years. Insufficient time has elapsed, and insufficient data has been gathered to enable us to be certain of the impact on costs of these proposals. However, from our research and study it appears that these proposals have not had any measurable impact on overall health costs. In looking into the issue we found that personal health care spending per capita approximately doubled throughout the United States from 1982 to 1990 regardless of whether a state had enacted "tort reforms" and regardless of the type of "reforms" enacted. We developed a chart (attached as Appendix A) showing the percentage of increase from 1982 to 1990 in personal health care spending per capita by state. It is derived from a February 1992 report entitled "Health Care Spending - Nonpolicy Factors Account for Most State Differences," published by the General Accounting Office (GAO). The GAO report

utilized 1982 data compiled by the Health Care Financing Administration (HCFA) and 1990 estimates from Lewin/ICF.

As the chart demonstrates, personal health care costs approximately doubled from 1982 to 1990 regardless of whether a state had enacted tort "reforms" and regardless of the type of "reforms" enacted.

For example, based on the figures utilized in the GAO report, the three states with percentage increases estimated to be slightly lower than average -- Arkansas, Kentucky and Mississippi -- had no caps on damages in medical malpractice cases. Alabama, with a slightly higher than average estimated percentage increase, had a cap on damages. Massachusetts and California, the two states with the highest estimated personal health care costs per capita, had in place a cap on damages.

Our findings are consistent with other studies. For example, in March 1993, the Coalition for Consumer Rights published False Claims: The Relationship Between Medical Malpractice "Reforms" and Health Care Costs. This study found there to be "no indication that enacting major tort 'reforms' is positively correlated with lower health care costs." In fact, the study found that "states with the lowest per capita expenditures are more likely to have enacted fewer tort 'reforms' overall than the average."[9] Regarding caps on damages, the Coalition's study concluded as follows:

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9 Andrea Dubin, False Claims: The Relationship Between Medical Malpractice "Reforms" and Health Care Costs, prepared for the Coalition for Consumer Rights, March 1993, at Page 2.

Since the medical establishment has made caps on damages its single highest priority, we would expect to see some correlation between states which have limits on recovery and inexpensive health care. However, only 30% of the ten states spending the least in health care have enacted limits on recovery of damages; 55% of the remaining 40 states have such a statute. A closer examination of the states ranked by spending shows that there is no correlation between the least expensive states and limits on damages.

Our findings are consistent with previous research we have conducted on the "health care savings" of caps. Indiana has one of the most restrictive caps laws in the nation, and yet a 1992 survey of hospital bed costs and delivery charges in comparable cities in Illinois and Indiana revealed that the small variance in fees could not be attributed to lower medical malpractice costs coming from caps on awards.

A recent study funded by the Texas Medical Association, the Texas Trial Lawyers Association and the Texas Hospital Association reported that its findings indicated that "changing the medical professional liability system will have minimal cost savings impact on the overall health care delivery system in Texas.[10]

The cost of medical malpractice insurance, for the most part, reflects the cost of the medical-legal system. In contrast to the increase in health care costs, medical malpractice costs decreased in recent years.[11] The number of medical malpractice claims peaked in 1985, and has continued to

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10 "Medical and Hospital Professional Liability," a report prepared for the Texas Health Policy Task Force by Tomm and Associates, July 1992.

11 1989 Profitability Study (By Line By State), 1990 Profitability Study (By Line By State), and 1991 Profitability Study (By Line By State), National Association of Insurance Commissioners, 1990, 1991 and 1992.

decline according to the most current figures available. From 1985 to 1990, the overall rate declined at an average annual rate of 8.9 per cent.[12]

WHAT ARE THE CONSEQUENCES TO THE PUBLIC OF PROPOSALS TO CAP NONECONOMIC DAMAGES OR ELIMINATE THE COLLATERAL SOURCE RULE IN MEDICAL MALPRACTICE CASES?

Proposals of this type have adversely affected the public. Elimination of the collateral source rule solely favors medical professionals by passing on the cost of the medical injury to another health care provider. Often, an insured person has the benefit of health or disability insurance which pays for a portion of the additional medical or other costs attributable to the injuries caused by a physician's negligence. Typically, the insurer will assert a lien against its insured's recovery or pursue a subrogation claim. Under proposals to eliminate the collateral source rule, the negligent physician would get a credit for the insurer's payment, and the insurer could not recover its payments from the person who injured its insured. An obvious consequence of the loss of lien and subrogation rights by a health or disability insurer will be an increase in those premiums. Where government proposals provide such insurance, government health care costs would increase. The net result is no reduction in health care costs but a windfall benefit to the defendant medical professional and his or her insurer at the expense of the injured person.

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12 Martin L. Gonzalez "Medical Professional Claims and Premiums 1985-1990," Socioeconomic Characteristics of Medical Practice 1992, page 23.

Proposals to limit noneconomic damages deprive individuals of compensation for the consequences of medical malpractice injuries. No one has stated that such injuries are not real or severe. In fact, noneconomic injuries may far exceed the economic damages. These proposals, if enacted, would make seriously injured persons who are the least able to afford it receive less than full compensation and thus help subsidize recoveries for less seriously injured persons who would be fully compensated. This would be grossly unjust and doubly so since doing so would not appreciably affect the cost of health care.

A bottom line is whether the economic benefits to the public in reducing health care cost is significant enough to warrant depriving other members of the public -- injured persons -- of full and adequate compensation from those responsible for their injuries. With the cost of the entire medical-legal system constituting less than one percent of health care costs, a pertinent inquiry is whether such proposals would have any noticeable impact except upon injured persons.

Such proposals would not eliminate the less than one percent of health care costs attributable to medical professional liability since no one seriously urges that the medical profession should be immune from liability. Rather, such proposals are directed at those injured persons who are ultimately compensated. These victims of medical negligence are the subject of such proposals. Any savings in the cost of health care would be a small fraction of a percent. Thus, even on an economic analysis, such proposals, if implemented, will

not have a measurable impact upon the cost of health care. Such proposals, however, would impact severely and dramatically upon the persons who are victims of medical malpractice.

It should be noted that in some states, even when the number and severity of malpractice claims and the total amount paid out decreased, medical malpractice insurance premium continued to escalate. A February 1989 report of the Department of Commerce of the State of Minnesota reviewed all claims filed with two insurers in Minnesota, North Dakota and South Dakota against physicians from January 1, 1982, through December 31, 1987. Among its conclusions are the following:

* With the exception of self-insured groups, the St. Paul Companies and Minnesota Medical Insurance Exchange insure nearly 100 percent of Minnesota's physicians. This report represents the only known comprehensive study of physician loss experience for any jurisdiction over the time period of the study.

* The frequency of claims per year did not materially change over the time period of the study.

* The severity of the claims payment did not materially change over the time period of the study.

* Claims determined by the insurer to be frivolous did not increase over the time period of the study.

* The likelihood of receiving compensation as a result of filing a malpractice claim was approximately 25 percent. The rate did not materially change over the time period of the study.

* No punitive damages were awarded against a physician.

* The average cost of investigating and defending a claim changed little over the time period of the study. Indeed, the amount appeared to be decreasing.

* **Despite unchanging claims frequency and declining loss payments and loss expenses, physicians, on average, paid approximately triple the amount of premiums for malpractice insurance in 1987 than in 1982.**

It is interesting to note, as well, that for the three states studied, Minnesota, North Dakota and South Dakota -- personal health care costs approximately doubled from 1982 to 1990, as they did for the rest of the nation. (See Appendix A.)

In addition to the impact on the individuals harmed by medical malpractice, it should also be noted that there is a serious question as to whether this type of proposal would be legally enforceable if enacted as part of a national health care proposal. There is some experience at the state level with legislative proposals to place caps on damages. Although there are variations in the legislation that has been enacted at the state level, some states have held that various types of proposals to cap damages violate various provisions of their constitutions.[12]

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[12] See Florida (Smith v. Department of Insurance, 507 So.2d 1080 (Fla.1987)); Illinois (Wright v. Central Du Page Hospital Association, 63 Ill.2d 313, 347 N.E.2d 736 (1976)); New Hampshire (Carson v. Maurer, 120 N.H. 925, 424 A.2d 825 (1980)); North Dakota (Arneson v. Olson, 270 N.W.2d 125 (N.D.1978)); Ohio (Morris v. Savoy, 61 Ohio St.3d 576 N.E.2d 765 (1991)); Alabama (Moore v. Mobile Infirmary Association, 592 So. 2d. 156 (1991)); Washington (Sofie v. Firebrand Corp., 771 p.2d 711. (1989)).

WHAT ARE THE CONSEQUENCES TO THE PUBLIC OF PROPOSALS TO UTILIZE MEDICAL PRACTICE GUIDELINES WITHIN THE TORT LIABILITY SYSTEM?

Because only a few jurisdictions have experimented with tort proposals that incorporate guidelines, there is insufficient experience to determine at this time the impact on the public of such proposals. Medical practice guidelines, in theory, should help to clarify what the standard of care should be in a particular case. The characteristics of such guidelines, however, are such that their potential for widespread use is limited since there are relatively few medical situations for which guidelines could realistically be adopted. The ABA Special Committee on Medical Professional Liability believes that, if used, guidelines should be handled like other evidence on the standard of care is handled. In other words, they should be offered into evidence for such weight as the trier of fact may give them, in much the same way as the testimony of expert witnesses is offered in evidence. This is because:

1) Guidelines are developed by numerous entities such as hospitals or other health providers, federal or state governmental agencies, insurers, and medical associations. Sometimes, the guidelines of one entity conflict with those of another entity.

2) Standards for medical care for purposes of guidelines are not constant. They change as medical knowledge grows and expands. To keep up with these changes would mean constantly defining and redefining medical practice guidelines. However, doctors and hospitals do need to be held accountable for recognizing when guidelines are out-of-date, and should also be expected to continue to stay on top of medical literature just as they would without guidelines.

3) Guidelines, of necessity, are generally written with too much generality to be adopted as legal standards.

The ABA's House of Delegates or Board of Governors has not considered the issue of or adopted policy on the use of medical practice guidelines.

WHAT ARE THE CONSEQUENCES TO THE PUBLIC OF THE INCREASED USE OF ADR?

The use of voluntary alternative dispute resolution techniques is consistent with the relevant policy considerations of alleviating an overburdened judicial system. Besides relieving court congestion and speeding up the conclusion of cases, alternative dispute resolution procedures are often less expensive and less stressful than seeing a case through its normal trial path in court.

Expanding the use of voluntary ADR options in the medical malpractice context could have positive consequences for the public. A complete discussion of the appropriate use of ADR in the medical malpractice context can be found in our White Paper entitled "Dispute Resolution and Health Care."

DOES THE USE OF JURIES PRESENT PROBLEMS IN MEDICAL MALPRACTICE LITIGATION?

A recent study of medical malpractice cases suggests that unjustified awards to plaintiffs are probably uncommon. In cases in which "physician care was deemed to meet community standards," the physician typically won. The study found that "[t]he defensibility of the case and not the severity of patient injury predominantly influences whether payment is made. Even in cases that require a jury verdict, the severity of the

patient injury has little effect on whether any payment is made." The study is based on 8,231 New Jersey medical malpractice cases from 1977 to 1992.[13]

Empirical research done on medical malpractice juries leads to the conclusion that there is no support for claims that medical malpractice juries are biased against defendants or unjustifiably generous in determining awards.[14]

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13 Mark I. Taragin et al, "The Influence of Standard of Care and Severity of Injury on the Resolution of Medical Malpractice Claims," Annals of Internal Medicine, November 1992; Vol.117, No. 9, page 780.

14 Neil Vidmar, "The Unfair Criticism of Medical Malpractice Juries," Judicature, October-November 1992, Vol.76, No.3., page 118.

Appendix A.

Percentage of Increase from 1982 to 1990 in Personal Health Care Costs Per Capita, State by State

*1982 RANKING/STATE**		*1982 HCFA data**	*1990 LEWIN/ICF Estimates**	*% of INCREASE***
1	Massachusetts	$1,508	$3,031	101
2	California	1,451	2,894	99
3	New York	1,417	2,818	99
4	Nevada	1,380	2,757	100
5	Rhode Island	1,351	2,707	100
6	Connecticut	1,348	2,699	100
7	North Dakota	1,325	2,661	101
8	Illinois	1,308	2,619	100
9	Missouri	1,285	2,568	100
10	Michigan	1,281	2,569	101
11	Pennsylvania	1,273	2,536	99
12	Kansas	1,271	2,548	100
13	Ohio	1,247	2,493	100
14	Maryland	1,232	2,436	98
15	Minnesota	1,229	2,480	102
16	Hawaii	1,228	2,469	101
17	Florida	1,228	2,427	98

1982 RANKING/STATE*		1982 HCFA data*	1990 LEWIN/ICF Estimates*	% of INCREASE**
18	Wisconsin	1,219	2,449	101
19	Nebraska	1,216	2,452	102
20	Colorado	1,209	2,415	100
21	Alaska	1,187	2,367	99
22	Iowa	1,176	2,351	100
23	Washington	1,165	2,311	98
24	Oregon	1,165	2,312	98
25	South Dakota	1,154	2,322	101
26	Delaware	1,153	2,268	97
27	Tennessee	1,144	2,262	98
28	New Jersey	1,115	2,224	99
29	Arizona	1,112	2,211	99
30	Texas	1,110	2,192	97
31	Louisiana	1,106	2,185	98
32	Indiana	1,101	2,201	100
33	Maine	1,091	2,175	99
34	Oklahoma	1,086	2,139	97
35	West Virginia	1,057	2,088	98

1982 RANKING	STATE*	1982 HCFA data*	1990 LEWIN/ICF Estimates*	% of INCREASE**
36	Virginia	1,054	2,076	97
37	Georgia	1,048	2,072	98
38	Montana	1,036	2,059	99
39	Alabama	1,033	2,286	121
40	Arkansas	994	1,944	96
41	New Hampshire	986	1,981	101
42	Vermont	978	1,956	100
43	Kentucky	957	1,875	96
44	North Carolina	931	1,833	97
45	New Mexico	904	1,792	98
46	Mississippi	897	1,751	95
47	Utah	896	1,784	99
48	Wyoming	873	1,756	101
49	Idaho	868	1,726	99
50	South Carolina	857	1,689	97
	U.S. Average	1,220	2,425	99

* *This data was obtained from a February 1992 GAO report entitled "Health Care Spending - Nonpolicy Factors Account for Most State Differences." Note that the Lewin/ICF estimates are not directly comparable with the HCFA data because the Lewin/ICF estimates also include administrative costs for private insurance which are excluded from HCFA's data on personal health care expenditures. GAO reported that it conducted its review "in accordance with generally accepted government auditing standards." HCFA estimates that 1990 U.S. personal health expenditures per capita averaged $2,255.*

** *Rounded off to the nearest whole number.*

AMERICAN BAR ASSOCIATION
WORKING GROUP
ON
HEALTH CARE REFORM

ISSUES RELATING TO AIDS AND HEALTH CARE REFORM

Discussion Draft
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The views expressed in this draft White Paper are solely those of the authors, one of whom is a member and the other a staff employee of the ABA AIDS Coordinating Committee, and do not necessarily represent the views of the Committee. This report has not been reviewed or approved by the Committee, or by the House of Delegates or the Board of Governors of the American Bar Association. Viewpoints expressed herein are those of the authors and do not necessarily represent the official position or policies of the American Bar Association, unless expressly stated.

William A. Bradford, Jr., Vice-Chair
Michele A. Zavos, Project Director
ABA AIDS Coordinating Committee

Douglas M. Jarrell, Student
University of North Carolina School of Law
Sheryl R. Miller, Student
Catholic University, Columbus School of Law

July 1993

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I. INTRODUCTION

The spread of HIV infection, as well as its changing epidemiological nature, highlight a variety of legal issues associated with providing access to health care for people with this disease. This paper is a survey of some of these issues. It begins with an analysis of the demographic trends among HIV-infected persons and persons with AIDS (PWAs). Next, the paper discusses the issues arising from the impediments such persons confront in obtaining access to health care, including an analysis of protections afforded by the recently-enacted Americans with Disabilities Act. The paper then examines the issues of access to health care in the context of private insurance coverage and self-insured employers. Finally, the paper analyzes the problem of uninsured HIV-infected persons and the resultant burden on Medicaid and public financing.

This paper is prepared by the AIDS Coordinating Committee of the American Bar Association, which was formed in 1987 and has among its members representatives of various relevant sections of the ABA as well as analogous organizations such as the National Bar Association and the New York State Bar Association. The AIDS Coordinating Committee drafted and co-sponsored the wide-ranging ABA Policy on AIDS, which was adopted by the House of Delegates in August 1989. This ABA Policy on AIDS will be noted, where relevant, throughout this paper.

Human Immunodeficiency Virus (HIV), the cause of Acquired Immunodeficiency Disease (AIDS), attacks the body's immune system and leaves

the host susceptible to a variety of cancers and infections.[1] AIDS is the term adopted by the Centers for Disease Control and Prevention (CDC) for the condition that occurs in the latter part of HIV disease when the immune system is the most damaged.[2] It is estimated that it takes about ten years for HIV infection to develop into full-blown AIDS.[3] Generally, PWAs will live approximately two years after the diagnosis of full-blown AIDS.[4]

The CDC is responsible in this country for defining what diseases constitute AIDS. Before 1993, an AIDS diagnosis was given to anyone who had one of twenty diseases included in the CDC definition.[5] In 1993, the CDC expanded its AIDS definition to include any HIV-infected person with severe immunosuppression.[6] In addition, the CDC added pulmonary tuberculosis, recurrent pneumonia, and invasive cervical cancer to its list of diseases.[7] The definition was revised and expanded after criticism that it was based on the medical condition of homosexual

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1 MICHAEL T. ISBELL, LAMBDA LEGAL DEFENSE AND EDUC. FUND, INC., HEALTH CARE REFORM: LESSONS FROM THE HIV EPIDEMIC 41 (1993) [hereinafter HEALTH CARE REFORM] (citations omitted).

2 Id. (citations omitted).

3 Id. at 42.

4 Id.

5 Id.

6 Severe immunosuppression is defined as a CD4+ lymphocyte count of less than 200/mm(3) or a CD4+ percent of total lymphocyte count of less than 200/mm(3) or a CDC4+ percent of total lymphocytes less than fourteen when it is not possible to get an absolute count. See Michele Zavos, Legal Considerations for Women with HIV, in UNTIL THE CURE: CAREGIVING FOR WOMEN AND HIV (Ann Kurth ed., forthcoming Oct. 1993)[hereinafter Zavos, Women with HIV].

7 Id.

men and did not include the experience of women, drug users, people of color, and poor people. [8]

By the end of 1992, more than 170,000 Americans had died of AIDS. [9] In the early 1980's, over three-fourths of reported AIDS cases were from six cities, but by 1991, thirty-one metropolitan areas and twenty-five states reported over a thousand AIDS cases. [10] In the early years of the epidemic in the United States, homosexual men comprised almost sixty percent of reported AIDS cases, with injection drug users making up the second largest group. [11] Drug users and their partners, and women in particular, however, have become the significant demographic groups affected by AIDS in the 1990s. [12] Poor people with no health insurance coverage are more likely to contract AIDS than insured, economically-stable persons, [13] although no population group is insusceptible to AIDS and HIV. African-American and Hispanics are also disproportionately represented.[14] The

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8 HEALTH CARE REFORM, supra, note 1, at 51 (citing Anastos & Marte, Women --the Missing Persons in the AIDS Epidemic, THE AIDS READER 190 (1990)).

9 CENTERS FOR DISEASE CONTROL, HIV/AIDS SURVEILLANCE, YEAR-END EDITION, Feb. 1993, tbl. 13.

10 REPORT OF THE NAT'L. COMM'N ON ACQUIRED IMMUNE DEFICIENCY SYNDROME, AMERICA LIVING WITH AIDS (1991) 11 [hereinafter 1991 NAT'L COMM'N REP.].

11 HEALTH CARE REFORM, supra note 1, at 47. (citations omitted). Blood transfusions were also responsible for many cases during the early 1980s. Id. at 48.

12 Id. (citations omitted).

13 Id. at 49.

14 African-Americans and Hispanics comprise 41 percent of AIDS cases generally, and over 75 percent among children. Health Benefits: How the System is Responding to AIDS, 22 CLEARINGHOUSE REV., 724, 725 (1988) [hereinafter CLEARINGHOUSE REV.].

disease is similarly becoming increasingly associated with the inner city and the impoverished. [15] Even these figures are deceiving; CDC estimates that reported AIDS cases consist of only ten to fifteen percent of the actual number [16] and do not include those individuals who have died of HIV-related conditions that do not meet the CDC definition of AIDS.

II. EMERGING EPIDEMIOLOGICAL TRENDS

The demographics of the AIDS epidemic have undergone substantial changes in recent years. [17] What was once considered a disease primarily affecting homosexual males [18] has now become an epidemic among the heterosexual population, particularly impacting women and people of color who reside in impoverished, urban areas. [19] Rather than being evenly distributed throughout the population, the AIDS epidemic has generally manifested itself in distinct population groups, comprised of individuals lacking access to health care and other resources. [20] As these specific populations become disproportionately affected by

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15 See 1991 NAT'L COMM'N REP., supra note 10, at 13-14.

16 Id. ("CDC estimates that, at present, approximately one adult male in 100 in the United States is HIV positive and one adult female in 600 is similarly infected.")

17 See HEALTH CARE REFORM, supra note 1, at 48.

18 Id.

19 PANEL ON MONITORING THE SOCIAL IMPACT OF THE AIDS EPIDEMIC, NAT'L RESEARCH COUNCIL, THE SOCIAL IMPACT OF AIDS IN THE UNITED STATES 7 (Albert R. Jonsen & Jeff Stryker eds., 1993).

20 Id. at 7-9.

AIDS and HIV infection, epidemiologists have observed a gradual decline in AIDS among male homosexuals. [21]

The shift in demographics of the AIDS/HIV epidemic partially resulted from the initiation of AIDS educational programs within the homosexual community in the 1980s, while minimal programs existed for the localities and population groups currently experiencing a dramatic upsurge in AIDS cases.[22] Thus, to reflect the shifting demographics of PWAs, the United States health care reform package should contain educational and treatment programs designed specifically for the concentrated populations heavily affected by AIDS and HIV. [23]

A. The Disproportionate Impact of AIDS on the Disenfranchised

Persons of low socio-economic status, residing in urban areas, comprise the population group experiencing the most rapid increase in reported HIV and AIDS cases. [24] These diseases are concentrated in isolated, low-income, inner-city communities, consisting of the homeless, jobless and injection drug users. [25]

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21 HEALTH CARE REFORM, supra note 1 at 48 (citations omitted).

22 Nan D. Hunter, Complications of Gender: Women and HIV Disease, in AIDS AGENDA: EMERGING ISSUES IN CIVIL RIGHTS (Nan D. Hunter & William B. Rubenstein eds., 1992).

23 American Bar Association, Policy and Report on AIDS, 21 U. Tol. L. Rev. 9 (1989), reprinted in AMERICAN BAR ASSOCIATION, POLICY AND REPORT ON AIDS 18, § 0.1 (1990) [hereinafter ABA POLICY & REPORT ON AIDS] "Accurate, effective education of the public regarding HIV, consistent with generally accepted public health recommendations, should be supported by public and private entities as essential to any informed response to legal issues arising from the HIV epidemic." Id. "Public and private entities should expeditiously develop and implement HIV-related programs targeted to serve minority communities." Id. § D.4, at 12.

24 See PANEL ON MONITORING THE SOCIAL IMPACT OF THE AIDS EPIDEMIC, supra note 19, at 7-8, 243-44.

25 Id. at 243.

The results of a case study on the shifting demographics of HIV and AIDS in New York City illustrate the recent population changes experienced in metropolitan areas throughout the country. [26] The study confirmed that the number of HIV-positive individuals and PWAs in the impoverished, urban areas far exceeded the number of such persons in more affluent suburban areas. The 1992 study revealed that ninety-five percent of New York City's PWAs resided in the inner-city boroughs, while the remaining five percent inhabited the four suburban counties surrounding the city. [27]

In March of 1992, the Centers for Disease Control reported that New York City contained 37,952 AIDS cases, as compared with 26,336 cases in December of 1989. [28] The study concluded that the reason for the disproportionate number of HIV/AIDS in low income, urban areas is the existence of certain kinds of "social interactions" in these communities, such as injection drug use, high-risk sexual activity, joblessness, homelessness, limited access to health care and overcrowding. [29] Educational and treatment programs are needed to lessen HIV transmission in low income urban communities. [30] The American Bar Association

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26 Id. at 243-44. The Panel indicated that the changing demographics observed in the New York study are representative of that in other urban communities. Id. at 243. The Panel concluded that "the New York City study, as it stands, offers a vivid portrait of the epidemic." Id.

27 Id.

28 Id. at 246. However, the Panel characterized this figure as an "underestimation of the numbers of actual AIDS cases," due to reporting problems, such as "lags" and "undercounting." Id.

29 Id.

30 Id.; see ABA POLICY & REPORT ON AIDS, supra note 23, § 0.1, at 18.

has recommended the development of distinct programs designed to confront the problem of widespread HIV transmission among drug abusers.[31]

Low-income persons with HIV or AIDS encounter great difficulty in obtaining access to health care. Such persons either are impoverished prior to the onset of their HIV infection or become poverty-stricken as a result their illness, which causes them to expend their resources to finance their treatment and care. [32] Moreover, once an individual with HIV diseases enters the phase of "full-blown" AIDS, he or she generally becomes unable to remain gainfully employed, which may cause the individual to become impoverished and either entirely uninsured, or reliant on Medicaid if the PWA has CDC-defined AIDS. [33] However, the current Medicaid system provides only minimal coverage for PWAs; therefore even where a PWA qualifies for Medicaid, the individual's access to health care remains limited. [34]

In addition to the barriers to treatment confronted by low income PWAs, many are not even diagnosed as HIV-positive until the disease has progressed to such an acute stage that death is imminent. [35] Their limited economic means

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31 ABA POLICY & REPORT ON AIDS, supra note 23, § M.1, at 17-18. "States and localities should address the HIV epidemic among drug abusers and their partners as a significant public health and medical interventions. Id.

32 Daniel Shacknai, Wealth=Health: The Public Financing of AIDS Care, in AIDS AGENDA: EMERGING ISSUES IN CIVIL RIGHTS, supra note 22, at 182.

33 Id. To become eligible for Medicaid, a person must meet a threshold poverty level and must be deemed "disabled" under the Social Security Administration's definition. A person with CDC-defined AIDS is considered presumptively disabled, and therefore entitled to Medicaid, subject to later consideration; see infra Part V, § B (delineating the general requirements for Medicaid coverage).

34 See id.

35 Shacknai, supra note 32, at 185.

prevent them from developing an ongoing relationship with a physician; many receive little, if any, preventive care. Often, their only encounter with a medical provider is in the emergency room of a public hospital. [36]

Even when impoverished persons receive treatment at public hospitals, they are unlikely to receive an HIV test due to the costs associated with such tests. [37] Some state Medicaid programs fail to reimburse providers altogether for such tests. [38] In 1988, the average cost of treating an AIDS in-patient was $630 per day, while, for example, in the Southern states hospitals on average received only $282 per day in Medicaid reimbursement, and the remainder of the facilities in the United States recovered $500 per day. [39]

Low income persons who receive an AIDS diagnosis and become eligible for Medicaid confront another significant obstacle to medical treatment. Under the combined federal and state Medicaid program, only ten states permit Medicaid reimbursement for alternative care treatments, such as out-patient care, hospice care and community-based health care. [40] The remainder of the states' Medicaid

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36 See HEALTH CARE REFORM, supra note 1, at 10.

37 See id.

38 See Shacknai, supra note 32, at 190-91; Daniel M. Fox & Emily H. Thomas, The Cost of AIDS: Exaggeration, Entitlement, and Economics, in AIDS AND THE HEALTH CARE SYSTEM 213 (Lawrence O. Gostin ed., 1990).

39 Shacknai, supra note 32, at 190 (citing REPORT OF THE PRESIDENTIAL COMMISSION ON IMMUNODEFICIENCY VIRUS EPIDEMIC 143 (1988)). Medicaid provides only $8.00 in reimbursement for each outpatient treatment provided by New York City hospitals, although the treatment costs the hospitals approximately $80.00 per visit. Id. (citations omitted).

40 Id. (citations omitted).

programs only cover in-patient care. [41] However, even in the ten states that permit such reimbursement, obtaining Medicaid for alternative care can be an arduous task; Medicaid recipients desiring alternative care must comply with complicated and time-consuming state waiver procedures before becoming eligible for such treatments. [42]

The foregoing problem has been exacerbated in recent years by the current trend in health care treatment for PWAs away from in-patient care, and toward alternative forms of care that are less costly and often more efficient than in-patient care. [43] Thus, in the majority of the states, Medicaid recipients are completely barred from alternative treatment programs since most state Medicaid programs do not cover these programs. [44] To treat effectively low income people with AIDS, state governments should permit Medicaid reimbursements for less costly, alternative treatments. [45]

B. Disenfranchised Women: The Newest At-Risk Population

During the 1980's men comprised approximately nine out of ten PWAs. [46] According to the National Institute of Health's 1992 report, women, who comprise

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41 See id. (citations omitted).

42 ABA POLICY & REPORT ON AIDS, supra note 23, at 54.

43 See Shacknai, supra note 32, at 190 (citations omitted).

44 See id.

45 See ABA POLICY & REPORT ON AIDS, supra note 23, § D.3, at 12. The ABA adopted the following policy concerning alternative forms of treatment for Medicaid recipients, "Government programs that cover HIV-related health care should incorporate flexible mechanisms for payment, including expediting the Medicaid waiver review process, to allow more treatment alternatives for HIV." Id.

46 HEALTH CARE REFORM, supra note 1, at 48.

51.3 percent of the total population, accounted for 11.4 percent of newly reported AIDS cases, while men who make up 48.7 percent of the population comprised 88.6 percent. [47] However, women presently represent the group most at risk of acquiring HIV. [48] In 1993, women comprised nearly 26,000 of the nation's approximately 240,000 AIDS cases. [49] Most women with HIV contracted the infection by injection drug use or through sexual contact with an HIV-positive man who usually contracted HIV by injection drug use. [50] During heterosexual contact in which one party is HIV positive, women are twenty-times more likely than men to contract HIV. [51] Epidemiologists estimate that 75,000 women will be diagnosed with AIDS by 1995, [52] and that by 1994 in New York State, more women than homosexual men will be diagnosed with AIDS. [53] Worldwide, experts predict that, by the year 2000, the number of women with AIDS will be equivalent to the number of male cases. [54] In Africa, the majority of HIV-infected persons contracted the disease through heterosexual contact. [55]

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47 NAT'L COMM'N ON AIDS, THE CHALLENGE OF HIV/AIDS IN COMMUNITIES OF COLOR 19 (1992) (citations omitted).

48 HEALTH CARE REFORM, supra note 1, at 48 (citations omitted).

49 Id.

50 See id.; see Zavos, Women with HIV, supra note 6.

51 HEALTH CARE REFORM, supra note 1, at 48 (citations omitted).

52 Id. (citations omitted).

53 Hunter, supra note 22, at 5.

54 Id.

55 See Wayne R. Cohen, An Economic Analysis of the Issues Surrounding Aids in the Workplace: In the Long Run, the Path of Truth and Reason Cannot be Diverted, 41 AM. U. L. REV. 1199, 1206 n.46 (1992)(citations omitted).

Women are more likely than men to not be diagnosed with HIV or AIDS until their illness has progressed to an acute stage. Medical providers are less likely to diagnose women with HIV because they do not generally consider women likely to be HIV infected. [56] Studies show that physicians often misdiagnose their women patients' gynecological symptoms as mere isolated conditions, even though gynecological infections may be the most frequent initial symptom of HIV in women. [57] Another rationale for physicians' failure to diagnose women as HIV infected is that a severe deficit in medical research exists regarding women and HIV/AIDS. [58] This research deficiency helps explain why some medical practitioners misdiagnose HIV-infected women; they may lack the requisite medical knowledge to recognize the symptoms associated with these diseases. [59]

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56 Hunter, supra note 22, at 10. "Misdiagnosis of women . . . has occurred because of the perception that HIV is a male disease has been widespread among health care providers . . . " Id. "Delay in an accurate diagnosis leads to delay in treatment and missed opportunities for medical intervention early enough in the course of the disease to significantly prolong life." Id.

57 Id. at 10 (citing Safrin & Dattel, et al., Seroprevalence and Epidemiologic Correlates of Human Immunodeficiency Virus Infection in Women with Acute Pelvic Inflammatory Disease, 75 OBSTETRICS & GYNECOLOGY 666 (1990)).

58 Id.

59 Id. at 14-15. Women's groups advocate for increased testing of women with HIV; see Zavos, Women with HIV, supra note 6, at 9. In 1992, Congresswoman Morella (D-Md.) introduced two bills, "Women and AIDS Research Initiative" (H.R. 1073) and "Women and AIDS Outreach and Prevention Act" (H.R. 1072), to authorize additional spending for research regarding women and AIDS and specifically earmark federal funds for educational programs for women, respectively. Id. Although both bills were referred to committee, neither became law. To date, no member of the 103rd Congress has reintroduced either bill. Telephone Interview with Legislative Dep't, United States House of Representatives (June 7, 1993).

Even where physicians correctly diagnose gynecological symptoms as initial manifestations of HIV, women confront the additional impediment that even the CDC's most recent AIDS definition excludes many gynecological manifestations. [60] Thus, low income women who experience gynecological conditions as indications of AIDS are generally ineligible for Supplemental Security Income (SSI), which, in turn, normally prohibits them from receiving Medicaid. [61]

Despite the absence of gynecological symptoms from the AIDS definition, the CDC revised its definition in 1993 to include a new indicator that broadens the official designation to include persons with T-cell counts below 200 per cubic millimeters of blood. [62] This new indicator may help alleviate the difficulty HIV-infected women with gynecological conditions confronted in the past because many of these women possess T-cell counts below 200, which would bring them within the revised AIDS definition. [63]

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60 Hunter, supra note 22, at 10-11. Gynecological illnesses, such as chronic pelvic internal organ or body cavity abscesses, chronic genital ulcers and recurrent herpes have been excluded from CDC's enumeration of symptoms that warrant an official AIDS diagnosis. See Zavos, Women with HIV, supra note 6, at 7; supra Part I for discussion of CDC defined AIDS.

61 Hunter, supra note 22, at 10-11. Furthermore, a prerequisite for many AIDS treatment programs is that its members must first meet the CDC definition of AIDS. Id. Thus, this requirement renders women with gynecological manifestations ineligible for participation in such programs. Id.; see infra Part V for discussion of Medicaid coverage generally.

62 Id. at 11 (citations omitted). Zavos, Women with HIV, supra note 6, at 6. The CDC proposed this change in August of 1991, but it did not become effective until January 1, 1993. Id. at 5.

63 See Hunter, supra note 22, at 11. However, the new indicator does not entirely resolve this problem because a woman will only obtain a T-cell reading of 200 or below if her physician construes her gynecological symptoms as possible indicators of HIV infection, and recommends that she submit to an HIV test, a course of conduct frequently overlooked by medical providers. See id. (citations omitted).

[Footnote continued]

In addition to the problems associated with diagnosis delays, some attribute the growing population of women with AIDS/HIV to the fact that a disproportionate number of such women are of color and reside in impoverished urban areas that lack access to health care. [64] In 1990, African-American women comprised 52.1 percent of women with AIDS in New York, and 29.8 percent of AIDS cases in that State were Hispanic women. [65]

Another important explanation for the growing population of women with AIDS stems from the lack of state, local and private educational programs geared toward women at risk of contracting HIV. [66] Most educational programs and media portrayals focus almost exclusively on the risks to male homosexuals, without informing at risk populations of the widespread phenomenon of females with HIV infection and AIDS. [67]

[Footnote continued]

In addition, impoverished women, who lack access to health care, will not receive a CDC defined AIDS diagnosis. See id. at 12.

64 Hunter, supra note 22, at 6.

65 Id. Some recent studies attribute the rise in AIDS cases among women to the fact that more women are addicted to crack cocaine than men. See PANEL ON MONITORING THE SOCIAL IMPACT OF THE AIDS EPIDEMIC, supra note 19, at 271. Impoverished women addicts have been known to contract HIV while engaging in risky sexual behaviors in exchange for the illicit drug. Id.

66 See Hunter, supra note 22, at 6-7.

67 See id.; see ABA POLICY & REPORT ON AIDS, supra note 23, § 0.1, at 18. The lack of educational programs geared to women at risk of contracting HIV indicates the necessity for public and private entities to adhere to the American Bar Association's Policy of ensuring that "[a]ccurate, effective education of the public regarding HIV, consistent with generally accepted public health recommendations . . . be supported by public and private entities as essential to any informed response to legal issues arising from the HIV epidemic." Id.

Since most women with AIDS are low-income, single-parent mothers, the adverse impact that their inevitable incapacitation and death has on the lives of the orphaned children they leave behind presents serious challenges to the social infrastructure in the United States. [68] Low income persons are unlikely to possess a testamentary instrument specifying a guardian for their children upon their death; therefore the state must step in and assume responsibility for the minor children, either by placing the children with foster parents or finding an adoptive parent for the child. [69] Parentless children not only pose challenges to government entities charged with caring for them, but the orphaned children obviously endure emotional distress as a consequence of their permanent separation from their parent. [70] Furthermore, although the foster care system provides children with shelter and financial support, it is an imperfect system, shown to have deleterious effects on some participants. [71]

The foregoing problems are exacerbated by the fact that most of these children will be perpetually impoverished. To provide a caregiver for orphaned children upon their parents' death or incapacitation, some experts suggest the institution of legal methods, such as a "springing guardianship," that would take effect whenever the parent's disease rendered him/her unable to care for the child,

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68 See Elizabeth B. Cooper, HIV-Infected Parents and the Law: Issues of Custody, Visitation and Guardianship, in AIDS AGENDA: EMERGING ISSUES IN CIVIL RIGHTS, supra note 22, at 70, 86-88.

69 See id.

70 See id. at 88.

71 Id. at 78, 88. Children with a parent with AIDS often feel "stigmatized or shunned as the result of having a parent with HIV disease." Id. at 78. "[P]arents who have placed their children in foster care . . . may be confronted with myriad problems primarily involving the foster care agency's intrusion into and oversight of the family's situation." Id. at 88.

but would then reinstate custody to the natural parent if the parent's illness entered remission. [72] Under the "springing guardianship" system, ultimate custody would be placed in the guardian upon the parent's death. Thus, given the important issues confronting children with AIDS and HIV, the health care reform package should contain social programs designed to alleviate the stresses confronted by children with AIDS/HIV infected parents. [73]

C. The Disproportionate Impact of AIDS on People of Color

The AIDS epidemic has disproportionately affected people of color. [74] While twelve percent of the United States population are African-American, they comprise thirty percent of the nation's AIDS cases. [75] Furthermore, Hispanics comprise seventeen percent of PWAs, although they account for only nine percent of the population. [76] Of the nation's 242,146 reported AIDS cases in 1992, African-Americans and Hispanics accounted for 71,984 cases. [77] In 1989, the "age-adjusted HIV-related death rate" among African-American men was three times that of

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72 See id. at 92-94; Zavos, Women with HIV, supra note 6, at 18.

73 See ABA POLICY & REPORT ON AIDS, supra note 23, §§ K.3-K.4, at 16. "Foster care and adoption agencies should provide HIV-related services to children under their jurisdiction consistent with the goal of providing appropriate services in the least restrictive setting." Id. § K.3.

74 HEALTH CARE REFORM, supra note 1, at 49 (citations omitted).

75 Id. (citations omitted).

76 Id. (citations omitted).

77 NAT'L COMM'N ON AIDS, supra note 47, at 4 (citations omitted).

Caucasian males. [78] Persons of color, who reside in poverty and lack access to health care, account for most of the AIDS cases in this population group [79]

Studies attribute the prevalence of the AIDS epidemic in poor, minority communities to the lack of access to health care in such communities as well as to behavior and situational patterns (i.e., drug abuse, homelessness, joblessness, overcrowding) that are conducive to the transmission of the HIV infection and other ailments. [80] Thus, the health care reform package should include efforts to provide these minority communities with increased access to health care and educational programs geared to the special needs of these high risk populations. [81]

D. Tuberculosis and HIV Among the Impoverished: A Lethal Combination

The growing population of impoverished persons with Tuberculosis (TB) presents novel challenges to health care providers. Although the overall number of reported TB cases in the United States has remained constant in recent years, the rate of such cases in low income, impoverished communities has reached epidemic

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78 Id.

79 Id. at 8. "[L]ow income and poor health are strongly linked. . . . The association of poverty, underdeveloped community structures, and disease is well demonstrated by the impact of the HIV epidemic in communities of color." Id.; see HEALTH CARE REFORM, supra note 1, at 49.

80 See NAT'L COMM'N ON AIDS, supra note 47, at 8-14; HEALTH CARE REFORM, supra note 1, at 49.

81 ABA POLICY & REPORT ON AIDS, supra note 23, § D.4, at 12. The ABA policy directs that "[p]ublic and private entities should expeditiously develop and implement HIV-related programs targeted to serve minority communities." Id.

proportions. [82] For instance, in 1982 in New York City, 22 persons per every 100,000 were TB infected, while in 1991, that number had grown to 50 persons per every 100,000. [83]

Persons most susceptible of developing TB disease live in low-income, urban and overcrowded areas, in which widespread HIV infection and other ailments exist. [84] Within this population group, HIV-infected persons are the most likely to contract TB because HIV severely weakens their immune systems, thereby making them unable to extinguish the TB infection. [85] Unlike HIV, which can be transmitted only via the exchange of bodily fluids, TB can be readily transmitted by casual contact within certain populations. TB is most commonly transmitted when a TB-diseased person emits, by the act of coughing, "airborne droplets" that come in contact with another. [86] Persons possessing intact immune systems, however, are generally able to inactivate the TB organism. Persons with damaged immune systems, however, normally cannot terminate the infection; therefore,

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82 UNITED HOSP. FUND OF N.Y., THE TUBERCULOSIS REVIVAL: INDIVIDUAL RIGHTS AND SOCIETAL OBLIGATIONS IN A TIME OF AIDS 8-9 (1992).

83 Id. at 10.

84 Id. at 8-12.

85 Id. at 10. The TB infection, if not inactivated or encapsulated by one's immune system, develops into TB disease. Id. at 9; see also Edward P. Richards & Katharine C. Rathbun, Tuberculosis: An Introduction for Health Care Attorneys, 6 HEALTH LAW. 11 (1993) (describing that tuberculosis is "inextricably linked to HIV infection").

86 See UNITED HOSP. FUND OF N.Y., supra note 82, at 9.

after an incubation period, they develop full-fledged TB disease. [87] Generally, the appropriate drug regimen effectively cures a person with drug sensitive TB. [88]

The alarming issue surrounding the increasing incidence of TB stems from the emergence of a lethal strain of the disease, designated multi-drug resistant TB. [89] Multi-drug resistant TB occurs in two circumstances. First, TB may become drug-resistant when a person infected with drug sensitive TB fails to remain on drug therapy for the specified time period required for a cure. [90] When this occurs, the disease often recurs and subsequently becomes resistive to drug treatment. [91] Some reports suggest that impoverished persons are most likely to terminate their drug treatment before fully cured, thereby causing them to develop multi-drug resistant TB. [92] Second, multi-drug resistant TB develops in situations where a person with an impaired immune system acquires the drug-repellent strain of TB through exposure to a person with this hazardous form of TB. [93]

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87 Id.

88 Id. at 11-12.

89 See Richards & Rathbun, supra note 85, at 13; NAT'L LEADERSHIP COALITION ON AIDS, MANAGING TUBERCULOSIS AND HIV INFECTION IN TODAY'S GENERAL WORKPLACE 52 (1992); see also UNITED HOSP. FUND, supra note 82, at 11-12.

90 UNITED HOSP. FUND OF N.Y., supra note 82, at 11; NAT. LEADERSHIP COALITION ON AIDS, supra note 52, at 1.

91 UNITED HOSP. FUND OF N.Y., supra note 82, at 11-12.

92 See id. at 6. According to the Centers for Disease Control, 44 percent of persons in New York City who received prior treatment for TB later developed a form of drug-resistant TB, whereby they became insensitive to one or more drug treatments. Id. at 12. "Poor patient compliance, . . . is the consequence of an inadequate medical and social infrastructure in New York City." Id. (other citations omitted).

93 Id.

Hospitals themselves may spread rather than cure TB. A 1991 study of New York City's multi-drug resistant TB cases revealed that eighty-two percent of persons with multi-drug resistant TB contracted the disease in public hospitals. [94] Furthermore, the study reported that approximately eighty-five percent of those persons with multi-drug resistant TB were HIV positive. [95] Because drug resistant TB is highly contagious, some facilities deny admission to TB infected persons in order to prevent transmission of the disease to others. [96]

Given that multi-drug resistant TB resists drug therapy, thereby posing serious health risks, medical programs are needed to address this specific problem. The United Hospital Fund of New York advocates the creation of programs designed to ensure that persons with drug-sensitive TB comply with their prescribed drug therapy to prevent the development of drug-resistant TB. [97] Other experts advocate the development of a five-pronged tuberculosis control program to minimize the rapid influx of the disease among at-risk population groups in the United States. [98]

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94 Id. at 12. (citing Centers for Disease Control, Nosocomial Transmission of Multi-Drug Resistant Tuberculosis Among HIV-Infected Persons - Florida and New York, 1988-1991, 266 JAMA, 1483-85 (1991)).

95 Id. (citations omitted).

96 See, e.g., Mixon v. Grinker, 595 N.Y.S.2d 876, 879 (N.Y. Sup. Ct. 1993) (discussing in part homeless shelter's practice of denying admission to TB infected persons so as to prevent contagion among other residents). Upon denying admission to TB infected persons, the shelter would refer such persons to an appropriate hospital. Id.

97 UNITED HOSP. FUND OF N.Y., supra note 82, at 21, 23.

98 Richards & Rathbun, supra note 85, at 14. The authors enumerate the five components of an effective TB control program:

1) Diagnosis of disease in infected individuals;
2) Reporting of infected individuals to the health authorities;

[Footnote continued]

III. WITHHOLDING MEDICAL CARE AND CONFIDENTIALITY BREACHES: IMPEDIMENTS TO TREATMENT AND EARLY DETECTION

A. The Treatment Impediment

In addition to the obstacle people with AIDS and HIV face in obtaining a payor for medical services,[99] other impediments hinder PWAs' access to health care. Persons with AIDS and HIV-infection often confront the barrier of being denied treatment by health care providers. [100] Some health care providers refuse to treat HIV-infected individuals due to their concerns about contracting HIV, even

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[Footnote continued]

3) Tracing of contacts of infected individuals to identify other infected persons;
4) Treatment of infected persons; and
5) Isolation of infected persons who have active disease until they are no longer infectious.

Id.

99 See infra parts IV and V (discussing the difficulty persons with AIDS/HIV face in obtaining insurance).

100 HEALTH CARE REFORM, supra note 1, at 141. "[A] considerable number of physicians are refusing to treat persons with AIDS or HIV infection, or threatening to refuse." Id. (citations omitted); see also PANEL ON MONITORING THE SOCIAL IMPACT OF THE AIDS EPIDEMIC, supra note 19, at 74; Wendy E. Parmet, An Antidiscrimination Law: Necessary But Not Sufficient, in AIDS AND THE HEALTH CARE SYSTEM, supra note 38, at 85.

though the risk from providing health care to infected individuals is minimal. [101] Studies indicate that HIV-infected persons of color confront the greatest challenge in obtaining medical treatment. [102] As the number of reported AIDS cases continues to increase annually, the difficulties that HIV-infected individuals and PWAs face in securing health care has become more pronounced. [103]

According to a 1991 study, almost one-third of doctors in the United States believe that they should not be required to treat HIV or AIDS patients, [104] and fifty percent of the medical practitioners who participated in the study indicated that, if permitted, they would decline to provide medical care to infected patients. [105] Twenty-two percent of the 560 hospitals surveyed in a 1990 study reported at least one circumstance in which a medical provider denied treatment to a person with

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101 HEALTH CARE REFORM, supra note 1, at 143-44. "In reality, the provision of health care to a patient infected with HIV presents only a minimal risk of HIV transmission to the provider. Careful adherence to CDC's universal precautions protocol for infection control virtually eliminates this small risk." Id. at 144. The fact that misconceptions exist regarding the transmission of HIV/AIDS from patient to health care provider reinforces the need for additional public and private programs designed to educate health care workers about these medical conditions. See ABA POLICY & REPORT ON AIDS, supra note 23, § 0.1, at 18.

102 HEALTH CARE REFORM, supra note 1, at 141 (citations omitted).

103 Id.; see PANEL ON MONITORING THE SOCIAL IMPACT OF THE AIDS EPIDEMIC, supra note 19, at 12-13. The Panel expressed its concern that, in the wake of the AIDS epidemic, young doctors might become reluctant to specialize in internal medicine, and may elect to avoid practicing medicine in areas inhabited by large numbers of HIV infected persons. Id. at 12. The Panel acknowledged that a shortage of nurses exists in public hospitals, but remains uncertain as to whether the deficiency is the result of the increasing numbers of AIDS cases in the United States. Id.

104 HEALTH CARE REFORM, supra note 1, at 142 (citing Gerbert et al., Primary Care Physicians and AIDS: Attitudinal and Structural Barriers to Care, 266 JAMA 2837 (1991)).

105 Id. (citations omitted).

AIDS. [106] Moreover, other studies indicate that, upon disclosure that a patient has AIDS or HIV infection, some physicians refer such patients to other medical providers. [107]

B. Statutory Prohibitions Against the Denial of Treatment to HIV-Infected Individuals

Two federal statutes, Section 504 of the Rehabilitation Act of 1973, [108] and the recent Americans with Disabilities Act (ADA) [109], as well as many comparable state statutes, generally protect persons with AIDS and HIV from being denied access to health care. Guidelines promulgated by the American Medical Association, the American Bar Association and the National Commission on Acquired Immune Deficiency Syndrome state that physicians may not ethically withhold treatment from individuals based solely on their HIV status. [110]

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106 Id. (citations omitted).

107 Id.

108 The Rehabilitation Act of 1973, § 504, 29 U.S.C. § 794 (1988).

109 The Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101-12213 (Supp. III 1991).

110 PANEL ON MONITORING THE SOCIAL IMPACT OF THE AIDS EPIDEMIC, supra note 19, at 73 n.9 (citations omitted). In 1987, the American Medical Association adopted a policy in direct response to the AIDS epidemic which stated in pertinent part:

> A physician may not ethically refuse to treat a patient whose condition is within the physician's current realm of competence solely because the patient is seropositive . . . . Neither those who have the disease [AIDS] nor those who have been infected with the virus should be subjected to discrimination based on fear or prejudice least of all by members of the health care community.

Id. (quoting 1987 JAMA 1360 (1987)); see also HEALTH CARE REFORM, supra note 1 at 143; ABA POLICY & REPORT ON AIDS, supra note 23, § D.1, at 12. "Health Care

[Footnote continued]

Section 504 of the Rehabilitation Act provides in pertinent part: "No otherwise qualified individual with handicaps in the United States . . . shall solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance . . ." [111] The statute defines persons with "handicaps" as individuals whose "physical or mental impairment substantially limits one or more major life activities;" persons with a prior record of such impairment; and individuals who lack an impairment, yet are perceived by others as disabled. [112]

The statute defines an "otherwise qualified" individual as any individual who possesses the essential qualifications for the program even if "reasonable accommodation" is necessary, and does not present a "direct threat" to others. [113] If it is determined that a person poses a "direct threat" to others, the Act imposes the additional requirement that, prior to excluding such person, the program must

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[Footnote continued]

providers should not refuse to treat or limit treatment of an individual, because of the individual's actual or perceived HIV status." Id. "Public and private entities should take appropriate steps to ensure that people in minority communities receive equal access to HIV-related treatment, prevention and research programs." Id. § 1.2, at 15. "The [National] Commission [on Acquired Immune Deficiency Syndrome] believes that health care practitioners have an ethical responsibility to provide care to those with HIV disease." 1991 NAT'L COMM'N REP., supra note 10, at 50.

111 29 U.S.C. § 794.

112 Id. § 706(8)(B).

113 Id.

determine whether it can make reasonable accommodations to minimize the potential risks. [114]

Although neither the Rehabilitation Act nor the ADA explicitly covers persons with contagious diseases, the Supreme Court has interpreted the definition of "handicaps" to include such individuals. [115] In the influential Nassau County v. Arline decision,[116] that would later serve as the framework for the tests set forth in the ADA, the Court held that an elementary school teacher with a prior record of a contagious disease, tuberculosis, qualified as "handicapped" under Section 504 of the Rehabilitation Act. [117] The Court explained that an infectious disease "substantially limits one or more major life activities" of the infected individual, thereby constituting a "handicap" within the meaning of the Act. [118] Furthermore, the Arline Court articulated a four-pronged test for determining whether a person with disabilities is "otherwise qualified." [119]

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114 45 C.F.R. § 84.3(k)(1)(1992)(defining a "qualified handicapped person". . . [as] a handicapped person who, with reasonable accommodation, can perform the essential functions of the job in question.").

115 See infra note 122 and accompanying text.

116 480 U.S. 273 (1987).

117 Id. at 280-81.

118 Id.

119 Id. at 288. The four-part test comprises the following:

(a) the nature of the risk (how the disease is transmitted)
(b) the duration of the risk (how long is the carrier infectious)
(c) the severity of the risk (what is the potential harm to third parties)
(d) the probabilities the disease will be transmitted and will cause varying degrees of harm.

Id. (quoting Brief for Am. Med. Ass'n at 19).

Drawing from the principles enunciated in Arline, courts have held that Section 504 covers HIV-infected individuals. [120] In Glanz v. Vernick, [121] an HIV-positive patient brought suit against a doctor and a federally funded clinic, alleging that their refusal to provide him with ear surgery violated Section 504. [122] After holding that Section 504 applies to HIV-infected individuals, [123] the court remanded the matter to determine whether, under the Arline test, the plaintiff was "otherwise qualified" for surgery. [124]

Although Section 504 has afforded HIV-infected individuals protections from treatment exclusions, it provides only limited coverage. Section 504 covers only entities of the federal government, groups contracting with the federal government

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120 See, e.g., Doe v. Centinela Hospital, No. Civ.A.87-2514 PAR, 1988 WL 81776 (D. Cal. June 30, 1988) (holding that § 504's coverage extends to an HIV-infected individual who was denied admission to federally-funded rehabilitation program). The court remanded the matter to determine whether the plaintiff was "otherwise qualified" and whether the defendant-hospital's alternative program qualified as a "reasonable accommodation." Id. at 2044. See also Dallas Gay Alliance v. Dallas County Hospital District, 719 F. Supp. 1380 (N.D. Tex. 1989). The Justice Department issued an advisory opinion in which it stipulated that § 504 covers HIV-infected persons. See Parmet, supra note 100, at 87 (citations omitted).

Although persons with HIV and AIDS have sought protection under the Rehabilitation Act from the denial of access to health care, most cases brought under § 504 of the Act involve challenges to work place exclusions. See, e.g., Shuttleworth v. Broward Co., 639 F. Supp. 654 (S.D. Fla. 1986).

121 756 F. Supp. 632 (Mass. Dist. Ct. 1991).

122 Id. at 634.

123 Id. at 635.

124 Id. at 638-39. In assessing the plaintiff's qualifications for surgery, the court determined that the Arline standard permits an inquiry into the potential risks posed to both the patient and health care providers who treat HIV infected individuals. Id. at 638.

and recipients of federal funds. [125] It applies to all public hospitals, as well as to private hospitals that receive Medicare and/or Medicaid payments. [126] However, private health care facilities, such as private medical and dental practices operating without federal funds, are not covered by Section 504. [127]

In partial response to the limited coverage provided to persons with disabilities in the Rehabilitation Act, all fifty states and the District of Columbia have promulgated legislation, modeled after Section 504, to grant more comprehensive protections. [128] Moreover, two-thirds of the states have mandated, either in statutory language, judicial or administrative decisions or policies, that their statutes apply to persons with HIV infection and AIDS. [129] Courts have enforced such statutes against health care providers who withhold treatment to PWAs or HIV-infected persons. [130] However, state statutes differ markedly in their

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125 29 U.S.C. § 794(b).

126 Parmet, supra note 100, at 87.

127 Id.

128 See, e.g., Sanchez v. Lagoudakis, 486 N.W. 2d 657 (Mich. 1993)(extending coverage under "Michigan Handicappers' Civil Rights Act" to person perceived by her private employer as having AIDS); Michele Zavos, Right to Work: Job Protections for People with HIV, TRIAL, MONTHLY MAG. OF THE ASS'N OF TRIAL LAW. AM. 6 (July, 1993); LISA BOWLEG, INTERGOVERNMENTAL HEALTH POLICY PROJECT, A SUMMARY OF HIV/AIDS LAWS FROM THE 1991 STATE LEGISLATIVE SESSIONS (1992).

129 See Zavos, supra note 128.

130 ABA POLICY & REPORT ON AIDS, supra note 23, at 143. See, e.g., Minnesota v. Clausen, 491 N.W.2d 662 (Minn. Ct. App. 1992) (defining dental patient with HIV as "disabled" under Minnesota statute prohibiting persons with disabilities from exclusion from public and private services). Cf. Sattler v. New York Comm'n on Human Rights, 180 A.D. 644, 580 N.Y.S.2d 35 (App. Div. 1992) appeal denied, 610 N.E. 2d 388 (N.Y. 1992). (holding that HIV-positive dental patient did not qualify as "disabled" under New York statute exclusively covering public entities).

content and application. [131] Thus, prior to the passage of the Americans with Disabilities Act, no uniform legislation existed to provide comprehensive protections to persons with disabilities in both the public and private sectors.

To afford increased protections for persons with disabilities and to remedy the coverage gaps of Section 504, Congress passed the Americans with Disabilities Act in 1990, which became effective on July, 26, 1992. [132] The ADA consists of four titles which prohibit discrimination against persons with disabilities in the areas of employment, public services, public accommodations, and public transportation. Title III of the ADA, the public accommodations title, mandates that "[n]o individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation . . ." [133]

In addition to satisfying the public accommodation requirement, only entities that "affect commerce," under the extremely broad definition set forth in the statute, are covered by the ADA's anti-discrimination prohibitions. [134] Embracing the principles in Section 504, the ADA's protections extend only to

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131 See id.; BOWLEG, supra note 128.

132 42 U.S.C. §§ 12101-12213 (Supp. III 1991).

133 Id. § 12182(a). The Justice Department's regulations for Title III emphasize that a place of "public accommodation" must be a "private entity" that provides services to the public, as defined by one of the fourteen facilities specified in the statute. See Nondiscrimination on the Basis of Disability by Public Accommodations and in Commercial Facilities, 28 C.F.R. § 36.104 (1992). Some of the facilities that qualify as public accommodations include hotels, restaurants, bars, theaters, stadiums, grocery stores, shopping centers and offices of "health care provider[s]." 42 U.S.C. § 12181(7)(A-L).

134 42 U.S.C. § 12181(1). The statute defines the term "commerce" broadly to conclude "travel, trade, traffic, commerce, transportation, or communication" among the United States or among states and foreign countries. Id.

persons with disabilities who do not present a "direct threat" to others. The ADA defines a "direct threat" as "a significant risk to the health or safety of others" that cannot be eliminated by reasonable accommodation of "policies, practices, or procedures." [135]

The ADA's inclusive coverage provisions go far beyond Section 504's application to federally funded entities. [136] They extend legal protections to people with disabilities in publicly accessible private work places and facilities. [137] Unlike Section 504, the ADA gives HIV-infected persons protection in access to health care by prohibiting private medical providers from excluding persons with disabilities. [138]

By utilizing Section 504's definition of persons with disabilities, as well as the holding in Arline, the ADA extends coverage to individuals with AIDS and HIV, to individuals perceived as being AIDS/HIV-infected, and to individuals who affiliate with PWAs or individuals with HIV. [139] Furthermore, the ADA's

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135 Id. § 12182(3). The regulations specify that entities must utilize the four-pronged, Arline standard to ascertain whether an individual presents a "direct threat" or "significant risk", and whether any potential risks can be reasonably accommodated. See 28 C.F.R. pt. 36, App. B (1992). A covered entity must make reasonable accommodation, "unless the entity can demonstrate that taking such steps would fundamentally alter the nature of the . . .service. . .or would result in an undue burden." 42 U.S.C. § 12182(b)(2)(A)(iii).

136 29 U.S.C. § 794.

137 See Parmet, supra note 100, at 88.

138 42 U.S.C. § 12181(7)(F). The statutory language, revealing Congress' intent that private medical facilities be covered under the ADA, states that "[t]he following private entities are considered public accommodations for purposes of this subchapter, if the operations of such entities affect commerce . . . (F) a . . . professional office of a health care provider, hospital, or other service establishment." Id.

139 29 U.S.C. § 706(8)(B); see supra note 112 and accompanying text.

legislative history evinces Congress' intent that persons with AIDS and HIV-infection are included in the ADA's protections. [140]

Because it is a new statute, there is as yet little reported litigation concerning the application of the ADA to persons with AIDS and HIV infection. [141] However, the ADA is likely to have a major impact on increasing access to health care services for persons with HIV and AIDS. [142] Since the ADA does not exempt private health care providers from its coverage, the ADA will help remove treatment impediments that persons with HIV and AIDS confront. [143] Health care reform efforts should be consistent with the provisions of the ADA.

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140 See Chai R. Feldblum, Workplace Issues: HIV and Discrimination in AIDS AGENDA: EMERGING ISSUES IN CIVIL RIGHTS, supra note 22, at 277 (citing Report on the House Committee on Education and Labor, H.R. REP. NO. 101-485, 101st Cong., 2nd Sess., pt. 2, at 52). The report stated in relevant part that "a person infected with the Human Immunodeficiency Virus is covered under . . . the definition of the term 'disability' because of a substantial limitation to procreation and intimate sexual relations." Id.

141 See, e.g., Downtown Hospital v. Sarris, 588 N.Y.S.2d 748, 752 (Civ. Ct. 1992) (holding that ADA's coverage extends to persons with AIDS); see also, HIV-Positive Surgeon Charges Discrimination Against Hospital Organizations Under the ADA 8 AIDS POLICY & LAW 1 (1993) (HIV-infected surgeon, who was placed on restricted duty by Mercy Catholic Hospital, commenced a suit in the Federal District Court for the Eastern District of Pennsylvania, alleging that the hospital's actions violated the ADA).

142 See Zavos, supra, note 128, at 5. The extended coverage afforded by the ADA comports with the American Bar Association's policy that "[h]ealth care providers should not refuse to treat or limit treatment of an individual because of the individual's actual or perceived HIV status." ABA POLICY & REPORT ON AIDS, supra note 23, § D.1, at 12.

143 Zavos, supra note 128, at 5.

C. Breaches of Confidentiality: Barriers to Testing

Concerns about breaches of confidentiality often deter individuals from taking an HIV test. [144] Studies indicate that many persons who receive a late diagnosis delayed testing out of concern that the results would not be kept confidential. Such persons were concerned with the repercussions that could ensue if their test results were made public, such as losing jobs and housing and being subjected to emotional distress. [145] Persons who suspect that they are HIV-infected have been known to delay early detection and treatment to avoid the potential negative consequences which flow from confidentiality breaches. [146] However, such testing delays translate into missed opportunities for treatment which could potentially prolong the life span of an HIV-infected individual. [147]

There is a developing line of case law in which HIV-infected persons, who suffered breaches of confidentiality, have sued health care providers who unlawfully disclosed their HIV status to others. [148] Thus, as advocated by the American Bar Association and the Presidential Commission on AIDS, health care

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144 See ABA POLICY & REPORT ON AIDS, supra note 23, at 35-40 "Rigorous maintenance of confidentiality is considered critical to the success of the public health endeavor to prevent the transmission and spread of HIV infection." Id. at 35 (citations omitted). "Health care provider's duty to preserve confidentiality of medical information is both an ethical and a legal obligation." Id.

145 See HEALTH CARE REFORM, supra note 1, at 144-46.

146 See id.

147 See Hunter, supra note 22, at 10.

148 See, e.g., Doe v. Shady Grove Adventist Hospital, 598 A.2d 507 (Md. 1991) (characterizing hospital's act of disclosing patient's HIV status as a breach of confidentiality); Behringer v. Medical Center at Princeton, 592 A.2d 1251 (N.J. Super. Ct. Law Div. 1991) (holding that defendant-medical center breached its duty of confidentiality, under New Jersey's anti-discrimination statute, by disclosing surgeon's HIV status).

reform should include methods of insuring compliance with existing confidentiality laws, [149] and efforts should be made toward developing uniform confidentiality laws. [150] Such efforts are currently underway. [151] Uniform laws would permit nationwide education on the rights and obligations of confidentiality and would eliminate the incentive to "forum shop" to seek a venue for HIV testing or treatment that offers the greatest confidentiality.

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149 Despite the absence of uniform federal law governing confidentiality in HIV testing, some states have enacted their own state confidentiality laws. Among the most comprehensive of such laws is New York State's confidentiality statute. See N.Y. PUB. HEALTH L. § 2782 (McKinney Supp. 1992). However, New York's statute only applies to employees in the state's correctional facilities and parole and probation divisions; the statute's protections not extend to personnel of the state's court system and law enforcement agencies. N.Y.S. BAR ASS'N., REPORT OF THE SPECIAL COMMITTEE ON AIDS AND THE LAW 35 (1992).

150 ABA POLICY & REPORT ON AIDS, supra note 23, § B.1, at 9. "[S]pecific confidentiality protections should be afforded to HIV-related information under state and federal statutes and judicial and administrative procedures." Id. "The Presidential Commission has identified the lack of uniform confidentiality protections as a significant obstacle to HIV prevention efforts, and has called for both the enactment of a federal law and for the development of model state confidentiality legislation which would enunciate a general confidentiality rule . . . ." Id. at 37 (citing REP. OF THE PRESIDENTIAL COMM'N ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC, supra note 39, at 120).

151 Id. at 37. The Harvard Journal on Legislation is in the process of publishing a model statute, entitled, "Comprehensive AIDS Confidentiality Act." Id. (citations omitted). Furthermore, the "Intergovernmental Health Policy Project" is devising a report regarding existing informed consent and state confidentiality laws. Id.; see also SHARON RENNERT, ABA, AIDS/HIV AND CONFIDENTIALITY: MODEL POLICY AND PROCEDURES (1991).

IV. AIDS AND PRIVATE PAYORS

A. The Comparative Cost of AIDS Care

AIDS and HIV-related medical conditions are among the most litigated and controversial diseases in the history of the United States. While the costs of HIV and AIDS medical care are great, they are not vastly different than for other serious medical conditions. In the early 1980's, however, some insurance companies and hospitals facing an increasing number of HIV patients with long hospital stays and potential labor-intensive care, claimed that the enormous costs of AIDS threatened to bankrupt them. [152] The first studies conducted seemed to confirm that the health care industry's costs related to HIV and AIDS would be extraordinary and in a different class than that of other serious illnesses. [153] By 1986 and 1987, subsequent reports tempered some of the high numbers that were initially utilized and estimated costs from diagnosis to death that were well below previous figures. [154] In 1992 the lifetime costs of treatment for a person with HIV illness were estimated at $102,000. [155] Although comparative cost studies are still viewed as relatively incomplete, [156] the costs of treating HIV and AIDS illnesses

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152 Fox & Thomas, supra note 38, at 198-200.

153 Id. at 202-203. A CDC study was among the first and most publicized analyses of health care costs and claimed a $147,000 hospitalization expense for persons with AIDS from diagnosis to death. Id. at 202.

154 Id. at 203-05 (citing studies from San Francisco, Maryland, Massachusetts, California, and New York).

155 HEALTH CARE REFORM, supra note 1, at 67 (citing Hellinger, Assessing the Medical Care Costs of the HIV Epidemic in the United States: 1992-95, Abstract No. WeC1033 (VIII Int'l Conf. on AIDS, July 19-24, 1992)).

156 See Fox and Thomas, supra note 38, at 209. ("Methods for studying the costs of routine care for patients with different diseases in particular hospitals

[Footnote continued]

are no more disastrous than for other serious illnesses. For example, patients who need liver transplants have lifetime medical costs that are three to four times that of a person with AIDS. [157] Medical expenses for other chronic illnesses yield a similar comparison. [158] In fact, studies of actual insurance claims indicate that AIDS-related costs have not had nearly the dramatic effect originally perceived. [159] Spending for AIDS is less than one percent of the total amount of medical spending in the United States, [160] and the National Commission on AIDS has predicted that it is likely that this amount will never rise above two percent. [161] Despite these figures, the early estimates of health care expenses for AIDS have created the perception that AIDS-related illnesses are uniquely costly to the health care and insurance industries. [162]

[Footnote continued]

remain inadequate, particularly in an era or reimbursement systems based on diagnosis.").

157 Harvey V. Fineberg, The Social Dimensions of AIDS, SCI. AM., Oct. 1989, at 128, 133, reprinted in HOSPITALS, HEALTH CARE PROFESSIONALS AND AIDS (World AIDS Day Conf., Boston, Mass.) Dec. 1988, at 312, 317.

158 Heart disease treatment cost $101.3 billion in 1990 health care expenditures, which was 20 times that of the amount required for AIDS-related care in 1991. Paraplegia resulting from automobile accidents, myocardial infarction, and breast cancer also have similar lifetime costs as that of persons with AIDS. The annual medical costs of a person with AIDS is actually less than the cost of a heart transplant or a year's supply of clotting factor for a hemophiliac. HEALTH CARE REFORM, supra note 1, at 67-68 (citations omitted).

159 Id. at 70 (citing studies).

160 Id. at 67 (citation omitted).

161 Id. (citing 1991 report by the National Commission on AIDS).

162 See Lawrence Bartlett, Financing Health Care For Persons With AIDS: Balancing Public and Private Responsibilities, in AIDS AND THE HEALTH CARE SYSTEM, supra note 38, at 211, 211; see also HEALTH CARE REFORM, supra note 1,

[Footnote continued]

At present, it is estimated that twenty to twenty-five percent of HIV-infected persons have no form of medical coverage. [163] One survey found that only seven percent of public hospital admissions with AIDS in 1985 were covered by private insurance. [164] Studies also show that persons with AIDS are eight times as likely to have completely lost health care coverage as persons without HIV. [165] Medicaid takes over much of the burden; forty percent of AIDS patients are covered by this program, which is over four times the rate of coverage of the general population. [166] Although Medicaid funds eleven percent of all medical costs in general, it provides for ninety percent of medical costs of children with AIDS and twenty-five percent of the national total for AIDS-related medical expenses. For the fiscal year 1992,

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[Footnote continued]

at 68 (quoting Jewett & Hecht, Preventive Health Care for Adults With HIV Infection, 269 JAMA 1144 (1993)). Clearly, the problems associated with private insurance coverage and the health care infrastructure in the United States are not unique to HIV disease. On the other hand, as one commentator has observed, AIDS "magnifies the deficiencies in financing of health care . . . [and] may show society in starkest form the hardship and despair of a system that does not guarantee health care for all." Lawrence O. Gostin, Hospitals, Health Care Professionals, and Persons with AIDS, in AIDS AND THE HEALTH CARE SYSTEM, supra note 38, at 3, 10.

163 HEALTH CARE REFORM, supra note 1, at 69 (citing National Commission on AIDS study).

164 Bartlett, supra note 162, at 213 (citations omitted).

165 HEALTH CARE REFORM, supra note 1, at 69 (citing Kass et. al., Loss of Private Health Insurance Among Homosexual Men with AIDS, 28 INQUIRY 249 (1991)). When they are able to maintain private coverage, PWAs generally pay higher premiums than those without the disease. Id.

166 Fineberg, supra note 157, at 318.

Medicaid and Medicare together spent $1.3 billion in federal funds for AIDS care. [167]

B. Limitations In Private Health Insurance

The high cost of AIDS medical care, the perception that it is even costlier, and the certainty that HIV infection leads to AIDS, all have made problematic securing third-party payment of health costs for HIV-positive persons. [168] The overwhelming majority of private insurers consider persons with AIDS or AIDS-related conditions to be "uninsurable." [169] As a result, a variety of methods have been employed to exclude PWAs from private coverage. The past ten years have shown a dramatic decline in coverage of people with HIV. [170] One effective underwriting method has been to require a test for the HIV antibody. By 1987,

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167 HEALTH CARE REFORM, supra note 1, at 70-72 (citations omitted). Commentators predict that the federal government in 1993 will spend $1.6 billion and the states will spend $1.2 billion to provide AIDS health care to Medicaid beneficiaries. Id.

168 The ABA believes that insurers should not cancel or refuse to renew policies because of an individual's HIV-related claims or a change in health status related to HIV. ABA POLICY & REPORT ON AIDS, supra note 23, § F.14, at 14. See Michele Zavos, ABA, AIDS and Insurance: No Guarantees, HUMAN RIGHTS, Winter, 1993, at 18, 19 [hereinafter Zavos, AIDS and Insurance]. The ABA believes that "health insurance plans that cover a comprehensive range of medical conditions should cover AIDS, ARC and HIV to the same extent as other serious medical conditions." ABA POLICY & REPORT ON AIDS, supra note 23, § F.10, at 13.

169 CLEARINGHOUSE REV., supra note 14, at 736. A 1987 survey by the Health Insurance Association of America found that 91 percent of HIV-infected persons were considered uninsurable and all persons diagnosed with full-blown AIDS were unable to get policies from insurance companies. HEALTH CARE REFORM, supra note 1, at 80 (citing INTERGOVERNMENTAL HEALTH POLICY PROJECT, INTERGOVERNMENTAL AIDS REPORTS, March/April 1990, at 6).

170 HEALTH CARE REFORM, supra note 1, at 73.

most insurance companies had imposed HIV-testing on insurance applicants. [171] Some jurisdictions, including Washington, D.C., Massachusetts and New York, responded by prohibiting this practice. [172] However, these laws have been widely challenged and many have been overturned. [173]

In addition to testing, the most direct exclusionary method, insurance companies have utilized other factors as proxies for HIV and AIDS diagnoses. Questions concerning sexual orientation, redlining of certain geographic areas or of occupations believed to be occupied by gay men [174] and inquiries into the history of sexually transmitted diseases, [175] have all been utilized to limit coverage to applicants considered to be at risk for HIV infection. Some companies have also been accused of denying policies to persons who lived with someone of the same

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171 See Peter Hiam, Insurers, Consumers, and Testing: The Aids Experience, 15 LAW, MEDICINE, AND HEALTH CARE, Winter 1987/88, at 212, 212, reprinted in HOSPITALS, HEALTH CARE PROFESSIONALS AND AIDS, supra note 157, at 246, 246.

172 CLEARINGHOUSE REV., supra note 14, at 737-38. The ABA urges that HIV tests conducted for underwriting purposes should conform to "generally accepted public health protocols." ABA POLICY REPORT, supra note 23, § F.5, at 13.

173 CLEARINGHOUSE REV., supra note 14, at 738; HEALTH CARE REFORM, supra note 1, at 80; see, e.g., Health Ins. Ass'n of America v. Corcoran, 551 N.Y.S.2d 615 (A.D. 3 Dept. 1990), (holding that use of HIV test results was a valid underwriting practice under state law and thus ban exceeds regulatory authority), aff'd, 565 N.E. 2d 1264 (N.Y. 1990); Life Ins. Ass'n of Mass. v. Commissioner of Ins., 530 N.E.2d 168 (1988) (same). The insurance industry's response to the law in Washington D.C. was to refuse to write policies in the district. The D.C. City Council subsequently rescinded the ban. Bartlett, supra note 162, at 215.

174 Bartlett, supra note 162, at 213-14. Redlining of occupations or geographic areas is targeted primarily at the homosexual populations. HEALTH CARE REFORM, supra note 1, at 82.

175 INSTITUTE OF MEDICINE, NAT'L ACADEMY OF SCIENCES, CONFRONTING AIDS, UPDATE 1988, at 113 (1988), reprinted in HOSPITALS, HEALTH CARE PROFESSIONALS AND AIDS, supra note 157, at 257, 277 [hereinafter CONFRONTING AIDS].

sex. [176] Some jurisdictions, however, have followed the guidelines adopted by the National Association of Insurance Commissioners by prohibiting the actuarial use of sexual orientation and redlining methods. [177]

Even when a person has obtained a policy, there are other ways in which coverage of PWAs can be limited. [178] Many policies impose waiting periods or fail to reimburse the costs of preexisting conditions. A preexisting condition triggers an average nine month waiting period, although some plans have a longer term. [179] State law also allows insurers to rescind policies upon the discovery of a materially false or misleading statement or omission on an application, and HIV-positive policy holders may lose coverage on such bases. [180] The applicant typically must fill out a comprehensive medical history questionnaire with a variety of HIV-related questions (e.g., past symptoms), and misstatements in response to these

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176 CLEARINGHOUSE REV., supra note 14, at 737.

177 Bartlett, supra note 162, at 215. The ABA also advocates laws prohibiting insurance discrimination on the basis of sexual orientation or lifestyle. ABA POLICY & REPORT ON AIDS, supra note 23, §§ F.2-F.4, at 13.

178 See CLEARINGHOUSE REV., supra note 14, at 738. The ABA's policy is that "[i]nsurers should not cancel or refuse to renew or increase premiums on an individual insurance policy because of the individual's HIV-related claims or a change in health status related to HIV. " ABA POLICY & REPORT ON AIDS, supra note 23, § F.14, at 14.

179 HEALTH CARE REFORM, supra note 1, at 82-83 (citations omitted). Although HIV infection alone, as a latent condition, may not be accurately classified as a preexisting condition according to standard use, many insurers treat it as one for claim purposes anyway. Id. (citations omitted).

180 See HEALTH CARE REFORM, supra note 1, at 84-85. Cf. Waxse v. Reserve Life Ins. Co., 809 P.2d 533 (Kan. 1991) (holding that HIV-infected person who answered negatively on an application question asking if he had "blood disorders" was not grounds for recision of the policy) (cited in HEALTH CARE REFORM, supra note 1, at 85).

questions can support a policy recision even if the alleged misstatements are not related to claims. [181]

In addition, the scope of insurance coverage is often inadequate for indicated treatment of persons with HIV and AIDS. Most private policies do not cover reimbursement for prescription drugs. [182] This is especially significant to HIV-infected individuals and PWAs because of the importance of drugs in their treatment [183] and the high cost of drugs that treat HIV infection. [184] Insurance policies usually do not cover experimental treatments and require FDA approval if drugs are to be covered. [185] As the National Commission on AIDS has observed, however, "[t]reatments that are technically experimental may be the standard of care for HIV disease."[186] Insurance policies also often exclude coverage

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181 HEALTH CARE REFORM, supra note 1, at 84 (citations omitted). The ABA advocates prohibiting questions as to whether the applicant has ever taken an HIV test or sought counseling regarding HIV. ABA POLICY & REPORT ON AIDS, supra note 23, § F.6, at 13.

182 HEALTH CARE REFORM, supra note 1, at 86.

183 "Prescription drugs dominate HIV care, which is chiefly delivered in outpatient settings rather than in hospitals. . . Prescription drugs consume as much as 92 percent of the average $10,000 price tag for early intervention services." Id. (citing Davis et al., FINANCING HEALTH CARE FOR PERSONS WITH HIV DISEASE: POLICY OPTIONS -- TECHNICAL REPORT PREPARED FOR THE NATIONAL COMMISSION ON AIDS 13 (1991)).

184 AZT cost approximately $10,000 per year when it first became available in 1987. Foscarnet has an annual expense of $20,000 and other drugs range from $2,000 to $8,000 for a year's supply. Id. at 88-90.

185 CLEARINGHOUSE REV., supra note 14, at 738; see also HEALTH CARE REFORM, supra note 1, at 91-95. The ABA suggests that insurers include coverage of experimental "Treatment Ind" drugs which have been approved by the FDA. ABA POLICY & REPORT ON AIDS, supra note 23, § F.12, at 14.

186 1991 NAT'L COMM'N REP., supra note 10, at 72.

for long-term and preventive care. [187] Preventive care, particularly testing and counseling, is increasingly recognized as the means with the most potential for curbing the spread of HIV.[188] Similarly, long-term care has become more important as the life expectancy of PWAs rises.[189] Finally, private insurance companies may simply write policies that explicitly limit or exclude AIDS-related benefits. [190]

On another front, self-insurers are also exploring means to lessen the covered expense of PWA treatment. Two out of three Americans use employment-based plans for their health coverage, making it the largest source of health care financing in the country. [191] Of this number, approximately sixty percent are covered by self-insured plans. [192] But because smaller employers have increasingly eliminated health benefits for their employees, the number of privately insured Americans has decreased in the past several years. [193]

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187 HEALTH CARE REFORM, supra note 1, at 97-98. When cost-effective, the ABA encourages insurers to cover treatments in nursing homes, hospices, and outpatient facilities. ABA POLICY REPORT ON AIDS, supra note 23, § F.10, at 12. Case management techniques are also advocated. Id. § F.11, at 14.

188 1991 NAT'L COMM'N REP., supra note 10, at 54-55.

189 HEALTH CARE REFORM, supra note 1, at 97.

190 See CONFRONTING AIDS, supra note 175, at 113 (citation omitted).

191 HEALTH CARE REFORM, supra note 1, at 10 (citing Rockefeller, A Call for Action: The Pepper Commission's Blueprint for Health Care Reform, 265 JAMA 2507, 2508 (May 15, 1991)).

192 Zavos, AIDS and Insurance, supra note 168, at 20. Eighty percent of large employers self-insure their workers. HEALTH CARE REFORM, supra note 1, at 14 (citation omitted).

193 See HEALTH CARE REFORM, supra note 1, at 10 (citation omitted).

Employers are also concerned about the cost of medical treatment for PWAs and those with HIV. Self-insured employers, however, may be able to avoid full coverage of AIDS and HIV more easily than insurance companies because they are regulated by the Employment Retirement Income Security Act (ERISA) rather than individual states. [194] The Supreme Court has held that this federal action preempts state regulation of self-insured benefit plans. [195] ERISA, however, has offered little restraint on the efforts of self-insured employers to escape HIV-related liability.

One of the most publicized of these efforts was upheld by the Fifth Circuit in McGann v. H & H Music Co. [196] In that case, a self-insured employer reduced its employees' lifetime $1 million maximum health insurance coverage for all medical claims to a $5,000 ceiling for AIDS-related claims. McGann, an employee with AIDS, sued the employer under Section 510 of ERISA when his benefits reached their limit. [197] The court held that ERISA did not prohibit a self-insured employer

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194 29 U.S.C. §§ 1001-1461 (1988).

195 FMC Corp. v. Holliday, 498 U.S. 52 (1990); see HEALTH CARE REFORM, supra note 1, at 13.

196 946 F.2d 401 (5th Cir. 1991), cert. denied sub nom Greenberg v. H & H Music Co., 113 S.Ct 482 (1992); see also Owens v. Storehouse, 773 F. Supp. 416 (N.D.Ga. 1991), aff'd, 984 F.2d 394 (11th Cir. 1993).

197 McGann, 946 F.2d at 403. Section 510 provides in relevant part:

> It shall be unlawful for any person to discharge, fine, suspend, expel, discipline, or 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).

from imposing insurance caps under the theory that an employer may terminate or amend a plan at any time, and that the availability of the $1 million maximum was not a "right" protected by Section 510. [198] This was the case even though McGann was the only employee adversely affected by the plan. [199] Although the ABA, among other groups including the American Medical Association and the National Governors' Association, urged the Solicitor General to support the plaintiff's petition for certiorari, [200] the Supreme Court denied the petition in 1992 and allowed the lower court decision to stand. [201] Another recent case on similar facts has also held that "defendant's unilateral modification of an existing plan cannot support a [Section] 510 claim." [202]

The current state of the law allowing limits to previously established health benefits is certainly not restricted to people with AIDS and HIV. Employers, however, in limiting coverage may be counting on the stigma of AIDS and that other employees will not object to the reduction of benefits to PWAs. [203] In any

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198 McGann, 946 F.2d at 405 ("McGann's allegations show no promised benefit, for there is nothing to indicate that defendants ever promised that the $1,000,000 coverage limit was permanent.").

199 Id. at 406-08.

200 See Zavos, AIDS and Insurance, supra note 168, at 19.

201 Greenberg v. H & H Music Co., 113 S. Ct. 382 (1992), denying cert. to McGann v. H & H Music Co., 946 F.2d 401 (5th Cir. 1991).

202 Owens v. Storehouse, 773 F. Supp 416, 419 (N.D.Ga. 1991) (imposing a $25,000 cap), aff'd, 984 F.2d 394 (11th Cir. 1993). One of the collateral effects of the uninsurability of persons with serious medical conditions is that they are forced to stay in a job if they are fortunate enough to get some coverage for fear of not being able to reinsure. This phenomena, known as "job lock," reflects the importance of health plan portability for people with HIV. See HEALTH CARE REFORM, supra note 1, at 14 (citations omitted).

203 See Zavos, AIDS and Insurance, supra note 168, at 19.

event, the National Association of Attorneys General seems accurate in its assessment that "ERISA has become a tool for employers who wish to avoid their obligations under state law." [204]

C. Confronting the Gaps in Private Insurance

Other employees are challenging the same type of insurance practices used in McGann under the Americans with Disabilities Act. [205] Section 102(a) of the Act, [206] applying to employers with 25 or more employees, prohibits discrimination based on a disability in the terms, conditions, and privileges of employment.[207] The crucial provision in this context, however, will likely be Section 501(c).[208] This section states that the ADA is not intended to restrict employers in the operation of bona fide benefit plans based on the underwriting, classification, or administration of risks that are consistent with state law, or to prohibit bona fide benefit plans not subject to state law.[209] Benefit practices, however, will not be protected if they are "a subterfuge used to evade the purposes" of the Act. [210] Because there is no statutory definition of this provision in the Act, courts may look at analogous

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204 HEALTH CARE REFORM, supra note 1, at 13-14 (citing N. Y. TIMES, Mar. 29, 1992).

205 42 U.S.C. §§ 12101-12213 (Supp. III 1991).

206 Id. § 12112(a).

207 The Act also reaches indirect discrimination by prohibiting the employer's participation in contracts or other arrrangements that have the effect of discriminating against employees with a disability. Id. § 12112(b).

208 Id. § 12201(c).

209 Id.

210 Id.

provisions in other anti-discrimination statutes to determine its meaning. For example, the Supreme Court construed this language in the Age Discrimination in Employment Act (ADEA) [211] in deciding whether a plan that limited benefits to those under age sixty constituted a subterfuge to evade the purposes of that Act. [212] The court took a narrow approach and held that there was no subterfuge unless the plan was adopted for the purpose of discriminating against an individual on the basis of age in a non-benefit aspect of the employment relationship. [213]

The Equal Employment Opportunity Commission (EEOC) recently issued interim guidelines for the application of the ADA to employer provided health insurance.[214] These guidelines provide that once a disability-based distinction is found in an employer's health insurance plan, the employer has the burden to prove that it comes within the protective ambit of Section 501(c).[215] The EEOC also defines subterfuge in the guidelines as "disability-based disparate treatment that is not justified by the risks or costs associated with the disability."[216]

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211 See 29 U.S.C. § 623(f)(2) (1988).

212 Public Employees Retirement Sys. v. Betts, 492 U.S. 158 (1989).

213 Id. at 181.

214 See EEOC Interim Guidance on Application of ADA to Health Insurance (issued June 8, 1993) [hereinafter Interim Guidance]; see also Disability Bias in Health Insurance Barred, WASH. POST, June 9, 1993, at A14.

215 Interim Guidance § III. "[I]t is the respondent employer who has control of the risk assessment, actuarial, and/or claims data relied upon in adopting the challenged disability-based distinction." Id.

216 Id. The guidelines also set forth a "non-exclusive" list of potential business/insurance justifications available to the employer. For example, the employer may prove that the disparate treatment is justified by legitimate actuarial data and that comparable conditions are treated similarly, or that the distinction is necessitated by the requirements of "fiscal soundness." Id.

In 1993, the EEOC found that a union health plan which excluded HIV or AIDS from its coverage violated the ADA on its face. [217] The Commission found that the employer had no "viable defense" under the Act. [218] In another decision, Kadinger v. IBEW Local 110, [219] the estate of a union member is challenging a cap on AIDS-related benefits set by the member's union and its health insurer. This may be the first case of this type. [220]

In addition, legislative efforts are being made to prevent the outcome upheld in McGann. [221] Representative William Hughes (D.-N.J.), has introduced the Group Health Plan Nondiscrimination Act of 1992, HR 6147 (introduced to the House on October 5, 1992). The bill would amend Title I of ERISA to prohibit a limitation or elimination of benefits in self-insured policies which occur after the employee has submitted his claim for reimbursement. [222]

There are other methods currently in use that also serve to extend private insurance coverage. Thirty-six states have conversion requirements that enable individuals previously covered under employment-based policies to switch to an

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217 Donaghey v. Mason Tenders Dist. Council Trust Fund, EEOC Charge No. 160-93-0419 (Jan. 28, 1993) (ruling from New York District office); see AIDS Activists Applaud Jan. 27 EEOC Ruling That Insurance Caps Are a Violation of ADA, 8 AIDS POL'Y AND LAW, Feb. 19, 1993, at 1, 7.

218 Donaghey, EEOC Charge No. 160-93-0 419.

219 CV No. 2-93-159 (D.C. N. Minn., Mar. 17, 1993).

220 To date there are no court decisions on this issue.

221 See Fight Against Greenberg Decision; Legislation to Amend ERISA Planned for 1993, 7 AIDS POL'Y & LAW, November 27, 1992 , at 1, 2; Zavos, AIDS and Insurance, supra note 168, at 19.

222 See Zavos, AIDS and Insurance, supra note 168, at 19. Senator Boxer (D.-Ca.) has introduced a companion bill in the Senate.

individual policy within a certain amount of time. [223] These individual policies, however, often provide for coverage that is significantly inferior to that under the group plans. [224] In 1985, the Consolidated Omnibus Reconciliation Act (COBRA) established a continuation requirement for employers of twenty or more workers mandating eighteen months of coverage for workers after they leave their jobs. [225] COBRA, however, may have limited potential for HIV-infected people. Many persons with HIV work for smaller employers than those covered by COBRA. [226] Furthermore, although the premiums are limited by law, they are often high enough to preclude individuals from paying them, particularly with the drop in income that accompanies the loss of a job. [227] Some states have addressed this issue by publicly funding COBRA premiums. [228] This policy is fiscally sound since studies show that financing COBRA premiums is less expensive than direct reimbursement of medical treatment. [229]

A third method by which states shore up private coverage is to establish risk pools. A risk pool requires insurers in the state to share the underwriting

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223 Bartlett, supra note 162, at 216.

224 HEALTH CARE REFORM, supra note 1, at 96. In addition, these state requirements do not effect self-insurers covered by ERISA. Id.

225 Id. at 95 (citations omitted). When a worker leaves employment due to a disability and qualifies for SSDI, the continuation term is extended to 29 months. Id. (citation omitted). Thirty-five states also have their own continuation requirements. Bartlett, supra note 162, at 216.

226 HEALTH CARE REFORM, supra note 1, at 96.

227 Id.; Bartlett, supra note 162, at 216.

228 See HEALTH CARE REFORM, supra note 1, at 122 (citations omitted).

229 Id. at 96 (citing National Health Law Program report).

responsibilities for otherwise uninsurable persons.[230] The purpose of these programs is to guarantee the opportunity to purchase health insurance to all persons, regardless of their medical condition.[231] The biggest barrier to effectiveness, however, is once again cost. Even though state law imposes price caps, risk pool premiums are generally 125-200 percent higher than standard private insurance rates.[232] Moreover, Wisconsin and Maine are the only states to establish a subsidy program for indigents' premiums.[233] A related problem is that because ERISA preempts state regulation of self-insurers, these employers cannot be required to contribute to state risk pools. The costs associated with these plans are thus carried by a much smaller base of insurers.[234] Consequently, risk pools are unable to provide a comprehensive solution to the health care problem of the impoverished who cannot afford to purchase insurance. Instead, these pools are aimed at the uninsured who are not poor, but who might become so when confronted with significant medical costs.[235]

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230 Bartlett, supra note 162, at 216-17. By 1991, 24 states had provided for risk pools. HEALTH CARE REFORM, supra note 1, at 138.

231 AARON K. TRIPPLER, COMPREHENSIVE HEALTH INSURANCE FOR HIGH-RISK INDIVIDUALS: A STATE-BY-STATE ANALYSIS 4 (4th ed. 1990). Maximum lifetime benefits, if any, range between $250,000-1,000,000. Id. at 23-24.

232 TRIPPLER, supra note 231, at 4; CLEARINGHOUSE REV., supra note 14, at 735.

233 CLEARINGHOUSE REV., supra note 14, at 735. As a result the participation in risk pools has been much lower than anticipated. Id.

234 CONFRONTING AIDS, supra note 175, at 279-80. In addition, all of the risk pools have waiting periods lasting from six months to a year that prohibit coverage of preexisting conditions. TRIPPLER, supra note 229, at 29-30; see Bartlett, supra note 168, at 217.

235 TRIPPLER, supra note 231, at 5.

V. THE UNINSURED AND PUBLIC FINANCING

A. The Burden on Public Financing

The exclusion of persons with AIDS and HIV from private coverage as described above necessarily means that a large number of these individuals will be forced to rely on public programs for the financing of their medical care. In essence, AIDS confronts a health care system that is designed around the concept that long-term, expensive illnesses occur primarily in old age. [236] This shift from a private health care system to public financing of AIDS care will only continue as the demographics of persons with AIDS change from homosexuals to drug-users and their sexual partners. [237]

Uninsured persons are generally poor, young, unmarried, uneducated, rural, of color, part-time or self-employed workers. [238] The lack of health coverage predictably leads to inadequate medical care. Even though they are typically in worse health than insured people, the uninsured are less likely to receive any medical care, see a doctor, or receive in-patient medical care. Persons with chronic ailments who have no insurance are about fifty percent as likely to see a doctor and are discharged sooner than those with insurance, even when they are

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236 Fox & Thomas, supra note 38, at 205, 208.

237 Bartlett, supra note 162, at 213 ("Members of this latter population are less likely to hold jobs that provide employment-related health benefits or, because they are often low income, to have purchased individual insurance coverage prior to their infection."). The National Commission on AIDS has suggested that the "Medicaidization" of AIDS health care stems from two sources: the spread of the virus among low-income persons and the simultaneous contraction of private health insurance coverage. 1991 NAT'L COMM'N REP., supra note 10, at 72-73.

The ABA advocates a shared responsibility between public and private groups for persons who are medically uninsurable. ABA POLICY & REPORT ON AIDS, supra note 23, § F.15, at 14.

238 HEALTH CARE REFORM, supra note 1, at 8-9 (citations omitted).

sicker. [239] Other studies have found that babies born to uninsured parents are thirty percent more likely to be sick or die than those with covered parents. The uninsured are thirty-nine percent less likely to have coronary angiograms and 29 percent less probable to have bypass surgery. [240] In addition, as will be discussed, the public financing of medical treatment contains other problems for uninsured HIV-infected persons.

B. Problems of Access in Medicare and Medicaid Coverage

1. Medicaid

In general, Medicaid has two separate eligibility requirements that must be met to qualify for coverage. [241] First, the applicant must satisfy the appropriate means test. In most states, this is tied to the Supplemental Security Income (SSI) program's monthly income limits. [242] Second, to receive Medicaid benefits, the applicant must be a member of one of the covered groups. Thus, an otherwise financially eligible person must be "disabled" as determined by the Social Security Administration (SSA), a member of a family receiving Aid to Families with Dependent Children (AFDC), blind, pregnant, under the age of seven, or over sixty-five. [243] The majority of states allow persons who meet SSI's disability requirements (disabled and unable to work) to qualify automatically for Medicaid.

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239 Id. at 9-10 (citations to studies omitted).

240 Zavos, AIDS and Insurance, supra note 168, at 20-21.

241 See Shacknai, supra note 32, at 183-84.

242 Id. at 184.

243 Id.

Other states, however, have established their own disability requirements which are stricter than that of SSI. [244]

Most persons with AIDS qualify for Medicaid on the basis of disability, although low-income women and children can also become eligible for Aid to Families with Dependent Children (AFDC). To expedite the process, PWAs are presumptively considered to be disabled under the SSI rules, subject to a later review. [245] Individuals who would otherwise be eligible for Medicare based on disability or AFDC, but whose income exceeds the SSI limit, may still qualify in most states for coverage as "medically needy" if their income dips below a certain level after they "spend down" in paying for medical expenses. In many states, this amount is calculated every six months, so that Medicaid will only be available to reimburse the amount below the spend-down level after the costs have been incurred. [246]

The eligibility requirements of Medicaid create special problems of access for persons with AIDS. A person with full-blown AIDS is considered "disabled" under the guidelines, but seropositive people with mild symptoms or those who are being treated only prophylactically (i.e., AZT maintenance) may have trouble gaining eligibility to the program. [247] Thus, applicants without an AIDS diagnosis do not get the benefit of a presumption and must show that they should qualify as disabled. This problem is even more acute for those persons who have the most

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244 CLEARINGHOUSE REV., supra note 14, at 727-28 (citations omitted).

245 Bartlett, supra note 162, at 219. This presumption is based on the CDC definition of AIDS. Id.; see supra notes 5-8 and accompanying text.

246 CLEARINGHOUSE REV., supra note 14, at 728-29.

247 Shacknai, supra note 32, at 184-85.

difficulty in gaining access to health care, women and children. [248] Qualifying as disabled requires the use of expensive tests that may be difficult to obtain in public hospitals. [249] Moreover, although CDC estimates that sixty percent of all persons with HIV would benefit by early intervention, Medicaid withholds this type of treatment through its strict disability rules. Consequently, low-income HIV-infected persons dependent on Medicaid are deprived of valuable and life-prolonging medical care and may die sooner than wealthier patients. [250]

The financial requirements create similar problems of access to people with HIV. Thirteen states have no "spend-down" provisions for the medically needy, [251] requiring applicants to effectively impoverish themselves before they become eligible for Medicaid funds. [252] In addition, once applicants do qualify, they can

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248 Id. at 185. For a discussion of HIV-infected women and problems with access to health care, see supra notes 46-67 and accompanying text. The variation in eligibility requirements also raises issues of fairness as HIV-infected patients in more affluent states can receive more coverage. For example, a 1987 study found that 54 percent of patients with AIDS were eligible for Medicare in the Northeast, compared to 18 percent in the South. HEALTH CARE REFORM, supra note 1, at 105 (citing National Commission on Aids report).

The ABA believes it important that both "[p]ublic and private entities . . . expeditiously develop and implement HIV-related programs targeted to serve minority communities." ABA POLICY & REPORT ON AIDS, supra note 23, § D.4, at 12.

249 Shacknai, supra note 32, at 185.

250 HEALTH CARE REFORM, supra note 1, at 103-04 (citations omitted). In fact, studies show that early intervention saves the government money by delaying expensive end-stage care into the future. Patients who have received early intervention also require less expensive hospitalization in the latter stages of the disease. Id. (citations omitted).

251 See supra note 244 and accompanying text.

252 Shacknai, supra note 32, at 187; see also HEALTH CARE REFORM, supra note 1, at 106-07.

easily rise above the required income level and disqualify themselves. Thus, even though HIV-infected persons may be able to work, Medicaid discourages employment by requiring those eligible for aid to remain poor. [253] In addition, in the states that have no provisions for the medically needy, Medicaid eligibility may be forfeited upon an individual's qualification for Social Security benefits after losing his or her job. These persons are effectively in "limbo" because they are precluded from obtaining private insurance and are placed out of Medicaid coverage. [254]

The types of Medicaid coverage and service adversely affect persons with AIDS and HIV as well. [255] Some services, such as in-patient hospital care, outpatient care, and laboratory services are required to be covered under federal mandate. Other services, including prescription drugs, hospice care, case management, and intermediate care facility services are optional. [256] Currently, however, only ten states provide for home- and community-based services, which are increasingly recognized as more effective than in-patient care for many HIV-infected persons. Hospice services are part of the Medicaid program in only about half the states. [257]

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253 Shacknai, supra note 32, at 188.

254 Bartlett, supra note 162, at 219.

255 The ABA advocates "flexible mechanisms for payment, including expediting the Medicaid waiver review process, to allow more treatment alternatives for HIV. ABA POLICY & REPORT ON AIDS, supra note 23, § D.3, at 12.

256 CLEARINGHOUSE REV., supra note 14, at 730.

257 Shacknai, supra note 32, at 190. In addition to their effectiveness, these alternatives are less costly than full hospitalization, the most expensive health care option. Id. at 194.

Home- and community-based care may be provided if a state first obtains a "section 2176 waiver." Congress has authorized states to focus on certain groups,

[Footnote continued]

It is also common for state Medicaid plans to place limits on whatever services they do offer. These limits restrict the effectiveness of health care available for low-income PWAs and may increase government expense in the long run.[258] For example, Medicaid agencies may limit the number of hospital days, doctor visits, or types of specific services that they will cover. [259] In addition, when Medicaid covers a service, it often has a low rate of reimbursement. [260] This discourages health care providers from treating HIV-infected persons and forces these patients into busy public hospitals and clinics. [261] Although all jurisdictions cover the optional service of prescription drugs, some states limit the number of refills or place cost limits on reimbursement. [262] Every state currently reimburses for AZT, but other drugs, such as aerosolized pentamidine and fansidar, may be excluded or limited. [263] In addition, low-income persons may be unable to take advantage of the recent liberalization in the availability of experimental drugs

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[Footnote continued]

such as persons with AIDS, in providing services like private nursing and hospice care. See 42 U.S.C. § 1396(n) (1988); CLEARINGHOUSE REV., supra note 14, at 733. There are limits, however. The waivers cannot be used to provide services otherwise provided by the state and cannot include vocational or educational activities. CLEARINGHOUSE REV., supra note 14, at 733.

258 HEALTH CARE REFORM, supra note 1, at 108.

259 CLEARINGHOUSE REV., supra note 14, at 730-31. For example, Arkansas limits recipients to twelve covered days of inpatient care per year and Louisiana provides for only ten. Bartlett, supra note 162, at 219.

260 See Shacknai, supra note 32, at 190.

261 HEALTH CARE REFORM, supra note 1, at 107.

262 Shacknai, supra note 32, at 191.

263 Id.

because most state Medicaid programs require full approval from the Food and Drug Administration for reimbursed treatments. [264]

Limitations on Medicaid services have been challenged in several states and jurisdictions have been split in their responses. [265] Federal rules require that the extent of covered Medicaid services must be "sufficient in amount, duration, and scope to reasonably achieve its purpose." [266] For example, the Fourth Circuit, citing the flexibility of states under Medicaid, has upheld limitations on the number of covered days of in-patient and outpatient hospital services. [267] California courts, on the other hand, have struck down a state rule that arbitrarily restricted the drugs the program would reimburse. [268] The Supreme Court has also

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264 See HEALTH CARE REFORM, supra note 1, at 110-111; Shacknai, supra note 32, at 191. Activists pressured the FDA to broaden the availability of investigational new drugs (INDs) for HIV-infected people. Medicaid, however, does not cover these INDs until there is complete FDA approval. Shacknai, supra note 32, at 191.

265 See HEALTH CARE REFORM, supra note 1, at 108-09. In general, state limitations must comport with federal regulations requiring the services to be adequate in amount, duration, and scope, and to cover all "medically necessary" services. See CLEARINGHOUSE REV., supra note 14, at 731.

266 42 C.F.R. § 440.230(b) (1992).

267 Charleston Memorial Hosp. v. Conrad, 693 F.2d 324 (4th Cir. 1982) (cited in HEALTH CARE REFORM, supra note 1, at 109 n.168; see also, e.g., Ellis v. Patterson, 859 F.2d 52 (8th Cir. 1988); Curtis v. Taylor, 625 F.2d 645 (5th Cir. 1980); Stan Dorn, et al., Maximizing Coverage for Medicaid Clients, 20 CLEARINGHOUSE REV. 411, 411-414 (1986).

268 Jeneski v. Myers, 163 Cal. App. 3d 18, 209 Cal. Rptr. 178 (Cal Ct. App. 1984), cert den'd sub nom Kizer v. Jeneski, 471 U.S. 1136 (1985) (cited in HEALTH CARE REFORM, supra note 1, at 109); see also Dorn et. al, supra note 267, at 218-19.

held that a state's reduction in Medicaid coverage of hospital days does not violate the Federal Rehabilitation Act. [269]

2. Medicare

In general, Medicare covers citizens over age sixty-five and persons with a disability who meet certain work history requirements. Medicare provides only one percent of the AIDS health care expenses. [270] Medicare is tied to Social Security Disability Insurance employment history requirements, and thus individuals with an inadequate past work record may be ineligible for benefits. [271] Even more significantly, an otherwise eligible participant must have received SSDI checks for two years -- making this program essentially irrelevant to many PWAs who never live long enough to take advantage of it. [272] Although there has been support for eliminating this waiting period, [273] this change may be prohibited by cost considerations. [274]

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269 Alexander v. Choate, 469 U.S. 287 (1985). The court expressly noted that it was not addressing federal Medicaid requirements. Id. at 304 n.23.

270 Bartlett, supra note 162, at 218.

271 HEALTH CARE REFORM, supra note 1, at 128.

272 See CLEARINGHOUSE REV., supra note 14, at 725 (citations omitted).

273 See e.g., CONFRONTING AIDS, supra note 175, at 280; Shacknai, supra note 32, at 197.

274 It has been estimated that the elimination of the two year delay for persons with AIDS would cost the federal government $2-8 billion over five years. Of course, persons with other disabilities would also demand a waiver, leading to even higher expense. Removal of the waiting period for all terminally ill Medicare participants is estimated at $6-15 billion. Bartlett, supra note 162, at 218-19 (citations omitted).

The primary advantage of Medicare is that it reimburses at a higher level than Medicaid, thereby increasing the options of patients looking for doctors and hospitals. [275] However, Medicare's emphasis on in-patient hospital care may exclude some treatments that are important to persons with HIV and AIDS. For instance, prescription drugs and long-term health care facilities are both left out of Medicare coverage. [276]

VI. CONCLUSION

From the basketball court to the courthouse, the AIDS epidemic has reached almost every facet of American life. In the context of access to health care, HIV infection is in many respects no different than other catastrophic and chronic illnesses that have historically affected large population groups. On the other hand, HIV and AIDS present somewhat unique problems that pose special challenges, many of them legal, to any comprehensive plan for health reform: the demographic trends which portray a disease that is increasingly becoming one of the inner city; the discrimination associated with AIDS due to its means of transmission and the social stigma that has accompanied its growth; the efforts of the private insurance industry to limit coverage for AIDS-related treatment; and the resulting burden on public finance and programs that appear inadequate to help many persons with HIV.

Some of these issues have only recently emerged and are becoming the objects of research and scholarship. What is clear, however, is that no successful modification of health care access for Americans can occur without confronting the effect that the AIDS virus has on almost every aspect of the American health care

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275 Shacknai, supra note 32, at 197.

276 Id. at 189; HEALTH CARE REFORM, supra note 1, at 128.

system. At the same time, the concerns raised by the AIDS epidemic in the last decade have made apparent the need for thoughtful and significant changes in the way health care is provided in the United States. Lawyers will play a significant role in these changes.