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State AIDS-Related Legislation in the 1990s: Adopting a Language of Hope Which Affirms Life

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Karen S. Lovitch*

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I. INTRODUCTION

The medical community first recognized the Human Immunodeficiency Virus, or HIV disease,² well over a decade ago,³ and the epidemic continues to progress worldwide.⁴ Unfortunately, legislative responses across the nation have lagged far behind the epidemic's epidemiological growth.⁵ Unmotivated by the urgency of this situation, the United States government has failed to outline a national strategic plan to combat the spread of HIV disease and to address the needs of those affected by it.⁶ In the absence of

2. See Chai R. Feldblum, *Workplace Issues: HIV and Discrimination*, in AIDS AGENDA 271, 276-77 (Nan D. Hunter et al. eds., 1992) (noting that the term "HIV disease" refers to the disease as it runs on a continuum from HIV-infection to full-blown AIDS). Incidentally, the Americans with Disabilities Act ("ADA") uses this term, which reflects the current medical view that strict categories cannot describe the disease's progression accurately. *Id.*

3. Helen Brett-Smith & Gerald H. Friedland, *Transmission and Treatment*, in AIDS LAW TODAY 18, 18 (Scott Burriss et al. eds., 1993) (commenting that a 1981 Centers for Disease Control ("CDC") publication first mentioned the disease in a brief article about pneumocystis pneumonia). Researchers subsequently pinpointed the Human Immunodeficiency Virus ("HIV") as the cause of Acquired Immune Deficiency Syndrome ("AIDS"). *Id.* For an HIV-carrier to transmit the virus, the infected person's blood, semen, or vaginal secretions must come into contact with the blood or mucous membranes of an uninfected person. *Id.* at 23. The virus cannot live long outside human tissue, and household cleaning agents easily eradicate it. *Id.* at 24. The virus is not passed by casual contact. *Id.*

4. See CENTERS FOR DISEASE CONTROL AND PREVENTION, HIV/AIDS SURVEILLANCE REPORT 5, 14 (Jun. 1995) [hereinafter SURVEILLANCE REPORT] (reporting that states have reported over 476,000 cases of AIDS since the epidemic began and about 290,000 of those individuals have died); *Meeting Lays Bare the Abyss Between AIDS and Its Cure*, N.Y. TIMES, Aug. 12, 1994, at A1, A9 [hereinafter *Meeting*] (summarizing the events of the 10th International Conference on AIDS). At the time of the first conference in 1985, the United States had reported only 9285 cases. *Id.* All states have laws requiring public health authorities to report AIDS cases, but not HIV infection. See SURVEILLANCE REPORT, *supra*, at 30. Public health officials estimate that approximately one million people currently carry the virus, and may do so unknowingly. See Brett-Smith & Friedland, *supra* note 3, at 19. Even if transmission ceased immediately, the epidemic's most ominous effects would take place in the future. *Id.*

5. See NATIONAL COMMISSION, *supra* note 1, at 13 (asserting that all levels of government have shirked the responsibility of searching for legislative solutions to dilemmas posed by the epidemic). This lack of interest is a problem of international proportions. Dr. Jonathan M. Mann, professor of epidemiology at the Harvard Law School of Public Health, has warned that countries all over the world have responded inadequately to the growing pandemic. *Meeting*, *supra* note 4, at A1, A9.

6. See NATIONAL COMMISSION, *supra* note 1, at 3 (admonishing President Clinton for his lack of coordination of AIDS activities within the executive branch, as recommended by the Commission in the past); Philip J. Hiltz, *AIDS Policy Chief Quits Clinton Post After Rocky Tenure*, N.Y. TIMES, July 9, 1994, at A1, A9 (quoting an AIDS advocate who

strong leadership at the federal level,⁷ state governments must lead the way in passing Acquired Immune Deficiency Syndrome ("AIDS")-related legislation.⁸

In its final report, the National Commission on AIDS listed a number of principles meant to guide future responses to HIV disease.⁹ Even though these tenets cover a wide range of concerns and the legislative possibilities are practically endless, this paper will concentrate on recommendations for state legislation necessary to place a "human face" on HIV disease.¹⁰ For a number of reasons, states must not lose sight of the fact that individuals, not just groups of people, suffer from HIV disease.

First, people living with HIV disease deserve special attention from state legislators because they have endured discrimination in a number of areas since the epidemic's beginning.¹¹ Prejudice has extended from individuals actually living with HIV disease to their friends and family, and even to uninfected people perceived to carry the virus because of their membership in so-called "high-risk" groups.¹² Individuals in society often discriminate against these individuals because of a fear of transmission or

expressed dissatisfaction with Kristine Gebbie's performance, based on her inability to build the coalitions necessary to form a national program).

7. See NATIONAL COMMISSION, *supra* note 1, at 2 (criticizing the federal government for its "complacent unresponsiveness" to the epidemic).

8. *Id.* at 13 (calling for the cooperation of leaders at all levels). The National Commission asserted that if all leaders engaged in honest discussions about HIV disease, their actions would profoundly affect the response of our nation as a whole. *Id.*

9. *Id.* at 12 (listing seven general principles that should guide specific steps in developing a more affirmative approach to the HIV epidemic).

10. *Id.* The principle reads as follows: "The human face of AIDS should be ever before us. Respecting personal dignity and autonomy, respecting the need for confidentiality, reducing discrimination, and minimizing intrusiveness should all be touchstones in the development of HIV/AIDS policies and programs." NATIONAL COMMISSION, *supra* note 1, at 12. Upon the death of Pedro Zamora, a 22-year-old AIDS activist, President Clinton noted the importance of Zamora's progress in teaching the nation that "AIDS is a disease with a human face." Jon O'Neill, *AIDS Crusader Fought for Awareness*, MIAMI HERALD, Nov. 12, 1994, at A1, A18.

11. See Arthur S. Leonard, *Discrimination*, in AIDS LAW TODAY, *supra* note 3, at 297 (lamenting that "a secondary epidemic of fear" has accompanied the HIV epidemic since it began).

12. *Id.*; see also Ann Devroy & David Brown, *Clinton Assails Helms's AIDS Stance: Anti-Gay Remarks Fuel Push for Reapproval of Treatment Program*, WASH. POST, July 6, 1995, at A6 (quoting Senator Jesse Helms (R-N.C.), who expressed such prejudice by stating that Congress should cut AIDS funding because "homosexuals get the disease through their 'deliberate, disgusting, revolting conduct'").

antipathy toward the groups hardest hit by HIV disease to date.¹³ As costs associated with HIV disease continue to rise, government agencies and private businesses also have engaged in AIDS-related discrimination based on financial as well as personal reasons.¹⁴

At the federal level, the Americans with Disabilities Act (“ADA”)¹⁵ appears to protect persons living with AIDS and asymptomatic HIV carriers from AIDS-related discrimination.¹⁶ Because the ADA does not cover all private-sector activities, states also must offer protection from discrimination.¹⁷ In addition, state legislation is important because it may provide stronger remedies than those available under federal law.¹⁸ Discrimination

13. *Id.*; see also Allan M. Brandt, *AIDS and Metaphor: Toward the Social Meaning of Epidemic Disease*, 55 SOC. RES. 413, 425-32 (1988) (discussing AIDS in a cultural context). Brandt argues that society discriminates against persons with HIV disease for a number of reasons. First, HIV disease is the only communicable, fatal disease to surface in recent times and, as a result, has threatened society’s sense of “medical security.” *Id.* at 425-26. Second, many individuals morally judge those affected by the disease. *Id.* at 428. Society’s historical disdain for two “high-risk” groups, homosexuals and intravenous drug users, and for promiscuity also have led to discrimination. *Id.* at 428-29, 431. These individuals often react by dividing victims into categories of “innocent” and “guilty.” *Id.* at 430.

14. Leonard, *supra* note 11, at 297. For example, the United States government now requires that all service members with the AIDS virus must leave the armed services, regardless of the severity of their condition. Dana Priest, *Army Sergeant with HIV Feels Deserted by Policy*, WASH. POST, Feb. 1, 1996, at A3. Representative Robert Doran (R-Cal.), who introduced the bill, stated “that AIDS ‘is spread by human God-given free will’” and that service members contract it only through intravenous drug use or unprotected sex with prostitutes or strangers. *Id.*

15. 42 U.S.C. §§ 12101-12213 (1994).

16. See *Doe v. Kohn, Nast & Graf*, 862 F. Supp. 1310 (E.D. Pa. 1994) (asserting that an asymptomatic HIV-infected individual is disabled, as defined by ADA). In that case, the court denied a motion for summary judgment filed by the defendant law firm, whom Doe contended fired him after his supervisor discovered he carried the virus. *AIDS Suit Against Philly Firm Proceeds*, NAT’L L.J., Aug. 22, 1994, at A1, A10. After three weeks of federal district court testimony, the case ended with a secret settlement. Joseph A. Slobodzian, ‘*Scott Doe*’ *AIDS Lawsuit Is Settled*, PHILA. INQUIRER, Nov. 1, 1994, at A1, A8. In a closing speech before dismissing the jurors, Judge Robert S. Gawthrop, III announced that “if nothing else, this case has humanized the terrible disease of AIDS.” *Id.*

17. See Leonard, *supra* note 11, at 311 (noting that the ADA does not apply to employers with less than 15 employees and to public accommodations that do not “affect commerce”). Further, state and local civil rights agencies historically have dealt with AIDS-related discrimination claims and, as a result, have developed expertise and efficiency in this area. *Id.*

18. *Id.* (pointing out that some state laws, unlike the federal scheme, do not cap punitive damages). In cases where discrimination is particularly overt or outrageous, a plaintiff may want to pursue a larger award under state law. *Id.*

is an underlying societal factor contributing to the spread of HIV disease, so states must act quickly to eradicate it.¹⁹

Second, states must enact legislation recognizing the individual needs of persons with HIV disease because it is a "resource-intensive" condition.²⁰ Recent treatments have prolonged the lives of many HIV-infected individuals, but a disadvantage of these improvements is that they require a great deal of time, physical and mental energy, and money.²¹ Much more than medical resources is needed to cope with HIV disease. Those infected require a host of services and forms of assistance to meet their needs.²² HIV disease not only places demands on HIV-infected individuals and their families but also on medical, social, and legal support systems.²³ States must protect all members of society from such a drain by passing appropriate legislation.

Some critics contend that "AIDS is just one disease"²⁴ and those infected by it do not deserve special attention. State governments, however, must consider the special characteristics of HIV disease before conceding to this point of view. As compared to other concerns, AIDS is an epidemic for which no cure or vaccine exists.²⁵ Even though it is theoretically preventable, AIDS is out of control; treatment can only slow its progression, and death is always its ultimate outcome.²⁶ Another way in which AIDS differs from other diseases is that it strikes mostly young, working-age individuals, and relative to other causes of death, it claims a disproportionate number of young lives.²⁷ Denial of the epidemic's urgency is an inade-

19. See *Meeting*, *supra* note 4, at A1, A9 (quoting Dr. Jonathan Mann, who stated that discrimination, poverty, and lack of education encourage the spread of AIDS).

20. Brett-Smith & Friedland, *supra* note 3, at 42. This article provides a detailed example of the obstacles that a 40-year-old woman with HIV disease must face. *Id.* at 41-42.

21. Don Colburn, *AIDS Patients Paying a Price for Longevity*, WASH. POST, July 30, 1995, at A1, A27 (explaining that long-term survivors face medical as well as economic hardship).

22. *Id.* at 42 (listing "psychosocial support, legal advice, pastoral counseling, and someone to help with public assistance or insurance paperwork" as just a few of the needs of an individual with HIV disease).

23. *Id.*

24. NATIONAL COMMISSION, *supra* note 1, at 1 (observing that this contention is often used to argue against allocating funds to HIV disease).

25. *Id.*

26. *Id.*

27. *Id.*; see also *AIDS Becomes Main Killer of Young Adults*, WASH. POST, Feb. 1, 1995, at A2 [hereinafter *Main Killer*] (revealing that AIDS and related infections now claim more young adult lives than accidents). A Centers for Disease Control ("CDC") official noted that the impact of AIDS deaths "goes far beyond their absolute numbers." *Id.*

quate response;²⁸ states must consider the fact that an average of ten years separates HIV infection and an AIDS diagnosis.²⁹ Even if infection ceased immediately, the system still would face enormous challenges in caring for those already infected.³⁰

This paper discusses ways in which state legislation can embody respect for the individual plight of those living with HIV disease. To illustrate the types of laws that states must pass to meet that goal, this paper uses the most effective provisions from states across the country. Part I examines ways in which state lawmakers can eradicate discrimination, a threat to those already living with HIV disease and to future prevention and control efforts. AIDS-related discrimination can pervade many facets of life. This paper explores those in which individuals face the largest number of difficulties before and after learning of their status and recommends laws that can prevent this unfair treatment. Part II surveys specific areas in which present laws inadequately address the needs of individuals and proposes legislation that states must pass to bridge this gap. This paper concludes that, to help those living with HIV disease while simultaneously encouraging prevention and control, states must mandate comprehensive HIV education programs as well as the other suggested legislation.

II. PREVENTING AIDS-RELATED DISCRIMINATION

A. *Extension of State Disability Discrimination Laws to Specifically Cover AIDS-Related Discrimination*

In calling for HIV/AIDS policies and programs that respect the human dignity of those involved, the National Commission on AIDS declared that reducing discrimination is an integral step toward this goal.³¹ State governments must protect persons with HIV disease by adding AIDS-related discrimination to the current protection offered in state anti-discrimination or disability discrimination laws.³² Although federal disability discrimina-

28. NATIONAL COMMISSION, *supra* note 1, at 1 (asserting that the effects of continued denial include homelessness, a lack of necessary research because of underfunding, and inadequate long-term and acute care facilities).

29. *Id.* at 5 (warning that AIDS diagnoses “tell a story that is out of date”).

30. *Id.* at 5-6 (forecasting that prevention efforts must improve to prevent new infections).

31. NATIONAL COMMISSION, *supra* note 1, at 12.

32. *See* Leonard, *supra* note 11, at 298 (noting that most states have supplemented federal disability discrimination protection by passing their own laws in the 1970s and early 1980s).

tion laws already provide vast protection, states also must show their support for individuals with HIV disease, and thereby fill the gaps left by federal laws.³³

1. The Americans with Disabilities Act

At the federal level, the ADA forbids disability discrimination in employment,³⁴ public services,³⁵ and public accommodations.³⁶ It applies to state and local governments,³⁷ and employment provisions cover private employers with fifteen or more employees.³⁸ Additionally, the ADA prohibits most all private businesses or individuals supplying goods or services to the public from engaging in public accommodations discrimination.³⁹ Although the ADA does not specifically mention HIV disease in its text, the regulations indicate that the statute's definition of "disability" covers HIV disease.⁴⁰ At least one federal court decision has agreed with this approach.⁴¹

33. *See supra* notes 15-19 and accompanying text (explaining that state laws often cover more private employers and offer more extensive remedies than federal disability discrimination laws). If an issue of sexual orientation is also involved, state law may offer better protection in that a few states forbid discrimination based on this characteristic. Leonard, *supra* note 11, at 312-13.

34. 42 U.S.C. §§ 12111-12117.

35. 42 U.S.C. §§ 12131-12165 (forbidding state and local government discrimination in public accommodations and services). This prohibition includes employment discrimination. 35 C.F.R. § 35.140 (1992).

36. 42 U.S.C. §§ 12181-12189 (directing private entities that disability discrimination in public accommodations is unlawful); *id.* §§ 12131-12165 (extending the same prohibition to state and local governments).

37. *Id.* §§ 12131-12165.

38. *Id.* § 12111.

39. *Id.* §§ 12181-12189. Examples of public accommodations include hotels, restaurants, theaters, stadiums, convention centers, museums, parks, private schools, malls, health care providers, and hospitals. 42 U.S.C. § 12181(7).

40. 29 C.F.R. app. § 1630.2(j) (1992) (noting that AIDS and HIV seropositivity may come within the classification). Individuals who are actually infected as well as those perceived to be infected receive protection because the regulations define a "person with a disability" as "(a) a person with a physical or mental impairment that substantially limits one or more major life activities; or (b) a person with a record of such a physical or mental impairment; or (c) a person who is regarded as having such an impairment." *Id.* § 1630.2(g).

41. *See Doe v. Kohn, Nast & Graf*, 862 F. Supp. 1310 (E.D. Pa. 1994) (holding that asymptomatic HIV infection is a covered disability under federal law).

2. The Rehabilitation Act of 1973

Before the ADA, the Rehabilitation Act of 1973⁴² (“Rehabilitation Act”) was the only federal law that covered handicap-related discrimination, and this statute, rather than the ADA, still applies to the federal government.⁴³ When Congress adopted the ADA, it modeled many of its provisions, including its definition of a “disability,” after the Rehabilitation Act.⁴⁴ The Rehabilitation Act, like the ADA, does not expressly cover HIV disease, but courts have extended its definition of a “handicap” to cover AIDS⁴⁵ as well as HIV infection.⁴⁶

3. Federal Disability Discrimination Protection

Protection under both statutes is not absolute, but it varies depending on the situation and the particular statute.⁴⁷ In an employment discrimination situation, for example, only a “qualified individual with a disability” receives protection under both statutes.⁴⁸ To become qualified, a disabled individual may require reasonable accommodations to perform the job’s essential functions.⁴⁹ Disability discrimination laws, therefore, do not offer

42. 29 U.S.C. §§ 701-797 (1994).

43. See 29 U.S.C. § 791 (forbidding federal agencies to engage in discrimination in the hiring, placement, and promotion of people with disabilities). The law also applies to federal contractors. 29 U.S.C. § 793.

44. Leonard, *supra* note 11, at 301 (noting that the two definitions are “virtually identical”). Court cases interpreting the Rehabilitation Act may, therefore, serve as precedent in ADA cases. See *id.*

45. See *School Bd. v. Arline*, 480 U.S. 273, 281 (1987) (declaring that tuberculosis, a contagious disease, is a handicap as defined by the statute). The Court refused to validate discrimination based on irrational fears of contagion and considered such reactions inconsistent with the Rehabilitation Act’s goals. *Id.* at 282. Lower courts subsequently extended this landmark decision to the AIDS-related discrimination context. See *Chalk v. United States Dist. Ct.*, 840 F.2d 701, 711 (9th Cir. 1988) (holding that AIDS is a handicap under the Rehabilitation Act).

46. See *Doe v. Centinela Hospital*, 57 U.S.L.W. 2034, 2034 (C.D. Cal. Jul. 19, 1988) (holding that a drug treatment program may not exclude an asymptomatic carrier of the HIV virus because of his condition).

47. Leonard, *supra* note 11, at 302.

48. See *id.* (noting that the ADA adopted this Supreme Court interpretation of the Rehabilitation Act); see also *Southeastern Community College v. Davis*, 442 U.S. 397, 414 (1979) (holding that disability law only protects those who can safely perform the position’s requirements).

49. 42 U.S.C. § 12111(8); Leonard, *supra* note 11, at 303 (pointing out that the “essential functions” requirement first arose in Rehabilitation Act case law and that Congress codified it in the ADA).

protection to those who cannot perform the job's essential functions or who present a significant risk of transmission in the workplace.⁵⁰ The former limitation presents a much greater obstacle for individuals with HIV disease than the latter because courts have held, and medical evidence shows, that the risk of casual transmission is minimal.⁵¹

4. Recommendations for State AIDS-Related Discrimination Legislation

All fifty states offer some type of disability discrimination protection.⁵² However, they still should pass legislation specifically covering AIDS-related prejudice to ensure that persons with HIV disease do not suffer "irrational and scientifically unfounded" discrimination.⁵³ Florida and Kentucky, for example, both have enacted laws that extend disability-related employment discrimination coverage to individuals with AIDS, AIDS-related complex, or HIV infection.⁵⁴ Florida goes one very necessary step further to protect those perceived as having any of these conditions.⁵⁵ Both laws also forbid HIV-related testing as a condition of employment, unless the absence of infection is a bona fide occupational qualification for the job in question.⁵⁶ If a state chooses to include such

50. See 42 U.S.C. § 12113(b) (allowing employers to disqualify an employee or potential employee who may pose such a threat in the workplace).

51. See *Chalk v. United States Dist. Ct.*, 840 F.2d 701, 701 (9th Cir. 1988) (holding that a teacher with AIDS did not pose a direct threat to students in the classroom). This paper does not address the controversy surrounding the employment of HIV-infected health care workers. See Feldblum, *supra* note 2, at 282-84 (discussing the debate about the possibilities of health care workers posing a "direct threat" in the workplace).

52. David L. Kirp & Ronald Bayer, *The United States: At the Center of the Storm*, in AIDS IN THE INDUSTRIALIZED DEMOCRACIES 7, 18 (Kirp et al. eds., 1991).

53. FLA. STAT. § 760.50(1) (1995). The Florida Legislature further elaborated that this discrimination causes harm to society in general and to "otherwise able-bodied persons" deprived of the ability to support themselves, to secure their own means of health care and housing, and to take advantage of societal opportunities otherwise available to them. *Id.*

54. *Id.* § 760.50(2); KY. REV. STAT. ANN. § 207.135(1) (Michie 1995); see also WASH. REV. CODE ANN. § 49.60.174(1) (West 1993) (providing that claims based on actual or perceived HIV infection should receive the same treatment as any other discrimination claim based on a disability).

55. See FLA. STAT. § 760.50(2). But see VA. CODE ANN. §§ 51.5-40 to 51.5-46 (Michie 1994 & Supp. 1995) (covering only actual, as opposed to perceived, disabilities).

56. See, e.g., FLA. STAT. § 760.50(3); KY. REV. STAT. ANN. § 207.135(2). The person requiring the test has the burden of proving that the test is necessary to determine if the individual can perform the duties of the job in a reasonable manner or presents a significant risk of transmitting the disease in the course of employment duties. FLA. STAT. §

testing provisions, it must construe them narrowly to respect individual privacy rights.

Both laws also forbid discrimination against those infected or perceived to be infected in housing, public accommodations, or governmental services.⁵⁷ Such treatment is warranted only if the person or entity can show that no reasonable accommodation can prevent transmission of the virus in the applicable context.⁵⁸ Again, states must ensure that these restrictions are applied only in limited circumstances so that HIV-infected individuals receive fair treatment.

To send a message of support to its citizens, states also must provide adequate remedies to persons aggrieved under their discrimination statutes. Florida does so in that it requires violators to pay actual damages, attorney's fees, and other appropriate relief and provides for court-ordered injunctions as well.⁵⁹

The ADA does not preclude disabled persons from bringing suit under another law that provides equal or greater protection,⁶⁰ so passing AIDS-related discrimination laws will serve a dual purpose. First, state legislatures will exhibit leadership by passing anti-discrimination laws that protect HIV-infected individuals,⁶¹ as called for in the National Commission's recommendations,⁶² and also lay the foundation for prevention efforts.⁶³ Second, if state laws include the necessary provisions as outlined above, they will complement federal laws and increase the possibility that AIDS-related discrimination will cease in all aspects of society.⁶⁴

760.50(3)(c)(1); KY. REV. STAT. ANN. § 207.135(2)(b)(1). No other reasonable accommodations short of the test may exist. FLA. STAT. § 760.50(3)(c)(2); KY. REV. STAT. ANN. § 207.135(2)(b)(2).

57. FLA. STAT. § 760.50(4); KY. REV. STAT. ANN. § 207.135(3).

58. See FLA. STAT. § 760.50(4)(c); KY. REV. STAT. ANN. § 207.135(3)(c). Both laws also prohibit adverse employment action against licensed health care professionals who treat HIV-infected individuals. FLA. STAT. § 760.50(4)(d); KY. REV. STAT. ANN. § 207.135(3)(d).

59. FLA. STAT. § 760.50(6)(a).

60. 42 U.S.C. § 12201(b).

61. See NATIONAL COMMISSION, *supra* note 1, at 13 (directing leaders at all levels to speak out because they can join communities and discover solutions to the problems posed by the epidemic).

62. *Id.* at 12 (identifying respect for personal dignity as an important part of AIDS/HIV policies and programs).

63. See *id.* at 10 (explaining that reducing discrimination and stigmatization can increase awareness, which will lead to more effective prevention efforts).

64. See Leonard, *supra* note 11, at 310 (exploring advantages of hierarchy of disability discrimination laws).

B. *Passage of Laws Requiring Voluntary Testing and Strict Confidentiality of HIV-Related Information*

One specific area in which discrimination often surfaces is in the debate surrounding HIV testing and confidentiality of HIV-related information. Because of the fears associated with transmission,⁶⁵ and disdain for the lifestyles of the majority of victims,⁶⁶ the public initially responded to HIV disease by calling for mandatory testing to identify those infected.⁶⁷

1. Voluntary vs. Mandatory Testing

For two primary reasons, the public health community,⁶⁸ and virtually all state jurisdictions,⁶⁹ agree that mandatory testing is not a viable option and that voluntary programs are more likely to increase prevention efforts. First, test results are not always reliable. The “window period” between infection and development of HIV antibodies usually lasts for at least six weeks,⁷⁰ and commonly extends to a period of six months.⁷¹ This latency period makes a negative test result virtually meaningless because the infected person may test negative even though that individual is a carrier

65. See Peter H. Berge, *Setting Limits on Involuntary HIV Antibody Testing Under Rule 35 and State Independent Medical Examination Statutes*, 44 FLA. L. REV. 767, 778 (1992) (examining the history of epidemics and asserting that human responses to them are motivated more by fear than compassion). Berge observes that:

[t]he picture of the AIDS victim is a shell of a man wasted by the opportunistic infections, his deeply recessed eyes staring out from a death's head skull in hopeless, disoriented pain. . . . This disease causes its victims to experience a hell on earth; people are terrified out of their rational minds.

Id. at 779.

66. See *id.* at 779-80 (arguing that, even though HIV disease has invaded the sanctity of most societal groups, average Americans still consider it immoral and associate it with “undesirables”).

67. See Lawrence K. Altman, *U.S. Is Considering Much Wider Tests for AIDS Infection*, N.Y. TIMES, Feb. 4, 1987, at A1 (relating that federal health officials may suggest that all persons seeking marriage licenses, hospitalization, and treatment for pregnancy or sexually transmitted disease undergo mandatory testing).

68. Berge, *supra* note 65, at 785-86 (reporting that CDC, National Academy of Sciences, American Medical Association, United States Surgeon General, United States Public Health Service, and most state and local public health services have rejected mandatory testing).

69. *Id.* at 786 (relating that most states' AIDS prevention laws center around voluntary testing provisions).

70. See Scott Burris, *Testing Disclosure, and the Right to Privacy*, in AIDS LAW TODAY, *supra* note 3, at 115, 118 (observing that the latency period in some individuals has lasted as long as two years).

71. See Berge, *supra* note 65, at 785.

and capable of transmitting the virus to someone else.⁷² In addition to the window period, human error also can compromise the reliability of testing programs.⁷³ A second reason that public health officials and lawmakers have rejected mandatory testing is that the financial costs of such programs are extremely prohibitive.⁷⁴

2. Features of Voluntary Testing Programs

Voluntary testing programs are an integral part of any state's AIDS-related legislative agenda⁷⁵ because they can prevent discrimination and deter the spread of HIV disease.⁷⁶ While most jurisdictions already require consent, or at least imply that individuals must consent to the test, states differ on the degree of confidentiality offered, the type of consent needed, and the number of exceptions allowed.⁷⁷ To encourage testing, all states must provide for written and informed consent, pre- and post-test counseling, strict confidentiality of HIV-related information, and anonymous testing, as an alternative.

a. *Written and Particularized Informed Consent*

Even though researchers have not discovered a vaccine or a cure, early detection is still vital because treatments, such as Azidothymidine ("AZT"), can prolong the lives of those affected.⁷⁸ The benefits, however, may not

72. Martha A. Field, *Testing for AIDS: Uses and Abuses*, 16 AM. J.L. & MED. 33, 41 (1990).

73. *Id.* at 40 (pointing out that human error poses a danger of false negative as well as false positive results).

74. *Id.* at 55-56 (examining the enormous costs spent in early mandatory testing programs for all marriage license applicants). Out of the 159,000 applicants tested in Illinois in 1988, only 23 individuals tested positive. *Id.* The estimated total cost was \$5.6 million, which equaled \$243,000 for each positive result. *Id.* at 56.

75. *See* Burris, *supra* note 70, at 120 (recalling that some states joined an early 1990s movement to encourage voluntary testing).

76. *See* 35 PA. CONS. STAT. ANN. § 7602(a) (1993) (recognizing that voluntary testing, coupled with informed consent and counseling, will control the spread of HIV disease if results are kept confidential). Confidential, informed, voluntary testing will encourage those most in need to seek testing and treatment. *Id.* § 7602(c).

77. *See* Berge, *supra* note 65, at 788 n.146 (supplying list of state statutes that cover HIV testing).

78. *See* Brett-Smith and Friedland, *supra* note 3, at 40 (explaining that, over the last five years, treatment strategies in the United States have evolved to emphasize AZT therapy as soon as the T4 cell count goes below 500); Philip J. Hilts, *Drug Said to Help AIDS Cases with Virus but No Symptoms*, L.A. TIMES, Aug. 18, 1989, at A1 (providing early report on

always outweigh the negative consequences of knowing one's status. For example, once an individual tests positive, he or she may face widespread discrimination.⁷⁹

Considering the costs and benefits involved, states must allow individuals to make their own decisions about testing.⁸⁰ To ensure that individuals thoroughly weigh their options, states must follow the lead of jurisdictions such as New York, Louisiana, and Pennsylvania and require written and particularized informed consent before anyone undergoes testing.⁸¹ Mere oral consent is not enough because it leaves room for misunderstanding.⁸² Further, particularized consent, rather than blanket consent to medical treatment, is necessary to prevent those administering the tests from "tricking" individuals into having a test without their knowledge. Connecticut protects the rights of potential test subjects by providing precise standards for consent.⁸³

the merits of AZT therapy).

79. See Field, *supra* note 72, at 46 (asserting that repercussions of a positive test result may include enduring discrimination in employment, housing, insurance, and education as well as falling victim to random acts of violence). Field also notes that this discrimination may originate in response to the disease's financial burden or adverse characterization as a member of a perceived high-risk group. *Id.*

80. See Ronald L. Bayer et al., *HIV Antibody Screening: An Ethical Framework for Evaluating Proposed Programs*, 4 NEW ENG. J. PUB. POL'Y 173, 177 (1988) (emphasizing the value of respecting individual choice in the context of testing programs).

81. LA. REV. STAT. ANN. § 40:1300.13.A (1992); N.Y. PUB. HEALTH LAW § 2781 (McKinney 1993); 35 PA. CONS. STAT. ANN. § 7605(a) (1993). In the Ryan White Comprehensive AIDS Resources Emergency Act of 1990, Congress expressed approval for this approach by ordering grant recipients to seek informed, written, voluntary consent. 42 U.S.C. § 300ff-61(b) (1994).

82. See, e.g., CAL. HEALTH & SAFETY CODE § 199.22(a) (Deering 1990) (requiring informed consent but allowing for oral or written agreement); FLA. STAT. § 381.004(3)(a) (1995); N.C. GEN. STAT. § 130A-148(h) (1995).

83. See CONN. GEN. STAT. ANN. § 19a-582(a) (West 1995) (requiring particularized consent, which need only be written "whenever practicable"). Connecticut's statute sets out detailed, minimum standards for the contents of an informed consent statement: (1) an explanation of the test, including its purpose and meaning and the benefits of early diagnosis and treatment; (2) acknowledgement that consent is not a prerequisite to health care but that refusal may affect the provider's quality of treatment and diagnosis; (3) explanation of testing procedures, including its voluntary nature and the fact that anonymous testing is available; and (4) an explanation of confidentiality laws. *Id.* § 19a-582(b). The subject must also receive notification that the law permits health officials to warn known partners without disclosing the subject's identity and that HIV-related information may appear on medical charts and records. *Id.* Before consenting, subjects must receive information about the illness itself and possible risk factors. *Id.* § 19a-582(c).

b. *Pre- and Post-test Counseling*

In addition to requiring informed consent, states must mandate pre- and post-test counseling as an extra guarantee that individuals understand the costs and benefits of testing. Counseling offers a number of advantages because it can clarify misunderstandings about HIV infection; educate people about the importance of prevention; communicate the meaning of test results; and help people handle the vast consequences of a positive result.⁸⁴ Pennsylvania appropriately requires counseling before testing, so that a patient understands the test and the meaning of its results as well as the proper measures for prevention of, exposure to, and transmission of the virus.⁸⁵ If an individual tests positive, states also must afford him or her the opportunity to receive immediate, face-to-face, post-test counseling. Delaware sets an example by providing the individual with an opportunity to discuss the result's emotional effects on the individual, its meaning, and proper preventive measures.⁸⁶ Post-test counseling also should include encouragement to notify sexual and needle-sharing partners.⁸⁷

c. *Strict Confidentiality of HIV-Related Information*

A categorical rule against disclosure of HIV-related information⁸⁸ is the last necessary element for a testing program that recognizes individual rights. To reach this worthy goal, states must give individuals control over the disclosure of their own HIV-related information.⁸⁹ New York, among other states, properly mandates that before release of such data occurs, the person disclosing the information must obtain a written consent form, signed

84. See Field, *supra* note 72, at 48.

85. 35 PA. CONS. STAT. ANN. § 7605(a); see also Burris, *supra* note 70, at 123 (summarizing the provisions of Pennsylvania's pre- and post-test counseling provisions).

86. DEL. CODE ANN. tit. 16, § 1202(e) (1995).

87. *Id.*

88. See N.Y. PUB. HEALTH LAW § 2780(7) (McKinney 1993) (defining "confidential HIV-related information" as that in the possession of one who provides health or social services or who receives the information pursuant to a release of such information). This definition includes not only test results but also the mere fact that the individual took such a test and any information that could identify the individual as carrying the HIV virus or suffering from AIDS or an HIV-related illness. *Id.*

89. Interview with Dinah Wiley, Esq., Legal Services Director, Whitman-Walker Clinic, in Washington, D.C. (Dec. 14, 1994). Ms. Wiley indicated that individuals must have control over their own information and noted that, if universal precautions are used as recommended, disclosure is seldom a necessary event. *Id.*

by the subject of the data.⁹⁰ It must state who will receive the information, for what purpose, and the period of time for which the consent is valid.⁹¹

Considering the effects that a disclosure may have on the individual, states must provide strict remedies for confidentiality violations. California distinguishes between negligent and willful disclosure and subjects guilty parties to civil penalties, payable to the subject of the information. If disclosure results in economic, bodily, or psychological harm, a court may find the disclosing person guilty of a misdemeanor, punishable by a jail term and/or a fine.⁹²

3. Exceptions to Voluntary Testing and Strict Confidentiality Laws

If a state chooses to allow for exceptions, an individual's consent for testing or disclosure is no longer necessary. Consequently, legislatures and courts must create as few of them as possible and construe them narrowly.⁹³ States have created a number of exclusions, but those affecting individual rights most often deal with "medical necessity."⁹⁴ Purportedly for the benefit of the patients, some states, such as New York, allow for release of information to employees within a health care institution or to a health care provider if necessary to carry out their respective duties or to provide appropriate care or treatment.⁹⁵

Other medical necessity exceptions are for the protection of others, rather than the patient.⁹⁶ In a number of states, an emergency worker may request that an individual reveal his or her HIV status if exposure may have

90. N.Y. PUB. HEALTH LAW § 2780(9) (excluding the use of a general release form, unless it specifically reveals its dual purpose).

91. *Id.*

92. CAL. HEALTH & SAFETY CODE § 199.21(a)-(d) (Deering 1990).

93. *See, e.g.*, Field, *supra* note 72, at 49 (asserting that the New York disclosure statute's exceptions could "swallow the rule").

94. Berge, *supra* note 65, at 790. Another area where exceptions often arise is in the criminal justice system. *Id.* at 793. The consensus for voluntary testing is overwhelming in the civil setting, but similar agreement does not exist in the criminal context. *Id.* This article, therefore, will not discuss testing in that context, because the medical necessity situations are more common for the majority of individuals.

95. *See generally* N.Y. PUB. HEALTH LAW § 2782(1)(c)-(d) (McKinney 1993). The law also allows for release of information when body parts are used in medical education, research, therapy, or for transplantation. *Id.* § 2782(e); *see also* 35 PA. CONS. STAT. ANN. § 7605(g)(1)(i) (permitting testing in such situations because no privacy issue exists once the person is dead).

96. *See* Burris, *supra* note 70, at 125 (suggesting that these exceptions are contrary to a doctor's ethical duty to act in the patient's best interest, rather than his or her own).

occurred during the course of the worker's duties.⁹⁷ Because the test result will not prove whether exposure occurred, the purpose of such laws is to give the worker "peace of mind," rather than a definitive answer to questions or fears.⁹⁸

Instead of allowing for such exceptions, states must concentrate on vigorously enforcing universal precautions in health care settings.⁹⁹ If states still insist on legislating such exceptions, lawmakers must require the individual requesting the test and/or information to present evidence that exposure actually occurred and that transmission could have resulted.¹⁰⁰ Even in this context, states must not forget the patient's rights; he or she must have an opportunity to give informed consent, to receive counseling, and to decide whether he or she wishes to know the result of the test.¹⁰¹

4. Anonymous Testing Alternatives

Because some individuals may not consider confidentiality safeguards enough to encourage testing, states must provide for anonymous testing programs.¹⁰² An anonymous test subject does not give any identifying information but, instead, calls for results using a number.¹⁰³ Although pre-test counseling still occurs, anonymous testing has some disadvantages in that post-test, face-to-face counseling is not possible, and long-term epidemiological research is hindered.¹⁰⁴ Until states can guarantee strict

97. *Id.* (explaining that some of these laws assume that people with HIV disease pose an inherent danger to health care providers).

98. *Id.*

99. *See, e.g.,* Field, *supra* note 72, at 80 (advocating the use of universal precautions).

100. *See* CONN. GEN. STAT. ANN. § 19a-582(e)(5) (requiring that "a health care provider or other person, including volunteer emergency medical services, fire and public safety personnel" show that "significant exposure" occurred during the course of occupational duties before an individual must submit to mandatory testing); *id.* § 19a-583(a)(7) (1995) (imposing the same requirements to overcome confidentiality laws). *But see* ALA. CODE § 22-11A-39 (1990) (compelling disclosure to "all pre-hospital agencies" who had any contact with the infected individual).

101. *See, e.g.,* CONN. GEN. STAT. ANN. § 19a-582(e)(5) (providing for post-test counseling but allowing the patient to choose not to know the results).

102. *See* Field, *supra* note 72, at 51.

103. *Id.* (adding that subjects may need to supply basic information for epidemiological research).

104. *Id.* at 52.

confidentiality of results, legislators must provide for anonymous testing¹⁰⁵ and widely publicize all testing sites, as Georgia has chosen to do.¹⁰⁶

5. Testing of Pregnant Women and Newborns

Commentators often assert that mandatory testing within certain societal groups is necessary.¹⁰⁷ With the rise of HIV disease in women, recent attention has turned to pregnant women and newborns.¹⁰⁸ Some states, including Arkansas, Missouri, and Florida, already allow mandatory testing for pregnant women.¹⁰⁹ Like all others in society, pregnant women deserve the opportunity to decide whether to learn their HIV status, but these mandatory testing laws disregard women as individuals.¹¹⁰ Evidence shows that mandatory testing will not prevent vertical transmission,¹¹¹ and

105. *Id.* (asserting that legislators must consider ways, such as telephone counseling, to minimize drawbacks of this type of program).

106. *See* GA. CODE ANN. § 19-3-35.1(b) (1991) (instructing the Department of Human Resources to prepare AIDS education brochures that include information about confidential, anonymous testing sites). Georgia requires distribution of such information to individuals applying for marriage licenses. *Id.* § 19-3-35.1(c).

107. *See, e.g.,* A. Alyce Werdel, Note, *Mandatory AIDS Testing: The Legal, Ethical and Practical Issues*, 5 NOTRE DAME J.L. ETHICS & PUB. POL'Y 155, 219 (1990) (contending that mandatory testing among high-risk groups is necessary to protect those citizens outside of the affected groups).

108. *See generally* Martha A. Field, *Pregnancy and AIDS*, 52 MD. L. REV. 402 (1993) (examining the prospect of mandatory testing of both pregnant women and newborns and rejecting the idea in both contexts); Nat Hentoff, *AIDS Breakthroughs and AIDS Politics*, WASH. POST, Dec. 22, 1994, at A19 (asserting that policies against mandatory testing of pregnant women is a political one, made to satisfy AIDS advocates).

109. *See* ARK. CODE ANN. § 20-15-905(c) (Michie 1991) (allowing a physician to test an individual for HIV infection without informed consent if the patient has consented to medical care); FLA. STAT. § 384.31 (1995) (requiring prenatal HIV testing as part of law that mandates testing of pregnant women for all sexually transmitted diseases); MO. ANN. STAT. § 191.674(1) (Vernon Supp. 1996) (providing for HIV testing if "reasonable grounds" exist to believe the patient is infected and "clear and convincing evidence" shows that the person threatened the health of others). The Missouri and Arkansas laws differ from the Florida statute in that the former two states do not openly screen pregnant women, but do so under the guise of general consent. *See* Field, *supra* note 108, at 408-09.

110. *See* Field, *supra* note 108, at 409-10 (examining the social costs of learning one's HIV status and arguing that a woman has the right to make her own individual medical decisions).

111. *But see* Hentoff, *supra* note 108, at A19 (arguing that, in light of recent studies about benefits of AZT, law may need to subordinate woman's freedom to newborn's health). Research now shows that AZT taken during pregnancy has decreased transmissibility from 25.5% in women not taking the drug to 8.3% in women taking the drug. *Id.*

will not necessarily result in the woman choosing to abort.¹¹² In addition, even though AZT may slow perinatal transmission, all women may not receive such treatment.¹¹³ Mandated counseling about the benefits of AZT during pregnancy and the dangers of having an HIV-infected baby is a more effective option at this point in time.¹¹⁴

Considering the current state of medical technology, the benefits of testing newborns do not outweigh the risks at this time. Testing the newborn will reveal the mother's status, rather than that of the child, who is born with the mother's immune system.¹¹⁵ Once a child develops his or her own immune system, the question of testing becomes more difficult because recent studies show that treatments are now available.¹¹⁶ States have reacted to this testing issue in a variety of ways. For example, Illinois and Oklahoma have made childbearing a crime for HIV-infected women while Rhode Island now requires neonatal testing.¹¹⁷ A more well-reasoned decision is to give new parents the necessary information and allow them to make their own decisions about treatment for their children.¹¹⁸ States should treat pregnant women and newborns like society at

112. See Field, *supra* note 108, at 414.

113. See *id.* at 413 (contending that AZT is not available to all seeking its medical benefits).

114. See Hentoff, *supra* note 108, at A19 (quoting new AIDS czar Patricia Fleming, who favors counseling about the benefits of testing, rather than a mandatory test that violates a person's rights). Incidentally, the CDC now recommends routine prenatal counselling about HIV and voluntary testing for all pregnant women in the United States. John Schwartz, *AIDS Testing Urged in All Pregnancies*, WASH. POST, July 7, 1995, at A1, A8.

115. See Field, *supra* note 108, at 423-24 (explaining that all babies born to HIV-positive mothers will test positive but that less than one third of them will ultimately develop the infection).

116. *Id.* at 430-31 (examining the treatments, including AZT and Bactrim, available to newborns).

117. See ILL. ANN. STAT. ch. 38, para. 12-16.2(c) (Smith-Hurd 1992) (criminalizing knowing exposure, rather than actual transmission, from one person to another); OKLA. STAT. ANN. tit. 21, § 1192.1 (West Supp. 1996) (criminalizing "knowingly engaging in conduct reasonably likely to transfer the HIV virus"); R.I. GEN. LAWS § 23-6 (1989) (dispensing with informed consent and allowing an HIV test if the person is under one year of age); see generally Carol Beth Barnett, *The Forgotten and Neglected: Pregnant Women and Women of Childbearing Age in the Context of the AIDS Epidemic*, 23 GOLDEN GATE U. L. REV. 863 (1993) (discussing laws requiring neonatal testing and criminalization of vertical transmission).

118. See Field, *supra* note 108, at 431 (asserting that the state must allow parents to make decisions for their children in such situations, as long as reasonable people can differ as to the course of treatment). Governments should only intrude upon parental choice in extreme circumstances. *Id.*

large, and not subject them to mandatory testing requirements, until the benefits of testing clearly outweigh the costs of denying pregnant women and new mothers their right to privacy.

C. *Protection from Discrimination in Insurance*

After an individual learns that he or she is HIV positive, the next step is to seek health care as soon as possible to increase one's chances of prolonging life.¹¹⁹ Obtaining the best health care available is often a luxury reserved for those who have insurance that will pay for these expenses.¹²⁰ In the United States, most individuals secure private coverage through their employers.¹²¹ Because an individual is basically uninsurable once HIV infection occurs,¹²² he or she must rely on personal assets and public benefits for health care financing after leaving employment.¹²³

119. See Brett-Smith & Friedland, *supra* note 3, at 41 (giving an example of the medical treatments needed by a typical person living with HIV disease). Basically, treatment consists of certain antiviral therapies, such as AZT, which limit the virus' reproductive abilities, and secondary therapy for opportunistic infections. *Id.* at 38-41. Treatment is usually exhausting as it can include numerous pills each day and doctor visits no less than once a month, but usually more. *Id.* at 41.

Presently, researchers are focusing on study of "long-term nonprogressors," people who carry the virus but remain healthy for a number of years. David Brown, *Survivors Offer Lessons in Resisting HIV*, WASH. POST, Aug. 10, 1994, at A3. The answer to their survival is most likely found in the individual's immune system or in the strain of virus he or she carries, rather than the treatments the individual receives. *Id.*

120. Mark Scherzer, *Private Insurance*, in AIDS LAW TODAY, *supra* note 3, at 404-05.

121. See Michele A. Zavos, *Right to Work: Job Protection for People with HIV*, TRIAL, July 1993, at 41, 43-44 (reporting that about 60 million individuals have employer-based insurance, which accounts for the majority of health care financing in the United States). The system has evolved in this manner because insurers assume that those who work are the healthiest and that an evaluation of each person in the work force is, therefore, impractical. See Scherzer, *supra* note 120, at 410.

As most individuals have employer-based insurance, this article will discuss only those laws necessary to protect individual interests in this context. For recommendations on reforming public programs, readers should refer to THOMAS P. MCCORMACK, THE AIDS BENEFITS HANDBOOK 99-110 (1990).

122. See Zavos, *supra* note 121, at 43.

123. *Id.*; see Alan I. Widiss, *To Insure or Not to Insure Persons Infected with the Virus that Causes AIDS*, 77 IOWA L. REV. 1617, 1620-21 (1992) (explaining that AIDS is a "progressively debilitating" condition and will eventually leave those infected unable to work and without health insurance).

1. Federal Laws Governing the Insurance Industry

The primary federal law regulating employer-provided plans is the Employee Retirement Income Security Act of 1974 ("ERISA").¹²⁴ This legislation overrides all state laws regulating employee benefit plans,¹²⁵ but it specifically excludes state insurance regulations from this preemption.¹²⁶ At the same time, however, ERISA exempts employer-funded benefit plans¹²⁷ from conforming to state regulation because ERISA forbids states to treat them as insurance policies.¹²⁸ Notably, self-insured plans account for over sixty percent of all employer-based coverage, so state laws reach only a minority of these plans.¹²⁹

In particular, ERISA prohibits discrimination against employees who exercise rights to which they are entitled under their benefit plans.¹³⁰ *McGann v. H & H Music Co.*¹³¹ illustrates the degree of freedom afforded employers using self-insured plans, limited only by ERISA.¹³² In that case, the Fifth Circuit held that H & H did not unlawfully discriminate against McGann, an HIV-positive employee, when it replaced its group policy with a self-insured plan.¹³³ The group plan had promised payment of a one million dollar lifetime maximum per employee, but, when the employer discovered McGann had AIDS, he instituted a self-insured plan

124. 29 U.S.C. §§ 1001-1461 (1994).

125. *Id.* § 1144(a).

126. *Id.* § 1144(b)(2)(A).

127. Mark H. Jackson, *Health Insurance: The Battle Over Limits on Coverage, in AIDS AGENDA*, *supra* note 2, at 147, 148 (differentiating a self-insured plan from a group plan). A self-insured employer creates its own fund for paying employee claims whereas commercially insured employers pay a premium to an insurance company, which bears the risks of paying claims. *Id.*

128. 29 U.S.C. § 1144(b)(2)(B); *see* Jackson, *supra* note 127, at 148 (explaining that ERISA has the effect of excusing self-insured plans from compliance with state insurance regulations).

129. *See* Zavos, *supra* note 121, at 44; Jackson, *supra* note 127, at 148 (noting that over 50% of employer-based coverage is self-insured).

130. *See* 29 U.S.C. § 1140 (outlawing discharge, suspension, discipline, or discrimination against an employee to prevent him or her from taking advantage of rights under a benefit plan).

131. 946 F.2d 401 (5th Cir. 1991), *cert. denied*, 113 S. Ct. 482 (1992).

132. *See* Scherzer, *supra* note 120, at 426 (asserting that the decision allows employers to eliminate an employee benefit as soon as an employee takes advantage of it, as long as all similarly situated employees are treated equally).

133. *McGann*, 946 F.2d at 408.

that continued to pay this maximum, unless the employee had AIDS.¹³⁴ The court reasoned that the employer acted out of financial concern, rather than a desire to personally deprive McGann of his benefits.¹³⁵

The ADA's enactment most likely will change the face of federal insurance regulation.¹³⁶ Even though the ADA prohibits discrimination in employer-based health insurance,¹³⁷ it still allows underwriting based on actuarial risk.¹³⁸ To prove that a distinction is valid, rather than disability-based, an employer must show that it provides a bona fide insurance plan.¹³⁹ Further, the employer must demonstrate that the term is not a "subterfuge"¹⁴⁰ for disability discrimination.

At the very least, the ADA prohibits disability-based distinctions in group plans, but application of discrimination laws to self-insured plans remains unsettled. ERISA specifically states that it will not "alter, amend, modify, invalidate, impair, or supersede" any other federal law.¹⁴¹ However, the courts have not yet decided on the relationship between

134. *Id.* at 403 (adding that the new plan only paid a maximum of \$5000 to HIV-infected employees).

135. *Id.* at 404. This law does not, however, allow self-insured employers to refuse claims of an HIV-infected employee when the plan does not contain caps or exclusions for HIV-related claims. *John Doe v. Cooper Investments*, 16 Pens. Rep. (BNA) 89-B-597, 766 (C.D. Colo. Apr. 18, 1989).

136. 42 U.S.C. § 12112(b)(1) (forbidding an employer from "limiting, segregating, or classifying an employee" so that his or her opportunities or status are adversely affected because of a disability). This section prohibits an employer from engaging in disability discrimination in the provision of health insurance. EQUAL EMPLOYMENT OPPORTUNITY COMMISSION, INTERIM ENFORCEMENT GUIDANCE ON THE APPLICATION OF THE AMERICANS WITH DISABILITIES ACT OF 1990 TO DISABILITY-BASED DISTINCTIONS IN EMPLOYER PROVIDED HEALTH INSURANCE, part II, app. JJ, at 101 (Supp. Jul. 1993) [hereinafter EEOC].

137. 42 U.S.C. § 12112(a) (forbidding discrimination in "other terms, conditions, and privileges of employment"); *id.* § 12112(b)(2) (preventing employers from "participating in a contractual or other arrangement" that subjects an employee to disability discrimination). These two provisions, read together, prohibit employers from discriminating in the provision of fringe benefits, in the form of commercially-insured or self-funded plans. 29 C.F.R. § 1630.4(f) (1995).

138. 42 U.S.C. § 12201(c)(1)-(3) (permitting underwriting practices that are consistent with state law, if group coverage, and part of a bona fide plan).

139. *Id.* § 12201(c)(2); *see* EEOC, *supra* note 136, at 104 (outlining the framework for determining if a health-related term is actually disability-based and, therefore, a violation of the ADA).

140. *See* EEOC, *supra* note 136, at 107 (warning that a distinction singling out a particular disability, a discrete group of them, or disabilities as a whole violates the ADA). The EEOC offers an AIDS-related term as an example of one that singles out a particular disability. *Id.*

141. 29 U.S.C. § 1144(d).

ERISA and the ADA and which of the two laws governs self-insured plans. The EEOC has interpreted the ADA to apply to these plans, rather than ERISA, and a number of cases on the issue are currently in litigation.¹⁴²

2. Recommendations for State Insurance Regulations

As mentioned, state insurance regulations only apply to group plans, and individual coverage outside the employment context, because ERISA governs self-insured plans. States, therefore, are limited in their ability to protect individual interests in the insurance context. States are somewhat restrained in this area for the additional reason that many of these issues were addressed in the epidemic's earlier years, and these laws are now well settled.

a. *Questions Asked During the Underwriting Process*

To prevent discrimination against individuals living with HIV disease, states must limit the types of questions asked by underwriters. In the early to mid 1980s, many underwriters tried to totally deny coverage to high-risk group members.¹⁴³ The National Association of Insurance Commissioners responded by announcing underwriting guidelines to prevent this problem.¹⁴⁴ Currently, only a few states have adopted these recommendations, and those that have not should follow suit.¹⁴⁵ Florida, for one, has passed a law forbidding underwriters to consider sexual orientation or certain other

142. See *Donaghey v. Mason Tenders Dist. Council Trust Fund*, 20 Pens. Rep. (BNA) 422 (N.Y. Dist. Office Jan. 27, 1993) (holding that a union health insurance plan violated the ADA because it denied payment for AIDS-related medical expenses). *Mason Tenders* has filed for a declaratory judgment in district court on whether the union's plan must comply with the ADA, as held by the EEOC, or with ERISA. See also *Zavos*, *supra* note 121, at 43.

143. Scherzer, *supra* note 120, at 417 (recalling the controversy surrounding underwriting policies in the epidemic's early years).

144. *Id.*

145. See generally Robert J. Blendon & Karen Donelan, *AIDS and Discrimination: Public and Professional Perspectives*, in *AIDS IN THE HEALTH CARE SYSTEM* 77, 79 (Lawrence O. Gostin ed., 1990) (reporting that the American public still feels no sympathy for people living with HIV disease who contracted the virus through homosexual activity or drug use). This survey indicates that discrimination against persons in high-risk groups still exists and that they still need protection from discrimination in a number of areas, including the underwriting process. *Id.*

factors that may allow the underwriter to draw conclusions about sexual orientation.¹⁴⁶

State lawmakers also must consider whether underwriters may inquire about an individual's HIV status. They will most likely allow underwriters to ask such questions because all jurisdictions already let insurers use the HIV antibody test,¹⁴⁷ except for California, which permits them to test the health of the immune system.¹⁴⁸ States may permit underwriters to inquire about the existence of a positive result, but legislators must ban them from considering negative test results in coverage or testing decisions because individuals should not suffer discrimination for merely taking a test.¹⁴⁹

b. *Use of the HIV Antibody Test in the Underwriting Process*

The introduction of the HIV antibody test into the commercial market in 1985 reduced the debate about intrusive questions to secondary status.¹⁵⁰ Today, insurance companies commonly use the test to predict risks, and those who test positive are uninsurable on an individual basis.¹⁵¹ Those states that initially regulated the use of HIV antibody tests quickly limited or repealed those provisions.¹⁵² Even though states have decided to authorize testing in this context, they still must balance the insurance company's need to know with the individual's right to privacy. Like Ohio and Texas, all states must ensure that testing is not requested on a discriminatory basis and that insurers ask individuals to submit to testing only for

146. FLA. STAT. § 627.429(4)(d) (1995) (forbidding underwriters to consider sexual orientation, marital status, living arrangements, occupation, gender, beneficiary designation, zip code, or other territorial classification).

147. *See, e.g., id.* § 627.429(4)(a) (allowing the insurer to "use only medical tests that are reliable predictors of risk"). *But see* WIS. STAT. ANN. § 631.90(2) (West 1995) (establishing that insurers cannot use an individual's HIV status in group plan underwriting). Because insurers seldom use medical tests in the group context, these bans are "meaningless." Scherzer, *supra* note 120, at 419.

148. CAL. HEALTH & SAFETY CODE § 199.21(f) (banning disclosure of HIV antibody test in determination of insurability, but not expressly prohibiting others, such as T-Cell Suppressor test); *see* Widiss, *supra* note 123, at 1684 n.180 (stating current position, as of 1992, of various state jurisdictions on testing in determining insurance eligibility).

149. FLA. STAT. § 627.429(4)(e) (authorizing questions about positive test results but not about negative test results); KY. REV. STAT. ANN. § 304.12-013(4)(e) (Michie 1994) (providing identical protection).

150. Scherzer, *supra* note 120, at 418.

151. *See* Widiss, *supra* note 123, at 1672-81 (asserting a number of justifications for the use of HIV antibody testing in the underwriting process).

152. Scherzer, *supra* note 120, at 419.

health-related reasons.¹⁵³ In addition, states must require insurance companies to follow rules of written and particularized informed consent, to provide for post-test counseling from a physician chosen by the applicant, and to reveal the results only to the applicant, persons designated by the applicant, and employees within the insurance company. Florida has announced clear rules on consent, counseling, and confidentiality.¹⁵⁴ Similarly, Texas has enacted tough penalties for violations of confidentiality laws in the insurance context.¹⁵⁵

c. *Excluding, Limiting, and Terminating Coverage Based on an Individual's HIV Status*

To supplement federal protection, states must enact laws prohibiting insurers from treating HIV disease differently than other sicknesses and illnesses.¹⁵⁶ State legislators must send a strong message to insurers and individual citizens that they will not condone discriminatory limits or exclusions.¹⁵⁷

153. OHIO REV. CODE ANN. § 3901.46(A) (Andersen Supp. 1989) (instructing insurers that they may ask individual policy applicants to submit to HIV testing “only in conjunction with tests for other health conditions” and not on the basis of sexual orientation); TEX. REV. CIV. STAT. ANN. art. 21.21-4(b) (West Supp. 1996) (requiring insurers to base testing on “medical condition or medical history” or on underwriting guidelines that require all within a risk class to submit to testing).

154. See FLA. STAT. § 627.429(4) (enumerating the specific requirements for consent, post-test counseling, and confidentiality). Florida requires the insurer to disclose its intent to test an individual in advance. *Id.* § 627.429(4)(b). Written consent is necessary, and it must include an explanation of the test, its purpose, uses, limitations, and meaning as well as the right to confidentiality. *Id.* The applicant may receive the results from a physician of his or her own choosing or from the Department of Health. *Id.* § 627.429(4)(c). At that time, the applicant must receive post-test counseling on the meaning of the results, its consequences, prevention of future transmission, and other pertinent information. *Id.* The results must remain confidential within the insurance company. FLA. STAT. § 627.429(4)(f).

155. TEX. REV. CIV. STAT. ANN. art. 21.21-4 (j)-(o) (enumerating the remedies for a confidentiality breach). The applicant may bring a civil action, and damages will vary based on whether the disclosure is negligent, willful, or criminal. *Id.*

156. See, e.g., KY. REV. STAT. ANN. § 304.12-013(5)(a) (banning insurance contracts that “contain benefit provisions, terms, or conditions which apply to [HIV] infection in a different manner than those which apply to any other health condition”). The statute also prohibits cancellation or nonrenewal because an individual receives an HIV positive diagnosis. *Id.* § 304.12-013(5)(b).

157. See Jackson, *supra* note 127, at 162 (noting that states may show this support through statutes, regulations, or department guidelines).

Unfortunately, neither federal nor state law can prevent termination of coverage upon certain events, including the loss of employment. In 1989, the federal government amended the Consolidated Omnibus Reconciliation Act of 1985 ("COBRA")¹⁵⁸ to allow continuation of the coverage period until a disabled individual can qualify for Medicare.¹⁵⁹ Two practical problems arise in conjunction with this law. First, the law only covers employers with twenty or more employees, so individuals working for small businesses cannot take advantage of COBRA's guarantees.¹⁶⁰ Second, former employees often cannot afford the high premiums required to continue the benefits.¹⁶¹

States must take action to remedy these problems. In the late 1980s, many states directed insurance companies to create state-subsidized "high-risk" pools for individuals who could not qualify for continuation or other coverage, but such plans have proven unsuccessful for states as well as participants.¹⁶² If states choose to pass high-risk-pool legislation, they still must take other action due to past difficulties encountered in administering these plans. One recommendation is that states, which regulate continuation rights of plans not covered by COBRA, must amend their statutes and regulations to parallel the coverage offered under COBRA.¹⁶³

To assist individuals who cannot bear the financial burden of COBRA premiums, Washington State, and others, have created COBRA assistance programs. Through such programs, the state pays COBRA premiums for

158. 29 U.S.C. § 1161-1169 (1994). COBRA amendments also help individuals in new jobs waiting to qualify under a pre-existing condition clause. *See id.* § 1162(2)(D)(i); Scherzer, *supra* note 120, at 422.

159. 29 U.S.C. § 1162(a).

160. *Id.* § 1161(b).

161. CONGRESSIONAL RESEARCH SERVICE, HEALTH INSURANCE CONTINUATION COVERAGE UNDER COBRA 8 (Nov. 1994) (summarizing COBRA's provisions and stating that the law allows employers to charge disabled individuals up to 150% of the premium for the last 11 months); Widiss, *supra* note 123, at 1730 (stating that COBRA conversion premiums are often costly).

162. *See* Scherzer, *supra* note 120, at 412 (discussing the creation of such programs to assist the medically uninsurable). Scherzer explained that over half the states had passed such laws by 1990 but that most programs had financial difficulties. *Id.* Even though the states appropriated money to assist members with payments, individuals still paid considerably more than if they had a private policy. *Id.* Another author noted that state-mandated high-risk pools are not an answer to the problem because "they do not exist in all states, the premium costs are high, the coverage is limited, and some exclude coverage for AIDS." Widiss, *supra* note 123, at 1731.

163. *See* Scherzer, *supra* note 120, at 424 (applauding New York's 1992 reforms that accomplished this goal).

qualifying individuals with HIV disease.¹⁶⁴ Such a program benefits the individual as well as the state in that the individual keeps his or her private insurance coverage, which is advantageous to the state because public benefits for the individual probably would cost a great deal more.¹⁶⁵

3. Insurance and Health Care Reform

Since the AIDS epidemic began, AIDS advocates have fought many battles over insurance issues. A number of them ended unsuccessfully, but, collectively, they have accomplished something more important: they have brought the issue of health care reform into the public forum.¹⁶⁶ The American public, as well as the federal government, must consider how to reform the current system based on underwriting¹⁶⁷ and employer-based plans.¹⁶⁸ People also have begun to realize that the insurance-related horrors suffered by people with HIV disease can happen to all individuals with chronic diseases.¹⁶⁹ As more women, children, and people of color contract the virus, the need to reform the system in response to HIV disease will become even more urgent.¹⁷⁰ In its final report, the National Commission on AIDS called for comprehensive health care reform that prudently considers HIV disease, and other chronic conditions.¹⁷¹ Until federal and

164. See, e.g., WASH. REV. CODE ANN. § 74.09.757 (West Supp. 1996) (enabling the “[a]cquired human immunodeficiency syndrome insurance program,” which is administered by the department of social and health services with state appropriated funds). This department is responsible for creating eligibility requirements beyond those mentioned in the statute, which include an HIV infection diagnosis and qualification for continuation benefits under COBRA. *Id.*

165. See Widiss, *supra* note 123, at 1620 n.8 (reporting that current estimates of health care costs for an HIV-infected person range from \$50,000 to \$125,000).

166. See Scherzer, *supra* note 120, at 420 (asserting that advocates provided a “model for disease group advocacy”).

167. See Widiss, *supra* note 123, at 1735 (arguing that revision of the underwriting process is not enough to cure the health care system’s difficulties).

168. See Scherzer, *supra* note 120, at 428 (contending that employers as well as employees are dissatisfied with the current system).

169. See *id.* (predicting that, as the groups realize their common pursuit, they will unite to encourage comprehensive health care reform).

170. See CONGRESSIONAL RESEARCH SERVICE, HEALTH CARE REFORM: OVERVIEW 1 (Sept. 1994) (reporting that nearly all of the 37.4 million uninsured Americans were under 65, and a majority were children and young adults, according to 1992 statistics); Zavos, *supra* note 121, at 44 (observing that this change in the disease’s epidemiology will increase the need to provide equitable access to health care).

171. NATIONAL COMMISSION, *supra* note 1, at 10 (stressing the importance of coverage for services such as home and long-term care); see also *id.* at 12 (asserting that the federal

state governments provide affordable access to the proper continuum of health care, individuals living with HIV disease will not receive the peace of mind that they deserve in their time of desperate need.

II. BUILDING ON EXISTING LAWS TO PROVIDE FOR THE NEEDS OF PEOPLE LIVING WITH HIV DISEASE

A. *Planning for Incapacity and Death*

The traditional mechanisms used for personal and estate planning often are inappropriate for HIV-infected individuals because of the unpredictable progression of HIV disease.¹⁷² While some individuals steadily decline in health over a period of months or years, many others alternate between sickness and health before succumbing to the virus.¹⁷³

“Living with HIV” means tolerating a high level of anxiety, which takes a tremendous toll at every stage. For those who are well, it means the uncertainty of waiting for the other shoe to drop, sometimes for years. For those who are already sick, it means worrying about what the next complication will bring, how their bodies will betray them next, whether they will lose some crucial faculty such as sight, or how much pain they may be asked to tolerate.¹⁷⁴

This compelling account illustrates the importance of providing state laws to make things as easy as possible for HIV-infected individuals to plan for their uncertain futures.

1. Health Care Decisions

Historically, state statutes have allowed an individual to execute a financial power of attorney, in which he or she may designate someone to

government must search for ways to provide health care to all).

172. See Elizabeth B. Cooper, *HIV-Infected Parents and the Law: Issues of Custody, Visitation and Guardianship*, in AIDS AGENDA, *supra* note 2, at 70, 82 (discussing this problem in the context of family law issues).

173. Brett-Smith & Friedland, *supra* note 3, at 37-38 (commenting on the inconsistency of HIV disease in its effects on individuals). For example, some people may live for a long period of time with a low T4 cell count while other may have a moderate count for a number of years that suddenly drops. *Id.* at 38.

174. *Id.*

make decisions on his or her behalf.¹⁷⁵ Typical powers delegated to an attorney-in-fact include making gifts, disclaiming property interests, withdrawing and receiving trust income, carrying out banking and financial transactions, and engaging in real property transactions.¹⁷⁶ The difficulty with the traditional power of attorney is that it becomes ineffective upon the grantor's mental incapacity, which is exactly the point when many people need its powers.¹⁷⁷

Every state now provides for a durable financial power of attorney.¹⁷⁸ To alleviate additional anxiety about future decisions, individuals living with HIV disease need such an arrangement for health care decisions as well. To accommodate this necessity, a number of states now have durable health care power of attorney provisions, which allow a principal to appoint someone to make health care decisions on his or her behalf upon incapacity. California, for instance, has passed detailed legislation allowing such agreements.¹⁷⁹ So that individuals have as much control as possible over future health care decisions, state law must give the principal power to decide whether to grant broad or specific powers to the attorney-in-fact.¹⁸⁰ Because people living with HIV disease may alternate between sickness and health for a long period of time, and personal relationships can change during that period, a statute also must allow the principal to alter the document and to revoke the appointment, if he or she has the capacity to do so.¹⁸¹ Most statutes require that individuals execute very specific documents to give the arrangements legal effect, but state legislatures must recognize that such actions are not always possible. Virginia has taken

175. Arnold J. Rosoff & Gary L. Gottlieb, *Preserving Personal Autonomy for the Elderly*, 8 J. LEGAL MED. 1, 37-38 (1987).

176. *See, e.g.*, 20 PA. CONS. STAT. ANN. § 5602 (listing a number of powers which a principal may delegate to an attorney-in-fact).

177. Rosoff & Gottlieb, *supra* note 175, at 38. Such provisions are based on agency law, which dictates that the power terminate upon incapacity because the agent can not have more power than the principal. *Id.*

178. Mark Fowler, Note, *Appointing an Agent to Make Medical Treatment Choices*, 84 COLUM. L. REV. 985, 1012 (1984) (noting that all 50 states have passed such legislation and asserting that it is a viable option in the health care setting as well).

179. CAL. HEALTH & SAFETY CODE §§ 2430-2510 (Deering 1992); *see also* D.C. CODE ANN. §§ 21-2201 to -2213 (Supp. 1995); VA. CODE ANN. §§ 54.1-2981, -2993 (Michie Supp. 1992).

180. *See* CAL. HEALTH & SAFETY CODE § 2430(b)-(c) (broadly defining "health care" as practically any action pertaining to the individual's physical or mental conditions and "health care decision" as consent, or refusal or withdrawal of consent, to health care).

181. *See id.* § 2437(a)-(c) (presuming that the principal has the capacity to revoke the appointment and placing the burden of proof on the other party).

action by allowing a terminally ill, but competent individual to orally appoint an agent to make health care decisions.¹⁸²

To accompany a durable health care power of attorney, a person living with HIV disease may want to execute a living will,¹⁸³ and states should pass legislation that empowers them to do so. Normally, an individual executes a living will to direct health care providers not to use artificial life support procedures if he or she becomes terminally ill.¹⁸⁴ Because these documents have a number of shortcomings in practice,¹⁸⁵ individuals should use them to complement, rather than to replace, a durable power of attorney. Additionally, states should pass or amend specific living will legislation, which takes these problems into account. By passing the recommended durable health care power of attorney and living will provisions, states will give individuals, especially the rising number of them with diverse family structures and relationships, an important degree of control over their future health care decisions.¹⁸⁶

2. Guardianships

Most current state laws regulating guardianships also do not address the needs of individuals living with HIV disease and other chronic conditions. Traditionally, a parent may use a guardianship arrangement¹⁸⁷ to transfer

182. See VA. CODE ANN. § 54.1-2983 (Michie 1994) (authorizing oral arrangements only if specific procedures are followed).

183. See Fowler, *supra* note 178, at 1000 (explaining that the living will allows patients some autonomy but that this instrument is not enough in and of itself).

184. See generally D.C. CODE ANN. §§ 6-2421 to -2430 (1995); MD. CODE ANN., HEALTH-GEN. §§ 5-601 to -614 (1987 & Supp. 1995). Both laws require that two physicians attest to the patient's terminally ill condition before discontinuing life support upon request. D.C. CODE ANN. § 6-2421(5); MD. CODE ANN., HEALTH-GEN. § 5-606.

185. See Fowler, *supra* note 178, at 999-1000 (asserting that an individual cannot foresee all health care possibilities when the document is executed and that living wills do not always protect patient rights because of formalistic statutory requirements).

186. See Arlene Zarembka & Katherine M. Franke, *Women in the AIDS Epidemic*, 9 ST. LOUIS U. PUB. L. REV. 519, 536-37 (1990) (stressing the importance of such provisions to the increasing number of women living with HIV disease, who may have nontraditional family structures). In these situations, women may not necessarily want their legal spouse or immediate family members to make decisions for them. *Id.* Additionally, homosexual men commonly object to immediate family members making their health care decisions. Robert Steinbrook et al., *Preferences of Homosexual Men with AIDS for Life-Sustaining Treatment*, 314 NEW. ENG. J. MED. 457, 457 (1986).

187. MARK I. SOLER ET AL., REPRESENTING THE CHILD CLIENT ¶ 3.06[2][a] (1994) (explaining that a guardianship of a minor's person discontinues a parent's custody and shifts that responsibility to another adult).

parental powers while retaining the right to support and visit the child.¹⁸⁸ Guardianship proceedings normally are governed by the state probate court¹⁸⁹ because a parent often names a guardian in his or her will.¹⁹⁰ The proposed guardian or a parent may initiate a petition for guardianship in a family court.¹⁹¹ The court, however, may reject the parent's choice if it is not in the child's best interest.¹⁹² Traditional guardianships are permanent and terminate only when the child reaches the age of majority, marries, or dies, whichever comes first.¹⁹³

For two primary reasons, current guardianship laws do not work for the growing number of individuals living with HIV disease, most of whom draw strength from their children and need to know the courts will respect their child-rearing choices after they have passed away.¹⁹⁴ First, traditional mechanisms allow only long-term transfers of custody.¹⁹⁵ Considering the unpredictability of HIV disease, permanent transfer is not always necessary, and the parent may want to regain custody of his or her children after returning to good health.¹⁹⁶ Second, the growing number of women with

188. *Id.* (stating that powers and duties of guardians are defined by state statute). Powers usually include deciding where the child will live, making health care decisions for the child, overseeing the child's educational and religious development, and reasonably disciplining the child. *Id.*

189. *Id.* ¶ 3.06[5][a] (adding that this court may also hear the juvenile and family law cases).

190. *Id.* ¶ 3.06[5][c].

191. SOLER, *supra* note 187, ¶ 3.06[5][d][i] (observing that the guardian usually files the petition); *see, e.g.*, N.Y. SURR. CT. PROC. ACT §§ 1701, 1703 (McKinney 1967 & Supp. 1996) (allowing a parent as well as a child fourteen or over to petition for appointment of a guardian).

192. SOLER, *supra* note 187, ¶ 3.06[5][d][vii].

193. *Id.* ¶ 3.06[11].

194. *See* Ann Kurth, *Introduction: An Overview of Women and HIV Disease*, in UNTIL THE CURE 1, 16 (Ann Kurth ed., 1993) (emphasizing that many HIV-infected women, who are usually the primary caretakers of their children, consider planning for child care their main concern).

195. SOLER, *supra* note 187, ¶ 3.06[3][f] (warning that no state law expressly authorizes informal guardianships but that parents still may execute them in writing, at their own risk); *id.* ¶ 3.06[7] (describing a temporary guardianship, as defined by many state statutes, and its limitations); *see also* Michele A. Zavos, *Legal Considerations*, in UNTIL THE CURE, *supra* note 194, at 125, 140 (asserting that temporary and informal guardianships are often complicated and contestable).

196. Zavos, *supra* note 195, at 140 (asserting that women must have the opportunity to designate a guardian without relinquishing full custody). One woman explains this dilemma:

I have been trying to draw up custody papers for my daughter for quite some time now (her biological father died of AIDS two years ago). I would not give

HIV disease, especially those of a low socioeconomic status, makes the need for reform even more urgent.¹⁹⁷ States originally designed guardianship statutes to serve the middle-class, traditional family,¹⁹⁸ but, for individuals with HIV disease, this model often does not hold true. Many single parents, mostly women, cannot rely on the other parent to assume responsibility for the child because the noncustodial parent already may have succumbed to HIV disease.¹⁹⁹ Further, HIV disease often strikes those in areas pervaded by drug use and poverty, and, as a result, the non-infected parent may not be available or interested in raising the child.²⁰⁰

Commentators have long suggested that a “springing” guardianship mechanism would remedy these problems because it would “spring” into existence when illness leaves a parent unable to care for the child but “lapse” if and when the parent regains health.²⁰¹ Motivated by the impact of HIV disease on single parents, especially single mothers,²⁰² New York became the first state to pass such a statute in 1992,²⁰³ and Maryland followed suit by passing its own statute in 1994.²⁰⁴

For the reasons stated above, other states must enact similar legislation to protect HIV-infected parents, especially the growing number of single mothers who make up this group. Basically, the New York and Maryland

up custody while I am well, perhaps not even when I am sick. For now, this is not an alternative for me. I relate this to you because you need to know that often the children in our lives are our survival. I work at staying healthy so that I can raise my daughter. It is she who keeps me on track, centered in my will to survive. This is an essential to women, to mothers living with this disease.

Id. at 125-26 (quoting an anonymous source).

197. *See id.* at 140 (reporting that most HIV-infected women are “functionally single parents”).

198. Cooper, *supra* note 172, at 82 (arguing that existing statutes only apply to family situations that do not conform to “socioeconomic reality of most HIV-infected parents”).

199. *Id.* (explaining that existing laws assume that, if one parent dies, another parent is standing by to care for the child).

200. *Id.*; *see Zavos, supra* note 195, at 140 (relating that many HIV-infected women cannot afford a lawyer and, as a result, do not execute a will in which they could name guardian).

201. Zarembka & Franke, *supra* note 186, at 539-40 (asserting that flexible law of this type would ensure that parent could regain custody when his or her good health returned without fighting for it in costly, exhausting court battle).

202. N.Y. SURR. CT. PROC. ACT § 1726 Practice Commentaries (McKinney Supp. 1996).

203. *Id.* § 1726; *see Zavos, supra* note 195, at 140-41.

204. MD. CODE ANN., EST. & TRUSTS §§ 13-903 to 13-904 (Supp. 1994) (providing for a springing guardianship arrangement that is almost identical to that allowed in New York).

statutes allow a parent to appoint a guardian by judicial appointment²⁰⁵ or by signed and witnessed instrument.²⁰⁶ If “medically unable” to appear in court, neither method requires the parents’ presence, an important improvement over existing law.²⁰⁷ These laws respect both parents’ rights, a concern of some critics,²⁰⁸ by ordering that both parents join in the petition.²⁰⁹ At the same time, Maryland recognizes that a single parent cannot always locate the other parent and requires only “reasonable efforts” to find an absent parent.²¹⁰ Furthermore, the parent retains a certain amount of control in that he or she decides when the guardianship will take effect, or terminate, in the event that he or she returns to good health.²¹¹

205. See N.Y. SURR. CT. PROC. ACT § 1726(3) (establishing that only parent or legal guardian may file a petition for appointment of a standby guardian); MD. CODE ANN., EST. & TRUSTS § 13-903(b) (specifying that only parent may file petition for appointment of standby guardian). The petition must specify a triggering event (incapacity, death, or whichever occurs first). N.Y. SURR. CT. PROC. ACT § 1726(3)(b)(i); MD. CODE ANN., EST. & TRUSTS § 13-903(b)(3). The petitioner must describe his or her stage of illness. N.Y. SURR. CT. PROC. ACT § 1726(3)(b)(ii) (requiring “progressively chronic illness” or “irreversibly fatal disease”); MD. CODE ANN., EST. & TRUSTS § 13-903(b)(3) (requiring “significant risk” of death or incapacity within two years of filing).

206. N.Y. SURR. CT. PROC. ACT § 1726(4) (allowing such arrangement if signed by the parent, two witnesses who are at least 18 years old, and the standby guardian); MD. CODE ANN., EST. & TRUSTS § 13.904(a)(1)(i)-(ii) (imposing same requirements). Both statutes permit another individual to sign for the parent, upon the parent’s consent, if he or she is physically unable to do so. N.Y. SURR. CT. PROC. ACT § 1726(4)(a); MD. CODE ANN., EST. & TRUSTS § 13.904(a)(2)(i)-(ii). A parent also may appoint an alternate standby guardian in this document and in the same manner. N.Y. SURR. CT. PROC. ACT § 1726(4)(b)(ii); MD. CODE ANN., EST. & TRUSTS § 13.904(b)(2). The standby guardian’s authority begins upon receipt of a determination of capacity or a determination of physical debilitation and a copy of written consent from the parent. N.Y. SURR. CT. PROC. ACT § 1726(4)(c); MD. CODE ANN., EST. & TRUSTS § 13.904(c). An appointment by written instrument ends after 60 days in New York and after 180 days in Maryland, if the standby guardian does not file a petition for guardianship with the court. N.Y. SURR. CT. PROC. ACT § 1726(4)(c); MD. CODE ANN., EST. & TRUSTS § 13.904(e).

207. N.Y. SURR. CT. PROC. ACT § 1726(3)(c); MD. CODE ANN., EST. & TRUSTS § 13-903(c).

208. See Cooper, *supra* note 172, at 93 (listing some commentators’ concerns, including apprehensions about locating and displacing the rights of the other parent).

209. N.Y. SURR. CT. PROC. ACT § 1726(2) (providing that other guardianship provisions still apply to standby guardianship arrangements); MD. CODE ANN., EST. & TRUSTS § 13-903(a) (expressly requiring both parents to sign unless the other cannot be found).

210. MD. CODE ANN., EST. & TRUSTS § 13-903(a)(1)-(3) (requiring both parents to sign or to document efforts to locate an unavailable parent before filing for judicial appointment).

211. N.Y. SURR. CT. PROC. ACT § 1726(3)(f), (4)(f) (providing rules for revocation of judicial and written appointments); MD. CODE ANN., EST. & TRUSTS §§ 13-903(f), 13-904(h) (duplicating New York’s statute on this point). By explicitly giving the parent the power to

Although these statutes are relatively new and untested in court, state legislatures cannot “play it safe” by waiting to pass them. HIV disease is rapidly affecting single parents, especially women, and these individuals need laws to accommodate their special needs right away.

B. *Fighting Custody Battles*

In addition to the problems inherent in guardianship statutes in most states, many HIV-infected parents may face custody and visitation disputes in which the law may not protect their rights. Even though courts should treat HIV disease like any other disability in this context,²¹² broad statutes governing custody and visitation still may allow for discrimination against the HIV-infected parent. Courts often consider the probability of transmission to the child, even though transmission cannot occur in casual situations; courts determine the parent’s ability to care for the child, despite his or her condition; and courts weigh the chance that the child could suffer discrimination because of the parent’s condition.²¹³ Courts have rejected all of these arguments at some point,²¹⁴ but custody and visitation determinations still leave room for judges’ personal opinions.²¹⁵ States, therefore, must pass legislation to ensure that HIV-infected parents receive fair determinations in custody and visitation disputes.

1. Existing Statutes and Case Law Governing Custody and Visitation

Because federal law plays little, if any, part in custody and visitation decisions, this issue is an especially important one for states to consider.

“unspring” the guardianship, the two legislatures allayed yet another concern about springing guardianship statutes. See Cooper, *supra* note 172, at 93 (explaining that critics have contended that the guardian and relinquishing parent may differ as to whether and when the arrangement should “unspring”).

212. Cooper, *supra* note 172, at 71 (asserting that courts should evaluate HIV-infected parents based on their ability to fulfill their parenting responsibilities and to ensure the child’s social and psychological well-being).

213. Zavos, *supra* note 195, at 141 (explaining that disputes based on these considerations are unrelated to the child’s best interests); Cooper, *supra* note 172, at 70 (arguing that parent may advance these contentions to disguise concerns about HIV-infected parent who is homosexual or has history of drug use).

214. See *infra* notes 223-49 and accompanying text (examining each one of these unsupported arguments).

215. See *infra* notes 221-22 and accompanying text (stating the ways in which a judge may abuse his discretion in custody and visitation decisions).

Most state courts use the “best interests of the child” standard and make decisions on a case-by-case basis.²¹⁶ Different states articulate their standards for this determination in diverse ways, but many follow the Uniform Marriage and Divorce Act (“UMDA”),²¹⁷ which suggests factors that courts should take into account.²¹⁸ Most states follow the UMDA in providing standards for visitation determinations as well.²¹⁹ The UMDA directs courts to grant visitation unless “visitation would endanger seriously the child’s physical, mental, moral, or emotional health.”²²⁰

Even though statutory and case law outlines a framework for these decisions, custody determinations still allow judges a great deal of discretion.²²¹ The “best interests” standard is vague, and, therefore, manipulable, so judges often rely on their own and the community’s value preferences in reaching decisions.²²² In the absence of clearly defined judicial standards, state legislatures must take the necessary steps to protect

216. Andrea Charlow, *Awarding Custody: The Best Interests of the Child and Other Fictions*, in CHILD, PARENT & STATE 3, 4 (S. Randall Humm et al. eds., 1994) (noting that some states list factors to consider while others leave it to court’s discretion).

217. Cooper, *supra* note 172, at 71 (noting that most states have either adopted the UMDA or used it as foundation for statutes outlining factors for courts to consider).

218. UNIF. MARRIAGE & DIVORCE ACT § 402 (1979). The five factors mentioned in the uniform act are:

- 1) the wishes of the child’s parent or parents as to his custody;
- 2) the wishes of the child as to his custodian;
- 3) the interaction and interrelationship of the child with his parent or parents, his siblings, and any other person who may significantly affect the child’s best interest;
- 4) the child’s adjustment to his home, school, and community; and
- 5) the mental and physical health of all individuals involved.

Id.

219. See Cooper, *supra* note 172, at 72.

220. UNIF. MARRIAGE & DIVORCE ACT § 407(a) (1979).

221. See Robert H. Mnookin, *Child-Custody Adjudication: Judicial Functions in the Face of Indeterminacy*, 39 LAW & CONTEMP. PROBS. 226, 255-68 (1975), reprinted in ROBERT H. MNOOKIN & D. KELLY WEISBERG, CHILD, FAMILY AND STATE 636, 648 (1989) (asserting that the broad standards provided to judges encourage value-based decisions by particular judges in each case). Mnookin advocates a system that favors family autonomy, rather than state paternalism, as the underlying value of policies in this area. *Id.* at 646. He further contends that government involvement is justified only in cases where private dispute settlement or child protection is necessary. *Id.* at 648.

222. See Martin Guggenheim, *The Best Interests of the Child: Much Ado about Nothing?*, in CHILD, PARENT & STATE, *supra* note 216, at 27 (lamenting that these value choices lead to an ironic result in that the judge often overlooks the child’s best interests in reaching a decision).

HIV-infected parents from arbitrary custody and visitation judgments based on the parents' seropositivity.

2. Applicable Case Law

In a number of states, courts have rejected the idea that a parent's disability is reason enough to deny him or her custody. In *In re Marriage of Carney*,²²³ the Supreme Court of California began this trend by holding that a disability does not constitute prima facie evidence that a parent is unfit.²²⁴ Instead, the court should make an individualized inquiry²²⁵ to determine whether the parent's disability will have a "substantial and lasting adverse effect on the best interests of the child."²²⁶ Consequently, a number of other state courts have chosen to follow this approach.²²⁷

Courts have specifically applied *Carney's* principles in custody and visitation disputes involving HIV-infected parents. For example, a New York court, in *Doe v. Roe*,²²⁸ held that a disability alone cannot prevent an otherwise qualified parent from having custody of a child.²²⁹ In addition to refusing to order a father to submit to an HIV antibody test,²³⁰ the court rejected the maternal grandparents' efforts to convince the court

223. 598 P.2d 36 (Cal. 1979).

224. *Id.* at 42.

225. *Id.* The court should:

inquire into the person's actual and potential physical capabilities, learn how he or she has adapted to the disability and manages its problems, consider how the other members of the household have adjusted thereto, and . . . the special contributions the person may make to the family despite—or even because of—the [disability].

Id. In addition, the court should consider any other relevant factors in reaching its decision.
Id.

226. *Carney*, 598 P.2d at 42 (citations omitted). The lower court was admonished for stereotyping the physically disabled father as unable to participate meaningfully in his child's life and for failing to give children credit for their ability to adapt to such situations. *Id.* at 42-23.

227. *See, e.g.*, *Bednarski v. Bednarski*, 366 N.W.2d 69, 73-74 (Mich. Ct. App. 1985) (remanding case back to trial court because it placed undue emphasis on mother's deafness when it granted custody to child's grandparents); *Hatz v. Hatz*, 455 N.Y.S.2d 535, 536-37 (Fam. Ct. 1982), (adopting *Carney* standard and holding that mother's paralysis did not warrant revocation of custody), *aff'd*, 468 N.Y.S.2d 943 (App. Div. 1983).

228. 526 N.Y.S.2d 718 (Super. Ct. 1988).

229. *Id.* at 726.

230. *Id.* at 725 (stressing that mandatory testing is contrary to public policy of protecting confidentiality). Reasoning that the petitioner must show a "compelling need" for involuntary testing information, the court held that this standard was not met. *Id.* at 725-26.

that the father's limited life expectancy and his propensity to take his own life and that of others made him an unfit parent.²³¹ Instead, the court found that the pertinent consideration is the effect, if any, of the father's disability on the child.²³² Applying this test to the facts at issue, the court decided that, even assuming the father was an HIV carrier, a shortened life span could not justify taking a child from a parent with whom he or she has a good relationship.²³³ Further, expert testimony revealed that the father displayed no suicidal tendencies.²³⁴ Considered together, *Carney* and *Doe* offer persuasive authority for protecting HIV-infected parents from the unwarranted loss of custody or visitation rights because of their condition.

In addition to rejecting unfounded claims based on disability alone, a number of courts also have declined to recognize fear of transmission through casual contact as a basis for denying custody or visitation. Rather than concentrating on the father's AIDS diagnosis, a New York trial court, in *Jane W. v. John W.*,²³⁵ dismissed the condition as a significant issue and stressed the father's capability to care for the child.²³⁶ Noting that "exceptional circumstances" must exist for a court to limit visitation, the court refused to terminate the father's unsupervised visitation rights.²³⁷ Relying on the *Jane W.* decision, an Indiana appellate court overturned a lower court decision²³⁸ denying visitation rights to a homosexual, AIDS-infected father, because of his condition, in *Stewart v. Stewart*.²³⁹ The

231. *Id.* at 726.

232. *Id.*

233. *Doe*, 526 N.Y.S.2d at 726 (relying on testimony of court-appointed psychiatrist who interviewed all parties and children).

234. *Id.* (elaborating that expert did not consider father a danger to his children).

235. 519 N.Y.S.2d 603, 605 (N.Y. Sup. Ct. 1987) (finding that the father's AIDS diagnosis should carry little, if any, weight in adjudicating visitation disputes).

236. *Id.* (stressing that father is health care worker and knows proper precautions to take in protecting family and friends from infection).

237. *Id.*

238. See Nancy L. Mahon, Note, *Public Hysteria, Private Conflict: Child Custody and Visitation Disputes Involving an HIV Infected Parent*, 63 N.Y.U. L. REV. 1092, 1121 (1988) (citing *Stewart v. Stewart*, No. S485-1128 (Sup. Ct. Marion City, Ind., Oct. 9, 1986). In *Stewart*, the court disregarded evidence of the mother's parental incompetence and awarded custody to her after learning of the father's condition. *Id.* The trial judge's approach not only defied the best interests standard but also misconstrued medical evidence and focused on the condition, rather than the child's needs. *Id.*

239. 521 N.E.2d 956, 959 (Ind. Ct. App. 1988) (recalling the lower court's decision to terminate completely the father's visitation rights, a remedy not requested by the mother, because of the slight chance of transmission through casual contact); see also Robert D. Zaslow, *Child Custody, Visitation, and the HIV Virus: Revisiting the Best Interests Doctrine*

appellate court in *Stewart* followed the *Jane W.* court's lead by taking a more reasonable approach²⁴⁰ and choosing to base its decision on the weight of medical evidence.²⁴¹ Consequently, the *Stewart* court remanded the decision with instructions that the trial court may not deny visitation privileges solely on the basis of the father's AIDS diagnosis.²⁴² Many state courts have since relied on the principles announced in *Doe* and *Jane W.*²⁴³ At the very least, judges have an obligation to individually assess the facts of each case, rather than to deny parental rights based solely on a parent's disability or a societal fear of transmission through casual contact.

The effect of the social stigma²⁴⁴ on the child of an HIV-infected parent is yet another factor that courts should not consider in reaching their decisions on parental rights. In *Palmore v. Sidoti*,²⁴⁵ the Supreme Court recognized that even though the law cannot reach private prejudices, courts must not, directly or indirectly, condone them.²⁴⁶ Soon after that decision, state courts extended *Palmore* to other contexts. The Supreme Court of Alaska offered protection to gay and lesbian parents,²⁴⁷ while an Ohio

to Ensure Impartial Parental Rights Determinations for HIV-Infected Parents, 3 J. PHARMACY & L. 61, 76 (1994) (asserting that this lower court decision exemplifies how judges may exploit the best interests standard, based on their own fears and prejudices).

240. *Stewart*, 521 N.E.2d at 965 (characterizing the trial court's action as "extreme and unwarranted" and contrary to the medical evidence presented).

241. *Id.* at 966 (referring to *Jane W.* and noting the similarity of the medical evidence in the two cases). The court mentioned that *Jane W.* was the only reported case addressing the visitation issue in this context. *Id.* at 965. The decision included a lengthy excerpt of the case's medical testimony and then expressly relied on the case in finding the trial court in error. *Id.* at 965-66 (citing *Jane W.*, 519 N.Y.S.2d at 604-05).

242. *Id.* at 966. On remand, the trial court was also directed to hear current medical evidence from either party about AIDS and to tailor its decision to all evidence presented. *Stewart*, 521 N.E.2d at 966.

243. See, e.g., *Steven L. v. Dawn J.*, 561 N.Y.S.2d 322, 326 (Fam. Ct. 1990) (denying father's petition for modification of custody order and refusing to consider mother's HIV infection as sole grounds for such alteration). The court observed that a change in custody could have a greater emotional effect on the child than the mother's condition and the possibility of her untimely death. *Id.*

244. See generally Brandt, *supra* note 13, at 425-32 (examining society's reasons for stigmatizing people with HIV disease, in the context of history, society, and culture).

245. 466 U.S. 429 (1984).

246. *Id.* at 433-34 (holding that effect of racial prejudice on child is not permissible factor for courts to consider in decisions concerning parental rights). The father sought custody after discovering that the child's mother, who had custody of their daughter, lived with, and later married, a black man. *Id.* at 430.

247. See *S.N.E. v. R.L.B.*, 699 P.2d 875, 879 (Alaska 1985) (holding that social stigma surrounding homosexual mother's sexual orientation is not pertinent consideration in custody

appellate court allowed a father overnight visitation rights over the mother's protests of his homosexuality and alleged HIV seropositivity.²⁴⁸ These cases provide courts the foundation for broadening *Palmore's* reach to cover the HIV-infected parent.²⁴⁹

3. Recommendations for State Legislation on Custody

In keeping with the spirit of recent federal measures, such as the ADA,²⁵⁰ states must follow suit and fill the gaps left by this measure. Specifically, states can accommodate HIV-infected parents by amending child custody statutes to prohibit judges from considering a parent's HIV-positive status as a per se bar to custody or visitation. Florida already has amended its custody and visitation statute in this manner,²⁵¹ and states should look to this law for guidance. The Florida statute expressly forbids a court to deny custody or visitation solely because a parent or grandparent is HIV positive.²⁵² The court may, however, condition its decision on the parent or grandparent's agreement to observe infection control measures for the protection of the child.²⁵³ To provide even more guidance to judges, lawmakers must go further than the Florida statute and instruct judges to consider each case individually.²⁵⁴ The judge must determine the effect, if any, of the parent's condition on the child and then consider the status only if "exigent circumstances" exist.²⁵⁵ The only two possible examples of such circumstances are deterioration of the parent's condition, leaving

determination, unless it has adverse effect on child). The court remanded the case for further fact finding on this issue and warned that the mother's conduct, rather than her sexual orientation, must be contrary to the child's best interests. *Id.*

248. *See Conkel v. Conkel*, 509 N.E.2d 983, 987 (Ohio Ct. App. 1987) (declaring that court's duty is to protect parent-child relationship and that court cannot discriminate against homosexuals in so doing). The court held that the trial court acted in the best interests of the child in allowing the father to visit with his children. *Id.*

249. *See, e.g., Doe v. Roe*, 526 N.Y.S.2d 718, 726 (Super. Ct. 1988) (calling upon court system to eradicate AIDS-related discrimination, stigmatization, and hysteria by repudiating personal attacks veiled as medical issues).

250. 42 U.S.C. §§ 12101-12213.

251. FLA. STAT. § 61.13(6) (1995).

252. *Id.*

253. *Id.*

254. Zaslów, *supra* note 239, at 81.

255. *Id.* (warning that "exigent circumstances" should be strictly limited to those two situations).

him or her unable to meet the child's everyday needs,²⁵⁶ and the rare situation where the parent becomes a threat to himself or herself, or to others.²⁵⁷

By reforming laws to serve the needs of HIV-infected parents, states will serve a dual purpose. First, lawmakers will exhibit respect for these parents and the obstacles they must face. In addition, reform in this area will benefit all citizens in that state by protecting the future of its children.

IV. A FINAL RECOMMENDATION: COMPREHENSIVE HIV EDUCATION PROGRAMS

To complement all of the aforementioned recommendations for legislation, states must take one more vital step toward ensuring that the rights of HIV-infected individuals receive the attention that they deserve. Federal efforts to educate the public have failed as a whole,²⁵⁸ so state governments must fill the gaps left by federal inaction and assume the leadership role in this area.²⁵⁹

Many state governments acted quickly in the earlier years of the epidemic to provide education to the public, and these efforts must continue, but with some reforms.²⁶⁰ States must begin by ensuring that all education programs provide a wide range of information.²⁶¹ While prevention and control measures obviously are important issues to cover, states also need to include much more.²⁶² Educating all citizens about the dangers of discrimination will encourage prevention as well as ease the burdens of

256. *Id.* at 81-82 (outlining these circumstances and adding that parent still must retain visitation rights to maximum extent practicable).

257. *Id.* at 82-83 (giving examples of situations where parent might lose custody, including: parent who openly threatens to infect others; HIV-infected mother who continues to breastfeed; one who knowingly fails to reduce risk of blood-to-blood contact; and one who engages in sexual contact with child).

258. See Scott Burris, *Education to Reduce the Spread of HIV*, in AIDS LAW TODAY, *supra* note 3, at 82 (characterizing federal education program as "halfhearted").

259. See NATIONAL COMMISSION, *supra* note 1, at 13 (calling on all levels of government to show leadership to combat AIDS crisis); Burris, *supra* note 258, at 89 (asserting that federal grants impose too many restrictions on content, which causes state and local programs to be ineffective). To avoid such results, states must not only pass their own legislation but also lobby the federal government to alleviate content restrictions placed on these grants.

260. See Burris, *supra* note 258, at 94 (reporting that about one-third of the states have required or encouraged education in the public school system).

261. See *id.* at 83 (discussing reducing the risk of contracting AIDS).

262. *Id.*

people already living with HIV disease.²⁶³ In addition, states must teach the principles of “universal precautions” to everyone in society, not just workers with occupational risks of exposure, to avoid global infection.²⁶⁴ All education programs, but especially those directed toward minority groups most affected by HIV disease, must work to empower these individuals if their safety is to be ensured.²⁶⁵ States may do so by requiring programs that advocate not only safer, but more communicative sex, so that women can protect themselves more effectively,²⁶⁶ and present pictures of people living with, rather than dying of, HIV disease.²⁶⁷

Because the rise in adolescent and young adult transmission presently endangers prevention efforts,²⁶⁸ states must pass comprehensive HIV education legislation that reaches as many citizens as possible. Education must begin in the public schools,²⁶⁹ but program administrators must realize that young people need more than condoms. Schools must reach these young people with realistic messages about responsible behaviors, and the programs must take their social and cultural context into account.²⁷⁰

As mentioned, HIV infection is also increasing in young adults, and states must do more than target high-risk groups if they intend to combat AIDS-related discrimination. Because so many people living with HIV disease are of working age, states must mandate workplace education programs.²⁷¹ State governments must set an example for private employ-

263. See NATIONAL COMMISSION, *supra* note 1, at 12 (characterizing reduction of discrimination one of cornerstones for all programs).

264. See Field, *supra* note 72, at 80 (arguing for “universal precautions” to avoid risk of global infection).

265. See Burris, *supra* note 258, at 87 (contending that “HIV is not spread simply by ignorance or carelessness or bad luck, but also by powerlessness, shame, racism and mistrust”).

266. See Kurth, *supra* note 194, at 18 (asserting that empowerment of women will lead to safer sex because they will communicate better with their partners).

267. Phyllis Arnold, *Betwixt and Between: Adolescents and HIV*, in AIDS AGENDA, *supra* note 2, at 41, 43 (stressing the importance of including this information in adolescent programs).

268. *Main Killer*, *supra* note 27, at A2 (providing statistics on the growing incidence of the virus among young adults).

269. See Arnold, *supra* note 267, at 43 (warning that education efforts will fail unless the needs of young adults are addressed).

270. Burris, *supra* note 258, at 86.

271. See, e.g., *id.* at 94-95 (noting Philadelphia ordinance which requires employees to educate individuals in workplace). This program requires employers with three or more employees to hold education programs, run by senior management officials. *Id.* Employers who do not comply are fined up to \$300 per employee. *Id.* States could follow the

ers by educating their own workers to encourage more compassionate responses to people living with HIV disease and to prevent further transmission. The federal government's limited commitment to HIV education includes an HIV education program for federal employees, and states must follow suit.²⁷²

States also must reach those who are not public school students or members of the private or public work forces. Campaigns to educate the general public must continue because many people still think they are not at risk.²⁷³ State governments must work even harder to dispel these unwarranted, incredibly dangerous assumptions through more publicity in a medium available to the public.²⁷⁴

While many governments and organizations concentrate on educating the public before they become infected, they often forget the importance of educating those already living with HIV disease. As more women, children, and people of color become infected, state governments will need to adopt new strategies of education. In addition to providing psychological counseling and information about prevention, states need to give HIV-infected individuals information about housing, estate planning, and public medical benefits during post-test counseling.²⁷⁵ Numerous community-based organizations provide a wealth of services to the HIV-positive, but the very people who can benefit from these services often are unaware that the programs exist.²⁷⁶

Providing effective HIV education programs will require state legislative efforts to empower individuals living with HIV disease. States must coordinate existing programs to provide education as well as adequate health care, housing, drug treatment programs, and a society free of unwarranted discrimination. In reality, such solutions are costly and require vast changes on the part of all citizens, but they are necessary to show individuals living with HIV disease the respect they deserve from the government and society as a whole.

Philadelphia plan in creating a model for workplace education programs.

272. See Hilts, *supra* note 6, at A1, A9.

273. See Berge, *supra* note 65, at 779-81 (examining attitudes of average, middle-class Americans about their chances of transmission).

274. See generally Burris, *supra* note 258, at 89-90 (discussing ways in which National Aids Information and Education Program informs public of HIV).

275. See Kurth, *supra* note 194, at 16-17 (imploing that HIV-infected women need more than just medical attention); Zavos, *supra* note 195, at 140 (explaining that women living with HIV disease often do not make wills because they cannot afford attorney).

276. See NATIONAL COMMISSION, *supra* note 1, at 11 (asking that these organizations receive acknowledgement and support).

V. CONCLUSION

HIV-infected individuals are living with, not dying of, the disease, and states must remember that important fact when making decisions that affect them. Even though HIV disease became a part of our culture over ten years ago,²⁷⁷ discrimination persists that haunts these individuals every day of their limited lives. Legislators, however, have the power to control such unwarranted reactions by passing laws that comport with federal disability discrimination measures and by mandating educational programs that reach as many citizens as possible. Because of HIV disease's novelty and unpredictability, many existing laws are inadequate to meet the needs of those living with HIV disease. States must consider creative measures, such as those discussed here, to accommodate their special situations. Mary Fisher, an outspoken AIDS advocate living with HIV disease, has called upon people worldwide to adopt a "language of hope which affirms life"²⁷⁸ and to recognize that HIV-infected people are indeed living with, rather than dying of, HIV disease. State legislatures must heed her firsthand advice before it is too late.

277. See *supra* notes 2-4 and accompanying text (discussing the genesis of HIV disease in the United States).

278. See NATIONAL COMMISSION, *supra* note 1, at 12 (quoting Mary Fisher).