

**MANY RIVERS TO CROSS: EVOLVING AND EMERGING
LEGAL ISSUES IN THE THIRD DECADE OF THE
HIV/AIDS EPIDEMIC**

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I. INTRODUCTION

Chang got up early one morning, walked into the busy village square, went into the jewelry shop and snatched all the jewels he could find. No sooner was he out of the store, the police caught him. They asked, "Chang, why did you take all those jewels in broad daylight? With all these people around?" Chang replied, "I saw no people."

In the end, this is what is particularly taxing about HIV/AIDS, and what separates it from so many other illnesses. Many of the people infected or affected are those who have always had a tenuous place in our American experiment. HIV has disproportionately affected minorities, injecting drug users, and gay/bisexual men. These individuals, long before HIV/AIDS, had their humanity, sanity, and rights questioned at every turn. I can hear the excuse, "I didn't see a person." Mirrors.

Yet, I believe there is hope. I have heard from more people willing to educate, fight or sue. We must continue to do this even as personally we always balance acceptance and fear.¹

As our culture evolves, so do our laws, although change is rarely quick or efficient in the realm of justice. First comes awareness of a problem, followed by a reaction, positive or negative, depending upon individual or collective experiences. As a problem grows, constituents pressure their legislators to respond, although sometimes these initial attempts at lawmaking are premature or just plain wrong. Critical facts are still unknown or obscured by differing ideologies and prejudices. Yet the process continues because society demands solutions, however temporary or facile. Next, the courts set precedent, which may pose as many questions as answers. New situations emerge, defying the scope of current law. The status quo is challenged, the public demands action again, and the legislative process begins anew. We are reminded that the law, like the culture from which it emerges, is never static.

The development of HIV/AIDS law in the United States over the past twenty years provides an excellent example of the cyclical course described above. First came the problem—and what a mysterious and complicated one it was. On June 5, 1981, the United States Centers for Disease Control and Prevention (CDC)

1. Juan Jackson, *Stigma: Its Impact*, AIDSLINE BRIEF, March 2001, at 6.

warned the public about an outbreak of the rare *Pneumocystis carinii* pneumonia in the gay community.² One month later, the CDC reported increased cases of Kaposi's sarcoma, an unusual form of skin cancer endemic to individuals with immune deficiencies, affecting the same population.³ By 1982, the "gay cancer" afflicting a growing number of people in primarily large urban areas was labeled "Gay Related Immune Syndrome" (GRID). Subsequently, the first of many misconceptions of the epidemic—that only gay men were affected and therefore were responsible for the problem—was born.⁴ That same year, the CDC announced an official name—Acquired Immune Deficiency Syndrome (AIDS)—and identified four high-risk behaviors or characteristics: sexual activity between men, intravenous drug abuse, Haitian origin, and Hemophilia A.⁵ As a result, individuals already subject to discrimination were marginalized further by the stigma connected with an actual AIDS diagnosis or the potential for one.⁶ Fear and misunderstanding grew. Accordingly, many people living with HIV/AIDS suffered not only physically, but emotionally when family members, employers, friends, teachers, doctors, and others began to treat them differently. They were treated more often with contempt than compassion.

By 1983, the discrimination increased. The CDC added female sexual partners of men with HIV/AIDS to its list of high-risk groups. The CDC attempted to reduce public scorn for HIV/AIDS through a publicity campaign designed to deter discrimination

2. The Henry J. Kaiser Family Foundation, *The AIDS Epidemic at 20 Years: Selected Milestones*, available at <http://www.kff.org/docs/AIDSat20> (last visited June 2001) [hereinafter *Milestones*]; Laurie Garrett, *AIDS at 20: Legacy of Hope and Despair*, NEWSDAY, May 29, 2001, at A4 [hereinafter *AIDS at 20*].

3. See *Milestones*, *supra* note 2; see also, *AIDS at 20*, *supra* note 2, at A4. Lawrence K. Altman wrote in the N.Y. TIMES on July 3, 1981:

Doctors in New York and California have diagnosed among homosexual men 41 cases of a rare and often rapidly fatal form of cancer. Eight of the victims died less than 24 months after the diagnosis was made. The cause of the outbreak is unknown, and there is as yet no evidence of contagion. But the doctors who have made the diagnoses, mostly in New York City and the San Francisco Bay area, are alerting other physicians who treat large numbers of homosexual men to the problem in an effort to help identify more cases and to reduce the delay in offering chemotherapy treatment.

Bob Herbert, *It Hasn't Gone Away*, N.Y. TIMES, May 31, 2001, at Editorial/Op-Ed.

4. See *Milestones*, *supra* note 2.

5. *Id.*

6. See NATIONAL LAWYERS GUILD AIDS NETWORK, AIDS PRACTICE MANUAL: A LEGAL AND EDUCATIONAL GUIDE 1-4 (1991) [hereinafter *AIDS PRACTICE MANUAL*].

against people with HIV/AIDS and inform the public that the syndrome could not be transferred through casual contact.⁷ In 1984, Luc Montagnier of the Pasteur Institute and Robert Gallo of the National Cancer Institute announced the isolation of the Human Immunodeficiency Virus (HIV) responsible for AIDS, opening the door to possible treatments and a possible cure.⁸ Yet, still public intolerance was rampant, reaching a new height when thirteen-year-old Ryan White was barred from his school in Indiana, as was nine-year-old Ricky Ray in Florida (arsonists also burned down the Ray family home a year later).⁹

The public's fear of HIV/AIDS began to plague many areas of society. The Immigration and Naturalization Service (INS) began excluding HIV-positive immigrants in 1987, and initiated mandatory antibody testing of all non-citizens applying for entry into the United States.¹⁰ Even today, immigrants must obtain an

7. See *Milestones*, *supra* note 2.

8. *Id.* The human immunodeficiency virus causes AIDS. It is found in certain body fluids including blood, semen, vaginal fluid, breast milk, and other fluids containing blood, such as amniotic fluid surrounding a fetus or cerebrospinal fluid. HIV is transmitted from person to person through sexual contact and blood-to-blood contact. See The Kaiser Family Foundation Capital Hill Briefing Series on HIV/AIDS, *The State of the HIV/AIDS Epidemic in America*, April 2000 [hereinafter *The State of the HIV/AIDS Epidemic*]. See also F. Barre-Sinoussi et al., *Isolation of a T-Lymphotropic Retrovirus from a Patient at Risk for Acquired Immune Deficiency Syndrome (AIDS)*, 220 SCIENCE 868 (May 20, 1983); Robert C. Gallo et al., *Frequent Detection and Isolation of Cytopathic Retroviruses (HTLV-III) from Patients with AIDS and at Risk for AIDS*, 224 SCIENCE 500 (May 4, 1984).

9. *The State of the HIV/AIDS Epidemic*, *supra* note 8.

10. AIDS and HIV infection were considered a "dangerous contagious disease" under section 212(a)(6) of the Immigration and Nationality Act of 1961, Pub. L. No. 87-301, § 11, 75 Stat. 650, 654 (1961). President Ronald Reagan signed the 1987 supplemental appropriations bill which included the "Helms Amendment" directing the addition of HIV to the contagious disease list; Supplemental Appropriations Act of 1987, Pub. L. No. 100-71, §518, 101 Stat. 391, 475 (1987). The final rule is at 52 Fed. Reg. 32540 (Aug. 28, 1987).

Significant controversy followed the Helms Amendment, specifically the 1989 detainment by the INS of a nonimmigrant attempting to enter the United States to attend an international AIDS conference. The INS denied his request for a waiver but an immigration judge later allowed the nonimmigrant to enter. *Matter of Verhoef* (Assoc. Commr. Apr. 7, 1989). All subsequent international AIDS conferences have been held outside of the United States because of this incident.

In 1990, the State Department began to grant ten-day visas to persons attending professional, scientific, or academic conferences in the United States but a conflict between Public Health Service (PHS), the General Accounting Office (GAO), and Congress almost led to the removal of HIV and AIDS from the contagious disease list. Nonetheless, the exclusions continued and in 1993 President Bill Clinton signed a National Institutes of Health (NIH) reauthorization bill that characterized HIV as "a communicable disease of public

HIV waiver in order to overcome the exclusion.¹¹ The same year, Congress adopted an amendment advanced by Senator Jesse Helms (R-NC) banning the use of federal funds for AIDS education materials that “promote or encourage directly or indirectly, homosexual activities,” otherwise known as the “no promo homo” policy.¹² In 1989, Kimberly Bergelis reported that she was infected with HIV by her dentist, igniting public concern about possible exposure to HIV/AIDS by people working in the medical and healing professions.¹³

Finally, and perhaps most consequential to the rapid growth of the AIDS epidemic and its accompanying climate of fear during the 1980’s, the administration under President Ronald Reagan paid scant attention to the burgeoning public health concern. Reagan biographer Lou Cannon noted, “Reagan’s response to this epidemic was halting and ineffective. In the critical years of 1984 and 1985, according to his White House physician, Brigadier General John Hutton, Reagan thought of AIDS as though ‘it was measles and it would go away.’”¹⁴ By 1988, nearly 90,000 people in the United States were diagnosed with AIDS and some 50,000 had died.¹⁵ By 1992, AIDS was the leading cause of death for men aged twenty-five to forty-four.¹⁶ Early recognition of the problem through increased funding, research, education, and frank discussion by government leaders, particularly the president, could have saved many lives.

The 1990’s did bring hope, however, in the form of new and varied drug treatments, public awareness campaigns, the search for a vaccine, and comprehensive legislation on all levels of government. For example, on July 26, 1990, the Americans with

health significance.” Pub. L. No. 103-43. As a result, individuals with HIV and AIDS are still singled out by the Immigration and Nationality Act. *See* THE DISTRICT OF COLUMBIA BAR PUBLIC SERVICE ACTIVITIES CORPORATION AND WHITMAN-WALKER CLINIC, INC., AIDS ADVOCACY X-36 to X-38 (1999) [hereinafter AIDS ADVOCACY]. Mandatory testing is governed by 56 Fed. Reg. 25,000 (1991); 42 C.F.R. § 34 (1994).

11. The INS has broad discretion as to whether to grant an HIV waiver application and the application process is particularly arduous. 8 C.F.R. § 3.8(c), 103.5 (1990).

12. Supplemental Appropriations Act of 1987, Pub. L. No. 100-71, § 518, 101 Stat. 391, 475 (1987) (codified at 52 Fed. Reg. 32,540 (Aug. 28, 1987)).

13. *See Milestones, supra* note 2.

14. Herbert, *supra* note 3, at Editorial/Op-Ed.

15. *Id.*

16. *See Milestones, supra* note 2.

Disabilities Act (ADA) was signed into law and new protections were made available for all individuals living with disabilities, including those disabled by HIV/AIDS (within the government and private employment contexts).¹⁷

By 1998, the United States Supreme Court clarified the application of the ADA to include asymptomatic people with HIV and AIDS, or people in the early stages of HIV disease in the landmark case *Bragdon v. Abbott*.¹⁸ The *Bragdon* decision was also important because it limited the “direct threat” defense.¹⁹ According to the Court, the “direct threat” defense does not allow discrimination if any risk of HIV/AIDS transmission exists, only if the risk is deemed significant.²⁰ Comprehensive and objective scientific evidence is necessary to prove the risk; a good-faith belief that a risk is possible, without support from objective evidence, is insufficient.²¹ *Bragdon* represented the Court’s acknowledgement of a tightly construed direct threat analysis in order to ensure application in a fair and uniform manner.²² The *Bragdon* decision, coupled with the ADA’s sweeping protections, assists individuals with HIV/AIDS in contexts where the mere mention of having the illness could lead to job loss, isolation, or even personal threats and attacks.

The advent of the ADA and the subsequent *Bragdon* decision exemplify two key legal responses in the epidemic’s evolution. Yet,

17. The ADA actually “became effective in three stages: January 26, 1992 for state and local governments and privately owned public accommodations; July 26, 1992 for private employers with twenty-five or more employees; and July 26, 1994 for private employers with fifteen to twenty-four employees.” AIDS ADVOCACY, *supra* note 10, at III-33. Title I of the ADA, 42 U.S.C. §§ 12111-12117 covers employment; Title II, 42 U.S.C. §§ 12131-12165 covers public accommodations and services operated by state and local governments; and Title III, 42 U.S.C. §§ 12181-12189 covers public accommodations that are privately owned or operated. AIDS ADVOCACY, *supra* note 10, at III-33. The ADA expanded upon the Rehabilitation Act of 1973, which provided protections for people with disabilities in the context of employment by the federal government, programs receiving federal funds, or government contractors. *See* 29 U.S.C. § 794 (1999).

18. 524 U.S. 624 (1998).

19. *Id.* at 648-49.

20. *Id.* at 649. “[F]ew, if any, activities in life are risk free.” *Id.*

21. *Id.*

22. *See, e.g.*, *General Electric Co. v. Joiner*, 522 U.S. 136, 144 (1997) (noting that scientific evidence and expert testimony must have a traceable, analytic basis in objective fact before it may be considered on summary judgment); *School Bd. of Nassau Cty. v. Arline*, 480 U.S. 273, 287 (1987) (balancing protection of people with disabilities with protecting others from significant health risk).

despite gains through legislation,²³ case law, public education, the expansion of HIV/AIDS service organizations, the broad range of treatment options, the increased availability of needle exchange programs, and the work of AIDS activist groups, the legal system still struggles to catch up to the crisis. Many areas of the law beyond disability rights are relevant to the lives of people with HIV/AIDS. Legal issues arising from housing, benefits, insurance, and debtor/creditor issues, among others, are critical because they impact quality of life. Discrimination and confidentiality issues impact employment, family matters (including child welfare and custody), housing, domestic violence, and access to affordable medical care. Estate planning and health care directives are necessary for people earlier in life than ever expected, particularly for individuals in same-sex partnerships where the relationship is not legally recognized by the state. In the area of criminal law, incidents of intentional or negligent transmission of the HIV virus often appear in the news. In some states, prisoners with HIV/AIDS are segregated from the general prison population. Some jails and prisons in all states, including Minnesota, at times improperly deny access to proper medical support and crucial medications. This is particularly damaging for individuals on protease inhibitors who cannot miss a dosage without harming their treatment regimes.

In sum, HIV/AIDS is a complex disease, often calling into question uncomfortable issues for the society at large—specifically

23. Other significant gains in the law include: The Health Omnibus Programs Extension Act of 1988, Pub. L. No. 100-607, 102 Stat. 3048 (authorizing the use of federal funds for AIDS education and prevention and anonymous HIV-antibody testing); The Ryan White Comprehensive AIDS Resources Emergency Act of 1990, Pub. L. No. 101-381, 104 Stat. 576 (providing funds to states and local communities to “improve the quality and availability of care for individuals and families with HIV disease”); The Housing Opportunities for People with AIDS (HOPWA) Act of 1991, Pub. L. No. 101-625 Tit. VIII, § 852, 104 Stat. 4375 (providing housing assistance to low-income people living with AIDS); The National Institutes of Health Revitalization Act of 1993, Pub. L. No. 103-43, 107 Stat. 122 (creating a permanent AIDS research office at the NIH); The Ricky Ray Hemophilia Relief Fund Act of 1998, Pub. L. 105-369, 112 Stat. 3368 (providing a single payment of \$100,000 to any individual infected with HIV who has a blood clotting disorder and was treated with blood-clotting agents between July 1, 1982 and December 31, 1987); The Health Insurance Portability and Accountability Act (HIPAA) of 1996, Pub. L. 104-191, 110 Stat 1936 (limiting the amount of time a pre-existing condition such as a person’s HIV could be excluded from insurance coverage in small group or some individual insurance policy markets); The Work Incentives Improvement Act of 1999, Pub. L. 106-170, 113 Stat. 1860 (extending Medicaid coverage to individuals with disabilities or potentially severe disabilities).

racism, poverty, sexual orientation, disability, and entitlement.²⁴ An equally complex response is demanded from the legal system in order to protect the rights of people living with, or affected by, HIV/AIDS.

This essay considers recent trends in HIV/AIDS law and limits its scope to three specific areas: confidentiality and discrimination, employment practices, and permanency planning in the context of family law. The essay opens with an examination of the state of HIV/AIDS today, internationally, nationally, and in Minnesota, setting a context for the discussion to follow. The next three sections present and analyze new case law and legislation on the national and Minnesota levels, offering commentary and critique as well as predictions and hopes for the legal community's response to the third decade of the epidemic. The essay will not attempt to present a comprehensive history of the law's evolution in response to HIV/AIDS. Instead, the essay considers where we are in 2001, and looks to the future. The essay makes conclusions about how far the legal community has advanced in protecting the rights of individuals with HIV/AIDS, but also acknowledges that our response will never be complete until we, as human beings, commit to unified action against the spread of HIV/AIDS.

II. THE STATE OF HIV/AIDS IN 2001: A GLOBAL CRISIS WITH LOCAL IMPACT

A. *The National and International Picture*

More than thirty-six million people have AIDS in the world today.²⁵ The epidemic has killed some twenty-three million people since 1981 and soon the number dead will surpass that of the bubonic plague responsible for killing one-third of Europe's population over 700 years ago.²⁶ Approximately 95% of the HIV cases in the world are located in developing countries where inadequate infrastructure, lack of medical resources, cultural taboos, and relative invisibility in the eyes of wealthier countries

24. "AIDS in this country is increasingly an epidemic of the poor, which means it is increasingly an epidemic of minorities." Sheryl Gay Stolberg, *After 20 Years, AIDS is Woven Into America's Fabric*, STAR-TRIBUNE (Minneapolis) June 3, 2001, at A3.

25. See Herbert, *supra* note 3, at Editorial/Op-Ed.

26. *Id.*

combine to increase the epidemic's spread.²⁷ Sub-Saharan Africa represents the hardest-hit region, with an estimated 70% of the world's cases.²⁸ More than twenty-five million people in the area are infected with HIV; nearly four million were infected in just the past year.²⁹ South Africa, Botswana, and Namibia have suffered the worst of the human cost on the African continent.³⁰ And the epidemic has only begun to explode in Asia.³¹ The future, without affordable treatment, a vaccine, or a cure, could bring worldwide infection rates as high as 400 million by 2021.³² It is not surprising, therefore, that the United States and the United Nations Security Council have identified HIV/AIDS as a world security threat.³³

The United States, as the world's richest nation, has seen a decrease in AIDS deaths thanks to greater commitment to public education as well as widespread availability of protease inhibitors and other drugs successful in treating the virus.³⁴ Still, HIV/AIDS cases are reported in all fifty states, with approximately 800,000 to 900,000 people diagnosed with HIV/AIDS throughout the country.³⁵ An estimated 438,795 people in the United States have died since 1981.³⁶

27. The Henry J. Kaiser Family Foundation, *American Views on the AIDS Crisis in Africa: A National Survey, 2000*, at <http://www.kff.org> (last visited May 29, 2001) [hereinafter *AIDS Crisis in Africa*] (quotations omitted); see also Salih Booker & William Minter, *Global Apartheid*, THE NATION, July 9, 2001, at 11 (comparing the pharmaceutical companies' refusal to provide AIDS drugs at low or no cost to the Apartheid system of racism once established in South Africa).

28. See *AIDS Crisis in Africa*, *supra* note 27 (quotations omitted).

29. *Id.*

30. *Id.*

31. See *AIDS at 20*, *supra* note 2.

32. *Id.*

33. See *Milestones*, *supra* note 2.

34. See Herbert, *supra* note 3, at Editorial/Op-Ed. For example:

Protease inhibitors are new drugs designed to stop the reproduction of HIV in the body. They work by blocking the enzyme that the virus needs in order to infect blood cells. . . Clinical trials have shown that protease inhibitors, taken in combination with other anti-viral drugs like AZT, ddI and d4T, can lower the amount of HIV in the blood. This triple combination slows HIV's ability to reproduce and make more HIV.

Minnesota AIDS Project, *Questions About AIDS*, at <http://mnaidproject.org/html/questions.htm> (last visited June 2, 2001) [hereinafter *Questions About AIDS*]. AIDS is no longer among the fifteen leading causes of death in the United States. Stolberg, *supra* note 24, at A3.

35. See *Milestones*, *supra* note 2.

36. *Id.*

HIV/AIDS affects all populations in the United States, however some groups are more disproportionately affected than others, fueling the relevance of social justice issues that drive discussions about the epidemic, not to mention the many cultural conflicts surrounding homosexuality.³⁷ According to a recent *New York Times* article:

[t]here is an inner-city epidemic, the rural epidemic, the epidemic among women, among intravenous drug users, among gay men, among blacks, among non-Hispanic whites and among Hispanics. But the most powerful determinant of how an HIV patient fares is not race or gender or sexual orientation. . . . It is class. In that respect there are just two epidemics: the one among people who, by virtue of their education and income, lead stable lives and the one among people who do not.³⁸

This inherent complexity makes HIV/AIDS a multi-faceted epidemic.

In 1998 African American leaders declared a “state of emergency” because of the many losses in the African American community due to HIV/AIDS.³⁹ By 2000 the CDC reported that among men who have sex with men, African-American and Latino cases surpassed those among white men.⁴⁰ A recent CDC survey showed 30% of gay black males between the ages of twenty-three and twenty-nine in six United States cities have HIV, and AIDS-related illnesses are now the leading cause of death for all African

37. See Centers for Disease Control and Prevention, *Taking Action to Combat Increases in STDS and HIV Risk Among Men Who Have Sex with Men, 2000*, at http://www.cdc.gov/nchstp/news/92288_AED_CDC_Report-0427c.htm (last visited May 29, 2001) [hereinafter *Taking Action*].

Blacks are 10 times more likely than whites to be diagnosed with AIDS, and 10 times more likely to die from it. . . . The Centers for Disease Control believes 1 in every 50 black American men is infected with HIV. . . . It believes 1 in every 160 black women is infected. By comparison, 1 in every 250 white men is infected, and 1 in 3,000 white women. . . . The denial runs so deep—and the stigma surrounding homosexuality is still so strong among blacks—that many black men who have sex with other men nevertheless think of themselves as heterosexual, not gay or bisexual. These men, while attempting to present a heterosexual image to the outer world, frequently engage in compulsive, high-risk sex with men while engaging in ongoing sexual relationships with one or more women.

Bob Herbert, *A Black AIDS Epidemic*, N.Y. TIMES, June 4, 2001, at Editorial.

38. Stolberg, *supra* note 24, at A1.

39. *Id.*

40. *Id.*

Americans aged twenty-five to forty-four.⁴¹ HIV/AIDS is also on the increase among Native Americans, a group that accounts for only 1% of the United States population but 6% of the new HIV cases reported since December, 1999.⁴²

Women represent approximately 30% of all new HIV infections in the United States and a growing percentage of new AIDS cases.⁴³ Women of color are among the majority of new AIDS cases and have been affected disproportionately since the beginning of the epidemic.⁴⁴ Women in their childbearing years represent the highest rate of infection, particularly between the ages of thirty to forty-nine.⁴⁵ However, the use of AZT during pregnancy has been extremely effective in nearly eliminating mother-to-infant transmission.⁴⁶ Drug use influences all populations' susceptibility to the virus, but in the case of

41. The Henry J. Kaiser Family Foundation, Kaiser Daily HIV/AIDS Report, *National Black Church Prayer Week Scheduled to Bring AIDS Awareness to the Pulpit*, at <http://report.kff.org/archive/aids/2001/2/kh010220.2.htm> (Feb. 20, 2001). "Blacks, who make up only 13% of the country's population, now account for more than half of all new HIV infections, according to the [CDC]." Stolberg, *supra* note 24, at A3. Despite the growing number of infections in the African American community, many black elected officials believe the government and community response is lacking. *Id.*; see The Henry J. Kaiser Family Foundation and Joint Center for Political and Economic Studies, *Survey of Black Elected Officials on HIV/AIDS*, at <http://www.report.kff.org/archive/aids/2001/5/kh010531.7.htm> (Jan. 2000).

42. The Henry J. Kaiser Family Foundation, *HHS Officials Warn of HIV/AIDS 'Threat' in Native American Communities*, KAISER DAILY HIV/AIDS REPORT at <http://www.report.kff.org/archive/aids/2000/11/kh001116.2.htm> (Nov. 16, 2000).

43. The Henry J. Kaiser Family Foundation, *Women and HIV/AIDS: Fact Sheet*, at <http://www.kff.org/content/2001/1631/1631.pdf> (May 2001) [hereinafter *Women and HIV/AIDS*] (quoting CENTERS FOR DISEASE CONTROL AND PREVENTION, HIV STRATEGIC PLAN THROUGH 2005 (Jan. 2001); CENTERS FOR DISEASE CONTROL AND PREVENTION, HIV/AIDS SURVEILLANCE REPORTS (year end eds. 1986, 1990, 1994, 1999)).

44. *Women and HIV/AIDS*, *supra* note 43. The Henry J. Kaiser Family Foundation reports:

In 1999, the AIDS case rate for African American women was 49 per 100,000 compared to 2.3 per 100,000 for white women—more than 21 times greater. The case rate for Latinas (14.9 per 100,000 was more than six times the rate for white women. In 1998, HIV was the 3rd [sic] leading cause of death among African American women ages 25-44 and the 4th [sic] leading cause of death among Latinas, compared to the 10th [sic] for white women in this age group.

Id.

45. *Id.*

46. Stolberg, *supra* note 24, at A3.

heterosexual women, particularly in rural areas of the southern United States, crack and the accompanying sex-for-drug trade is helping to spread the virus.⁴⁷ Mysteriously, women as a whole do not appear to respond to treatment advances and prevention interventions as readily as men. Between 1993 and 1999, the number of new AIDS cases among women fell by 36% while men's cases fell by 60%.⁴⁸ These numbers support the existence of gender disparities in access to medical care, not just for HIV/AIDS but also sexual, prenatal, and reproductive health.⁴⁹

Complacency about HIV/AIDS has emerged in the United States in recent years and "AIDS fatigue," namely prevention burnout and myths about the results of antiretroviral therapies, has contributed to a new spike in the epidemic.⁵⁰ New data shows alarming increases in the infection rates among men who have sex with men, as well as a rise in sexually transmitted diseases in all populations.⁵¹ Another frightening statistic is the growing rate of infection among younger people, especially under the age of 18. One United States teenager is infected with HIV every hour.⁵²

Finally, burdensome, expensive, and unreliable treatment regimes have led to difficulties with medication adherence, increasing the risk of transmission when safer sex practices are not followed.⁵³ Only a small percentage of people with HIV/AIDS in the United States can afford the drug therapies, which often range in cost from \$15,000 to \$20,000 per year.⁵⁴ Some experience debilitating reactions to the drug treatments and have to stop taking them.⁵⁵ Those who do adhere to treatment find themselves taking upwards of twenty or more pills a day according to strict

47. *Id.*; see also Kevin Sack, *Aids Epidemic Takes Toll on Black Women*, NY TIMES, July 3, 2001.

48. Sack, *supra* note 47. The AIDS death rate has a similar correlation, with estimated deaths between 1993-1998 declining by 35% for women and 60% for men. *Id.*

49. *Id.* "One in five HIV infected women is uninsured." *Id.*

50. When Kevin Hill "warned friends about the dangers of HIV, one responded that if he became infected he would 'just take the little blue pill and be fine.'"

51. See *Taking Action*, *supra* note 37. Transmitting HIV is two to five times more likely if another sexually transmitted infection is present. Minnesota AIDS Project, AIDSLINE BRIEF, Mar. 2001, at 4.

52. *Questions About AIDS*, *supra* note 34.

53. *Id.*

54. *Id.*

55. *Id.*

intervals and rigid conditions.⁵⁶ Skipping doses or not following medication protocol can weaken the drug's potency, and increase the possibility that a stronger, drug-resistant strain of HIV will develop within the person's body.⁵⁷ Other long-term effects are unknown because the drugs have only been available for a short time.⁵⁸ Essentially, people's lives are dramatically changed not only by having HIV/AIDS but also by all of the precautions necessary to keep on living. The burden is tremendous but the alternative, the loss of life, is daunting.

B. Minnesota Statistics and Priorities

There have been 2,916 reported cases of HIV and 3,803 reported cases of AIDS in Minnesota, with 2,128 AIDS deaths since the beginning of the epidemic.⁵⁹ The estimated number of HIV cases in the state ranges from 4,000 to 17,000.⁶⁰

The Minnesota state legislature has provided important support for people living with HIV/AIDS in Minnesota although recent funding trends suggest that complacency about the epidemic exists among lawmakers. Budget impasses in the 2001 session led to uncertainty about funding for K-12 HIV Regional Sites, sexually transmitted infection prevention funding, funding for workplace education, and cuts to HIV/AIDS grants in the Health and Human Services Budget.⁶¹ Even though some of the requested funding was eventually granted, the very existence of battles about education and prevention indicates that although knowledge is the most important weapon in fighting the spread of HIV/AIDS, government is not always willing to make the necessary investment in building that knowledge. Further, HIV/AIDS presents the sort of complicated issues many politicians like to avoid—race, poverty, sex, drugs, and sexual orientation—all capable of stirring up conflict among constituents and conservative lobbying groups. Nonetheless, recent survey results show that

56. *Id.*

57. *Id.*

58. *Id.*

59. Minnesota AIDS Project, AIDS LINE BRIEF, June 2001 (quoting statistics from the Minnesota Department of Health (MDH) as of June 2001).

60. *Id.* The population of Minnesota is 4,919,479. *Id.*

61. Minnesota AIDS Project, *MAP Advocate: AIDS Advocacy Update*, May 30, 2001 and June 26, 2001; see also The Henry J. Kaiser Foundation, *Minnesota: Editorials Blast House Abortion, HIV/AIDS Measures*, KAISER DAILY HIV/AIDS REPORT at <http://report.kff.org/archive/aids/1999/05/kh990513.5.html> (May 13, 1999).

Minnesotans still believe that education and prevention resources are important. Specifically, 88% support current or increased levels of HIV prevention funding and 78% say a portion of a budget surplus should go toward sexually transmitted infection prevention. Some 61% agree that teenagers are likely to be sexually active and need comprehensive sexual health education that includes, but is not limited to, abstinence as an option.⁶²

Despite majority agreement about the importance of prevention and education, there is still a shocking amount of ignorance about HIV/AIDS nationally and in the state of Minnesota, twenty years into the epidemic. A recent national poll indicates that many misperceptions persist, across all generations, indicating the urgent and continuing need for legal protections for people living with HIV/AIDS. For example, 55% of Americans still believe HIV can be contracted by using the same drinking glass as a person with the disease.⁶³ A case involving a north-central Minnesota café asking an HIV-positive man to bring his own glass was recently brought to the attention of the Minnesota AIDS Project (MAP) Legal Program and bears out survey results showing uncertainty among Greater Minnesotans about HIV/AIDS transmission by sharing drinking glasses.⁶⁴ Forty-one percent of Americans believe HIV can be contracted from a toilet seat and 54% believe the virus can be transmitted by a cough or a sneeze; 52% percent of Minnesotans are not sure whether HIV can be transmitted in this manner.⁶⁵ In another Minnesota case a person who informed his gym trainer about his HIV status discovered that others in the gym overheard his conversation and as a result refused to use the whirlpool with him and cleaned equipment after he used it.⁶⁶ Forty-seven percent of Minnesotans still indicate discomfort with having an HIV-positive co-worker and 57% would not feel comfortable having their children attend school with a child who has HIV/AIDS.⁶⁷ Seventy-seven percent of Americans

62. *Knowledge and Attitudes About HIV in Minnesota: A Survey Commissioned by the Minnesota AIDS Project*, conducted by Mason-Dixon Polling & Research, Inc. of Washington, D.C. on February 5 and 6, 2001 [hereinafter *MAP Survey*]. A total of 625 Minnesota voters were surveyed by telephone. Inquiries about the results or interpretations of the survey findings may be obtained by contacting MAP's Community Affairs Department.

63. AIDSLINE BRIEF, *supra* note 51, at cover.

64. *MAP Survey*, *supra* note 62.

65. AIDSLINE BRIEF, *supra* note 51, at cover; *MAP Survey*, *supra* note 62.

66. AIDSLINE BRIEF, *supra* note 51, at 2.

67. *MAP Survey*, *supra* note 62.

believe people with HIV are treated unfairly in our society and yet the cases described above are just two examples of the hundreds received by the MAP Legal Program alone each year.⁶⁸ The effects of stigma on the lives of people with HIV/AIDS will be explored in case law and anecdotes throughout subsequent sections.

III. CONFIDENTIALITY AND DISCRIMINATION

A. *Confronting Stigma: The New Scarlet Letter*

The CDC has identified access to HIV counseling and testing as key to controlling the epidemic.⁶⁹ One barrier to testing, however, is the stigmatization of persons with HIV/AIDS and the groups primarily affected by HIV/AIDS (men who have sex with men and illegal drug users).⁷⁰ Stigma encompasses prejudice, all forms of discrimination, and in extreme cases, violence. Some people with HIV/AIDS may not have experienced any stigmatizing behaviors themselves but have heard enough examples from others that they allow fear of disclosure and possible recrimination to keep them from seeking the help they need.⁷¹ For example, the Minnesota HIV Services Planning Council conducted a survey in 1999 and concluded that “a number of the barriers [to care and services] . . . are self-imposed, due to the stigma and consequent fears of disclosing positive status.”⁷² A significant number of survey respondents did not have health insurance and/or seek medical care because they feared revealing their status to professionals and believed others, specifically family members and friends, would shun them upon discovering the truth.⁷³ Aside from personal loss,

68. *Id.* at cover.

69. *HIV-Related Knowledge and Stigma—United States, 2000*, MMWR WEEKLY at <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm4947a2.htm> (December 1, 2000); but see The Henry J. Kaiser Foundation, *HIV Testing: Fewer Anonymous Tests Suggest Stigma is Waning*, KAISER DAILY HIV/AIDS REPORT, at <http://report.kff.org/archive/aids/1999/06/kh990625.1.html> (June 25, 1999).

70. *HIV-Related Knowledge and Stigma*, *supra* note 69.

71. AIDS LINE BRIEF, *supra* note 51, at 5.

72. *Id.*

73. *Id.*

Only 82% of the survey respondents indicated they had health insurance. Less than the 96% insurance rate for the Minnesota population as a whole. . . . A significant number of people hid their HIV status out of fear. The isolation is a barrier to emotional support and full integration into community life. . . . Each year Minnesota reports approximately 340 new cases of HIV. Thirty three percent of these individuals also have

stigmatization can also lead to job firings, demotions, harassment, evictions from apartments, inability to obtain housing because of landlord prejudice, isolation of HIV-positive children in their schools, and many other negative consequences. These problems can happen anywhere, at any time.

HIV/AIDS is often perceived as an urban problem because people mistakenly believe that the high-risk behaviors associated with the transmission of the virus only occur in big cities. Lack of education leads to misinformation about HIV/AIDS beyond the suburban ring. Current statistics show that 11% (704 reports) of the HIV infections since the beginning of the epidemic occurred in Greater Minnesota.⁷⁴ Many rural and small town residents with HIV/AIDS find that it is very difficult to maintain confidentiality.⁷⁵ Recent reports have shown that individuals with HIV/AIDS in rural areas across the United States are more susceptible to depression or suicidal thoughts than similarly situated individuals in urban areas.⁷⁶ Those individuals threatening suicide cite fear of disclosure, stigma, and discrimination as prime stressors.⁷⁷

For one HIV-positive woman in Greater Minnesota, a doctor's loud statement about her status in an emergency room was enough to set off a devastating life-changing series of events. The hospital was in a small town and as the news traveled about the woman's health, she lost her job, her parents lost their jobs, and her children were summarily kicked out of day care. A careless remark

AIDS at the time they first report. [I]nterviews with these individuals [reveal] that the majority test late or only when sick because of stigma or fear. Half of those interviewed in the 1998 Black Services Needs Assessment said they were not receiving medical care. The two principal reasons they gave were denial and 'Don't feel sick.' Individuals said they were afraid of others finding out, afraid of how they would be treated if medical staff knew, and afraid of losing friends and family. They feared this because they had watched it happen to others.

Id.

74. AIDSLINE BRIEF, *supra* note 59, at cover.

75. *Id.* According to statistics collected by the Rural AIDS Action Network (RAAN), in 1998, only 8% of persons living with HIV/AIDS were "out" about their status in their communities. Rural AIDS Action Network, at <http://www.raan.org/facts.htm> (last visited June 4, 2001).

76. The Henry J. Kaiser Foundation, *HIV-Positive Individuals in Rural Areas More Likely to Experience Depression, Suicidal Thoughts*, KAISER DAILY HIV/AIDS REPORT, at <http://report.kff.org/archive/aids/2001/4/kh010419.7.htm> (April 19, 2001).

77. *Id.* "It is important for residents of rural communities to realize that, when they stigmatize or discriminate against a rural person living with HIV/AIDS, they may very well be contributing to his or her psychological demise." *Id.*

was all it took for the woman to discover that her HIV-status made her an outcast in her own community.⁷⁸ Such negligence, coupled with instances of intentional nonconsensual disclosures by parties other than the person infected, exemplify the need for clear and comprehensive laws protecting confidentiality and punishing discrimination.

B. National Trends: Focus on New Federal Health Privacy Rule

Privacy is at a premium in our increasingly wired society. Of course, not all breaches of privacy can be remedied under the law. An unauthorized disclosure by a family member or friend, for example, is not likely to be actionable.⁷⁹ But disclosure by a federal government agency or employee, on the other hand, can lead to a constitutional privacy claim unless a qualified immunity defense or the individual privacy interest does not succeed in a balancing test against the legitimate interests of the state.⁸⁰

Privacy laws are becoming more comprehensive across the United States, and as a result, people with HIV/AIDS have more legal tools to combat unwanted disclosure and resulting discrimination. Nonetheless, the federal and state governments are still grappling with appropriate methods of HIV disclosure, and as to be expected, laws are neither uniform nor consistent from state to state. For example, some states have either considered or

78. *Id.*

79. Minnesota does have a limited right to privacy, but common law remedies and monetary damages are available only if a concrete harm can be established, such as lost business, lost wages, therapy expenses, etc. *See, e.g.* *Lake v. Wal-Mart Stores, Inc.*, 582 N.W.2d 231 (Minn. 1998).

80. *See Whalen v. Roe*, 429 U.S. 589 (1977) (holding that patient has a limited right to privacy in medical records). Many courts have held that individuals infected with HIV possess a constitutional right to privacy regarding their condition; *see, e.g.*, *Doe v. Southeastern Pa. Transp. Auth.*, 72 F.3d 1133 (3rd Cir. 1995) *cert. denied*, 117 U.S. 51 (1996); *Doe v. City of New York*, 15 F.3d 264, 267 (2d Cir. 1994); *Harris v. Thigpen*, 941 F.2d 1495 (11th Cir. 1991); *Incitti v. Skinner*, No. 88-CV-60b, 1994 U.S. Dist. LEXIS 13997 (N.D.N.Y. Sept. 13, 1994); *Doe v. Attorney General*, 941 F.2d 780, 795-96 (9th Cir. 1991); *Woods v. White*, 689 F. Supp. 874, 876 (W.D. Wis. 1988), *aff'd*, 899 F.2d 17 (7th Cir. 1990); *Doe v. Town of Plymouth*, 825 F. Supp. 1102, 1107 (D. Mass. 1993). The right to privacy has also been extended to members of an immediate family of a person with AIDS. *See Doe v. Borough of Barrington*, 729 F.Supp. 376, 385 (D.N.J. 1990). Appropriate federal laws include the Federal Privacy Act of 1974, 5 U.S.C. § 552a (1994), the Americans with Disabilities Act, 42 U.S.C. § 1983, and the Freedom of Information Act, 5 U.S.C. § 522(a) (1988) (does not permit disclosure of medical records if invasion of privacy is unwarranted).

implemented names-based HIV reporting practices, while others are using a unique identifier-based reporting system to protect patient confidentiality.⁸¹ Despite its use in the majority of states, names-based reporting is controversial because of concerns that confidentiality will be compromised, deterring many from seeking appropriate medical care or disease testing in the first place.⁸² The individual is harmed and so too is the public health interest. Some believe that keeping names on file could lead to abuses through HIV/AIDS-related legislation requiring legal disclosure of HIV test results or misuse of information by employers, for instance, in order to discriminate against infected persons.⁸³ Others argue that keeping track of names will help health officials track people who test positive so that counseling and medical care can be provided.⁸⁴ A number of states also use this information to notify partners (although states like Minnesota do not report names to a partner, only the possibility of exposure to infection).⁸⁵

Computerized records are accessible by many in the health care context, some of whom through abuse of information or simple negligence, allow it to be used inappropriately. Such was the case for a MAP client whose ex-wife worked in maintenance at his health clinic in a small Minnesota town and gained access to his health records. A recent poll shows that one in five Americans believes his or her personal medical information has been improperly disclosed at some time, and at least half believe that this disclosure resulted in personal embarrassment or harm, including job loss, loss of dignity, discrimination, and stigma.⁸⁶ Lack of enforceable privacy rules often leads individuals to shield themselves from potentially beneficial treatment for fear of information abuse by doctors, insurance companies, pharmacies,

81. See The Henry J. Kaiser Family Foundation, *Oregon Names-Based HIV Reporting Delayed Until October to Ensure Public Awareness*, KAISER DAILY HIV/AIDS REPORT, at <http://report.kff.org/archive/aids/2001/5/kh010513.3.htm> (May 15, 2001).

82. The Henry J. Kaiser Family Foundation, *Names Based Reporting: The Pros and Cons*, KAISER DAILY HIV/AIDS REPORT, at <http://report.kff.org/archive/aids/1998/06/kh980612.6.htm> (June 12, 1998).

83. *Id.*

84. *Id.*

85. *Id.*

86. Health Privacy Project: Institute for Health Care Research and Policy, Georgetown Univ., *New Federal Health Privacy Regulation: Questions and Answers*, at <http://www.healthprivacy.org> (last visited June 3, 2001) [hereinafter Health Privacy Project].

researchers, and employers.⁸⁷

On April 14, 2001, new federal health policy regulations went into effect as mandated by the Health Insurance Portability and Accountability Act (HIPAA). Although the Department of Health and Human Services (HHS) will still consider modifications to the rules, the implementation period has commenced, and health care entities covered by the regulation now have two years to comply (smaller health plans have three years).⁸⁸ The new rules are important because they set legal limits on how health-related information can be used. Prior to the new rules, virtually no protections were in place. In fact, medical records were not as protected as credit reports or even video rental records.⁸⁹ The new regulations, which cover health plans, health care clearinghouses, and certain health care providers using computers to transmit health claim information, provide patients with many important new rights. These rights include broad access to their own medical records, restrictions on employer access to health information, requirements that health care providers give people notice about how their medical information will be used and disclosed, and options as to how to restrict access to medical information.⁹⁰ HIPAA does not preempt or override stronger state law but rather sets a national “floor” of privacy standards.⁹¹ The new rules apply equally to private sector and public sector health entities, and set civil and federal criminal penalties for violation of the privacy protections.⁹²

87. Health Privacy Project: Institute for Health Care Research and Policy, Georgetown Univ., *Welcome to Health Privacy 101*, at <http://www.healthprivacy.org> (last visited June 3, 2001).

88. The 1996 Health Insurance Portability and Accountability Act (HIPAA), Pub. L. 104-191, required the Clinton Administration to issue rules to protect the privacy of health information. Draft regulations were unveiled November 1999 and some 52,000 comments were submitted. On December 20, 2000, President Clinton issued the privacy rules but on February 28, 2001, the newly-appointed Bush administration Department of Health and Human Services (HHS) Secretary Tommy Thompson re-opened the comment period for 30 days. 45 C.F.R §150.207 (2000).

89. Health Privacy Project, *supra* note 86.

90. 45 C.F.R §150.207.

91. *Id.*

92. *Id.*

Civil money penalties are \$100 per violation, up to \$25,000 per person, per year for each requirement or prohibition violated. Criminal penalties are up to \$50,000 and one year in prison for obtaining or disclosing protected health information . . . under “false pretenses”; and up to \$250,000 and up to 10 years in prison for obtaining or disclosing protected health information with the intent to sell, transfer or use it for

Some concerns have been raised about the new rules, but the standards include enough flexibility to suit the needs of medical providers and patients alike.⁹³ The key benefit, of course, is that patients will have more confidence in the medical profession and will therefore seek help when necessary. This is particularly important for people with HIV/AIDS because fear of disclosure has already been demonstrated in Section A as a prime barrier to medical care. The new regulations place a “minimum necessary” standard on all disclosures by health care providers meaning for treatment purposes only.⁹⁴ Only two mandatory disclosures exist within the rules: (1) to the individual who is the subject of the protected health information, and (2) disclosures to HHS for purposes of enforcing the regulation.⁹⁵

The new rules will also help people with HIV/AIDS because they extend and improve upon protections provided under the ADA. Prior to the rules, the ADA and several state anti-discrimination laws prohibited discrimination based on real and perceived disability, but these laws did not prevent employers from accessing health information.⁹⁶ Employees had to pursue costly discrimination claims whenever employers used information improperly. Now the privacy regulations will allow employers limited access to health information (i.e. for purposes of paying health insurance only).⁹⁷ The potential for abuse of health information still exists, but the new privacy protections coupled with the ADA will give injured persons with HIV/AIDS more and better options for pursuing claims against employers.

C. *Minnesota Perspective*

Minnesota’s body of privacy law, its Human Rights Act (MHRA),⁹⁸ the ADA, and now the new federal privacy rules described in the preceding section, provide a broad, but still incomplete, range of protections for people with HIV/AIDS.

commercial advantage, personal gain or malicious harm.

U.S. Department of Health and Human Services, *HHS Fact Sheet: Protecting the Privacy of Patients’ Health Information*, at <http://www.aspe.hhs.gov/admnsimp/final/pvcfact2.htm> (Apr. 23, 2001).

93. See Health Privacy Project, *supra* note 86.

94. 45 C.F.R § 150.207.

95. *Id.*

96. 42 U.S.C.A. §12101.

97. 45 C.F.R § 150.207.

98. MINN. STAT. § 363.03 (2000).

Minnesota's confidentiality and disclosure law in the areas of medical care and employment are discussed in this section. It is important to note that the MHRA also provides many protections for people with HIV/AIDS in the areas of housing law, law enforcement, and public accommodations.⁹⁹ In sum, under Minnesota law a person can be asked about their HIV/AIDS status only when being tested, seeking medical care, or applying for health, life, or disability insurance.¹⁰⁰ A person cannot be asked when applying for an apartment, buying a house, applying for or being interviewed for a job, seeking a business's service, or using public buildings or lands.¹⁰¹

HIV testing in Minnesota requires an individual's informed consent.¹⁰² If a test is completed in a doctor's office the results will become part of a medical record which cannot be disclosed without authorization. Physicians, however, are required by law to report positive test results to the Minnesota Department of Health (MDH).¹⁰³ The results include name, birth date, ethnic or racial origin, home address, phone number, place of work, school, or childcare.¹⁰⁴ State law provides that medical records can only be disclosed in cases of medical emergency when the provider cannot obtain a patient's consent or to other providers within related health care entities when necessary for current treatment, although the new federal rules fine-tune this information sharing to the minimum necessary.¹⁰⁵ If the state or a public testing site breaches a patient's confidentiality, damages up to \$10,000 may be recovered under the Government Data Practices Act (the new federal rules also provide civil and criminal penalties described in the previous section).¹⁰⁶ Private entities that breach confidentiality are subject to claims under the Patient Bill of Rights and medical privacy statutes.¹⁰⁷

99. See generally Minnesota AIDS Project, Lynn M. Mickelson, Esq. and Vanessa Hansen, *HIV Confidentiality and Disclosure in Minnesota: Rights and Obligations* (2000) [hereinafter *HIV Confidentiality and Disclosure*] (on file with author).

100. AIDSLINE BRIEF, *supra* note 51, at 7. Limitations are placed on these practices by privacy and patient rights laws.

101. *Id.*

102. *HIV Confidentiality and Disclosure, supra* note 99.

103. MINN. R. 4605.7030, 7090 (1999).

104. *Confidentiality and Disclosure, supra* note 99.

105. MINN. STAT. §§ 13.384, subd. 3, 144.335, subd. 3(a) (2000).

106. MINN. STAT. §§ 13.08-13.09 (2000).

107. MINN. STAT. § 144.335, subd. 3a(e) (2000).

Minnesota offers privacy protections that expand upon the ADA in the employment context. Under Minnesota law (and the ADA), before an employer extends a job offer, it cannot ask a potential employee about a disability.¹⁰⁸ Any inquiry must be related to essential job duties and business necessity. The MHRA protections apply to all employers while the ADA applies only to employers with more than fifteen employees.¹⁰⁹ Although an employee's request for reasonable accommodations must be accompanied by documentation of the qualifying disability, this can be achieved without disclosing HIV status.¹¹⁰ A supervisor must be informed of the accommodation but not the underlying medical reason for the accommodation.¹¹¹ Employers must keep any medical data separate from the employee's personnel file and can never request, demand, coerce, or pressure an employee to reveal his or her HIV status.¹¹² Violation of any of these laws can cost an employer dearly under the MHRA and the ADA. Penalties include injunctive relief, triple compensation of any actual financial loss, punitive damages up to \$8,500 in actual financial loss, civil penalties to the state, and attorney's fees and costs.¹¹³

Minnesota has a Minors Consent Law which assists minors in obtaining timely and confidential medical care.¹¹⁴ The law is vital because it gives minors the freedom to seek services in all areas of their health care, but particularly reproductive health, sexually transmitted infections, substance abuse, and mental health.¹¹⁵ Many young people resist seeking out certain health care needs because they fear discussing concerns with their parents or guardians. This fear results in potentially costly delays in vital health care.¹¹⁶ Recent

108. MINN. STAT. § 363.02, subd. 1(9)(i)(a-c) (2000).

Some government jobs are exempt from this limitation and may require a medical exam before the extension of a job offer. Other employers may require a medical exam after the extension of a job offer, if they test all employees and the exam is looking for abilities that are essential to job related activities.

HIV Confidentiality and Disclosure, supra note 99.

109. MINN. STAT. § 363 (2000).

110. MINN. STAT. § 363.02, subd. 1(9)(ii) (2000).

111. MINN. STAT. § 363.02, subd. 1(9)(i)(d) (2000). First aid safety personnel may be informed of medical conditions when appropriate. *Id.*

112. 29 C.F.R. § 1630.14(b)(1) (2000); 29 C.F.R. § 1630.12(b) (2000).

113. MINN. STAT. § 363.071, subd. 2 (2000); 42 U.S.C.A. §1201.

114. MINN. STAT. § 144.341 (2000).

115. *Id.*

116. Minnesota AIDS Project Public Policy Action Center, *Confidential Health Care for Minors*, at http://mnaidproject.org/html/health_care_for_minors.htm

studies have shown that if parental knowledge was required, only 15% of minors would visit their doctors for questions about, or treatment of, sexually transmitted infections; if confidentiality was assured more than 50% would seek care.¹¹⁷ The Minnesota State Legislature has considered allowing parental access to minor's confidential medical records and the new federal privacy regulations do not affect state parental notification or consent laws.¹¹⁸ It is important that Minnesota not allow parental access to minor medical records so that youth continue to seek medical care and information related to sexually transmitted infections, including HIV/AIDS.

Finally, despite many positive steps made in Minnesota's privacy laws, the state still lacks a comprehensive AIDS Confidentiality Act. Illinois, for example, presents such a model with its law containing broad guarantees for confidentiality in the areas of testing, medical care, and disclosure.¹¹⁹ As Minnesota's laws continue to evolve and strengthen it is hoped that eventually all protections for persons with HIV/AIDS will be contained in a comprehensive privacy law that provides strong civil and criminal penalties for privacy violations and asserts a committed public policy toward reducing stigma and discrimination.

IV. EMPLOYMENT PRACTICE

A. *Returning to the Workplace*

HIV/AIDS can rob a person of many things important to his or her life. For some, work or career is a passion as well as a means of affording the basic necessities and special treats that life offers. Early in the epidemic an HIV/AIDS diagnosis often signaled the end of a person's livelihood. Now successful drug therapies have made work possible again for people with HIV/AIDS.¹²⁰ This happy

(last visited June 2, 2001).

117. *Id.* "According to the article *Confidentiality in Health Care* in the 1993 issue of the Journal of the American Medical Association, 25% of adolescents surveyed would forego health care rather than risk their parents finding out." *Id.*

118. 45 C.F.R. § 150.207.

119. Aids Confidentiality Act, 410 ILL. COMP. STAT. 305 (1993).

120. The Henry J. Kaiser Family Foundation, *Employment: NPR Outlines Issues On Returning to Work*, KAISER DAILY HIV/AIDS REPORT, Aug. 20, 1998, at <http://report.kff.org/archive/aids/1998/08/kh980920.4.html> (last visited May 29, 2001).

turn of events, however, has also led to complicated situations. Issues surrounding disclosure in the workplace, reasonable accommodation, and discrimination on the job are more prevalent than ever. Large and small employers in Minnesota, for example, still dismiss employees upon discovering their HIV status and are often negligent in handling employee medical information.¹²¹ Employees need to depend upon their employers to treat them fairly especially when the employee has maintained his or her job qualifications. They need assurances that they will not lose their jobs based on their health status. Legal consequences are always possible for an employee victimized by discrimination, but even more likely are personal consequences such as emotional distress, and, in some cases, the dangerous possibility that an employee will lose the private health insurance coverage provided by an employer.¹²²

The ADA, the Family and Medical Leave Act (FMLA), the Rehabilitation Act, and state human rights acts mandate reasonable accommodations and protections in the workplace for employees with disabilities but employers and employees alike are often challenged by the extent and reasonability of the accommodations.¹²³ Reasonable accommodations include, but are not limited to, making facilities readily accessible to and usable by disabled persons, job restructuring, modified schedules, reassignment to a vacant position, provision of aides on a temporary or periodic basis, and acquisition or modification of essential equipment or devices.¹²⁴ An employee with HIV/AIDS, for example, may need to take drugs with his or her food, or eat at different times of the day, i.e. not just at lunch. Other employees may question these practices, leaving the employee with the problem of disclosure and the concern that the employer might

121. Minnesota AIDS Project, Public Policy Action Center, *Creating Supportive Workplaces*, at http://www.mnaidsproject.org/html/people_with_HIV_in_the_workpla.htm (last visited June 2, 2001). Twenty-five percent of the 800 cases handled in the MAP Legal Program in 2000 were related to discrimination in employment or housing. "Discrimination exists even within the vocational rehabilitation system intended to provide support to people with HIV. MAP recently received a report of a counselor who refused to shake the hand of a person with HIV." *Id.*

122. *Id.*

123. 42 U.S.C. § 12101; 29 U.S.C. § 794 (1999 & Supp. 2001); Family and Medical Leave Act, 29 U.S.C. § 2601 (1999); Americans with Disabilities Act, 42 U.S.C. § 12101 (1995 & Supp. 2001).

124. 42 U.S.C. § 12101 (1995 & Supp. 2001).

inform someone who has no need to know.¹²⁵ A work environment can become so tense or forbidding that an employee with HIV/AIDS is slowly downsized or forced out of his or her job.¹²⁶ On the other hand, employers are beginning to educate employees about HIV/AIDS with a special emphasis on managers' need to protect employee confidentiality, although broad employer participation in education programs has yet to be realized.¹²⁷

B. National and Local Trends: The Garrett Problem

A home health care worker loses her regularly scheduled clients after disclosing her HIV-status to a supervisor. A construction worker arrives at work one morning to find out that everyone on the job site knows his HIV-status even though he only informed his boss. A package handler requests an indoor job with his air courier employer during winter to protect his lungs from pneumonia (an ailment related to his AIDS diagnosis) but his request is denied. An employee is fired, after two raises and a satisfactory performance review, because of his HIV-status. A doctor is fired after reporting his status to the state medical board per

125. See The Henry J. Kaiser Family Foundation, *Time Reports on Accommodating the Chronically Ill in the Workplace*, KAISER DAILY HIV/AIDS REPORT at <http://report.kff.org/archive/aids/2001/1/kh010125.5.htm> (Jan. 25, 2001); see also The Henry J. Kaiser Family Foundation, *AIDS in the Workplace: HHS Secretary Encourages Business and Labor Unions to Respond to AIDS*, KAISER DAILY HIV/AIDS REPORT, at <http://report.kff.org/archive/aids/2000/109/kh000912.4.htm> (Sept. 12, 2000).

Richard Williams manages Polaroid's AIDS Awareness program and said the company encourages 'people to disclose their HIV status' as a way to 'accommodate time off ... and prevent possible resentment from colleagues that HIV-positive employees may face.' Still, Williams notes that the program is not for every company. 'Of course people are frightened about disclosing their HIV status. The reality is that you can be discriminated against in a dramatic way,' he said. Director of the CDC's business and labor AIDS response program Victor Barnes said such programs are uncommon. 'There are some rare environments where revealing HIV status is okay. I wouldn't encourage it,' he added.

Id.

126. See The Henry J. Kaiser Family Foundation, *Time Reports on Accommodating the Chronically Ill in the Workplace*, KAISER DAILY HIV/AIDS REPORT, at <http://report.kff.org/archive/aids/2001/1/kh010125.5.htm> (Jan. 25, 2001).

127. See The Henry J. Kaiser Family Foundation, *AIDS Education: Companies Promote Education, Awareness in the Workplace*, KAISER DAILY HIV/AIDS REPORT, at <http://report.kff.org/archive/aids/2000/09/kh000908.5.htm> (Sept. 8, 2000) "According to a National AIDS Fund survey, 73% of working Americans want AIDS education in the workplace while only 18% say their employers provide it." *Id.*

legally mandated safety protocol for HIV-positive health workers.¹²⁸

These are just a few of the all-too-common scenarios people with HIV/AIDS may face in the workplace. Although the ADA and the *Bragdon v. Abbott* decision have helped individuals with HIV/AIDS assert their rights in the workplace, the law is still evolving.¹²⁹ Of particular note is a recent United States Supreme Court decision, *Board of Trustees of University of Alabama v. Garrett*.¹³⁰ The chief question in *Garrett* is whether the ADA exceeds congressional authority provided under the United States Constitution to enforce the equal protection rights of individuals with disabilities.¹³¹ The case involved two lawsuits brought against Alabama state employers by two former employees who suffered from breast cancer and severe asthma, sleep apnea and other health problems, respectively.¹³² Each employee had been forced out of his or her jobs—Patricia Garrett through demotion during an unpaid leave of absence for radiation and chemotherapy, and Milton Ash by his employer's refusal to enforce a non-smoking rule and maintain a truck Ash was required to drive so it would not spew toxic fumes.¹³³ The employees sought money damages under Title I of the ADA which prohibits states and other employers from “discriminat[ing] against a qualified individual with a disability because of th[at] disability . . . in regard to . . . terms, conditions, and privileges of employment.”¹³⁴ The District Court granted the University of Alabama summary judgment, stating that the ADA exceeds congressional authority to interfere with the immunity afforded to states under the Eleventh Amendment.¹³⁵ On appeal, the Eleventh Circuit reversed, stating that the ADA indeed abrogates such immunity.¹³⁶

The Court allowed that Congress does have authority to force

128. These situations are based on several cases brought to the attention of the MAP Legal Program. The final case is based on an Arkansas pediatrician's lawsuit based on employment discrimination. The Henry J. Kaiser Family Foundation, *Medical Privacy: HIV-Positive Physician Files ADA Lawsuit Over Firing*, KAISER DAILY HIV/AIDS REPORT, at <http://report.kff.org/archive/aids/2000/01/kh000104.1.htm> (Jan. 4, 2000).

129. 42 U.S.C. § 12101 (1995); see *supra* note 18 and accompanying text.

130. *Board of Trustees of Univ. of Ala v. Garrett*, 531 U.S. 356 (2001).

131. *Id.* at 358.

132. *Id.* at 362.

133. *Id.*

134. 42 U.S.C. § 12112(a) (1995).

135. *Garrett*, 531 U.S. at 361.

136. 193 F.3d 1214 (1999); see also *Garrett*, 531 U.S. at 361.

non-consenting states into suits in federal court, but only when exercising its power under section five of the Fourteenth Amendment of the United States Constitution.¹³⁷ This power allows Congress to enact “appropriate legislation” to protect guaranteed rights.¹³⁸ However, only the Court, not Congress, can determine a guaranteed right under the Constitution, and must do so according to a balance of interests, namely “the injury to be prevented or remedied and the means adopted to that end.”¹³⁹

The Court went on to analyze the constitutional right at issue and what evidence was gathered by Congress to demonstrate a pattern of disparate impact, without a rational basis, in every state.¹⁴⁰ It came to the conclusion that the ADA did not meet the level of “congruence and proportionality” necessary to overcome the Eleventh Amendment protection to the states.¹⁴¹ For example, the Court discussed the requirement of making facilities readily accessible to individuals with disabilities and decided that while the ADA does allow exceptions to employers who cannot make reasonable accommodations because of an “undue burden” the ADA also imposes a duty on employers that exceeds constitutional purview.¹⁴² The court also took issue with the ADA requirement that the employer, not the employee, demonstrate the burden.¹⁴³ The Court concluded that the ADA’s national mandate to eliminate discrimination based on an individual’s disability is not based in sufficient fact, specifically the pattern of discrimination by states was not demonstrated by Congress.¹⁴⁴ As a result, the Court held that the ADA could not force states to pay money damages to injured individuals because the remedy imposed by Congress was not “congruent and proportional to the targeted violation.”¹⁴⁵

The dissent by Justice Breyer, joined by Justices Stevens, Souter, and Ginsberg, argued vigorously that Congress “compiled a vast legislative record documenting ‘massive, society-wide discrimination’ against person with disabilities.”¹⁴⁶ He concluded

137. *Garrett*, 531 U.S. at 361.

138. *Id.*; see also *City of Boerne v. Flores*, 521 U.S. 507, 536 (1997).

139. *Garrett*, 531 U.S. at 361. See *City of Boerne*, 521 U.S. at 519-24.

140. *Garrett*, 531 U.S. at 361.

141. *Id.* at 360.

142. *Id.* at 360. 42 U.S.C. §§ 12112(5)(b), 12111(9) (1990).

143. *Garrett*, 531 U.S. at 361.

144. *Id.*

145. *Id.*

146. *Garrett*, 531 U.S. at 370 (quoting S. REP. NO. 101-116, at 8-9 (1989) (testimony of Justin Dart, chairperson of the Task Force on the Rights and

that the ruling would only present greater challenges for Congress in making policy to address widespread issues like disability discrimination.¹⁴⁷ Breyer wrote:

[I]ronically, the greater the obstacle the Eleventh Amendment poses to the creation by Congress of the kind of remedy at issue here—the decentralized remedy of private damage actions—the more Congress, seeking to cure important national problems, such as the problem of disability discrimination before us, will have to rely on more uniform remedies, such as federal standards and court injunctions, 42 U.S.C. §12188(a)(2) which are sometimes draconian and typically more intrusive. For those reasons, I doubt that today's decision serves any constitutionally-based federalism interest.¹⁴⁸

In essence, the Court created a scenario in which Congress cannot ever be expected to effectively enforce basic civil rights, a fact that did not escape the legions of amicus curiae supporting *Garrett* and *Ash*, including the States of Arizona, Connecticut, Illinois, Iowa, Kentucky, Maryland, Massachusetts, Minnesota, Missouri, New Mexico, New York, North Dakota, Vermont, and Washington, all of whom apparently did not believe the ADA violated their Eleventh Amendment rights.¹⁴⁹

The ADA now joins the Violence Against Women Act (VAWA) and the Age Discrimination in Employment Act as laws deemed unconstitutional with respect to their application to the states.¹⁵⁰ As a result the ADA has been weakened, and employees with HIV/AIDS who suffer discrimination at the hands of state employers will find that their remedies are now limited under the ADA. Other state remedies may clash with qualified immunity protections for state entities. *Garrett*, therefore, represents a major setback for the rights of employees with HIV/AIDS. It could also signal a chilling effect on congressional action designed to address what it perceives as state-sponsored discrimination.

By leaving the final authority with the judicial rather than the legislative branch, the Supreme Court has effectively transformed

Empowerment of Americans with Disabilities)). The dissent also pointed to evidence assembled at 13 congressional hearings, and 300 examples of discrimination by state governments within the legislative record. *Id.* at 371.

147. *Id.* at 376.

148. *Id.*

149. *Id.* at 356.

150. 42 U.S.C.A. § 2000(e)(5); 42 U.S.C.A. § 12101.

itself into a legislative court, something it has been historically loathe to do. The Court is not equipped to do the type of fact-finding Congress does, nor can it avail itself of the evidence brought forward by legislators from their own states. The *Garrett* decision does, however, reflect the Court's general unwillingness to interfere with state's rights (the notable exception, of course, being *Bush v. Gore* in which the Court overturned a Florida Supreme Court ruling on how to conduct a recount during the 2000 presidential election).¹⁵¹

Disability discrimination in the twenty-first century, particularly against people with HIV/AIDS, represents the proverbial no-brainer, just like racism, classism, gender discrimination, and homophobia. The media carries stories all the time, the anecdotal evidence is readily available, countless legal services organizations have the case files at the ready. The Court's judgment is seriously flawed in *Garrett* and the repercussions from this case have the potential to leave many wronged workers without recourse, rendering them doubly victimized by their employers and the legal system, both of which are meant, ostensibly, to protect disabled employee rights. One hopes that one day cases in which states accepting federal funds are forced, validly under Congress's spending power, to waive immunity to suits under specific statutes, will emerge in the ADA context.¹⁵²

V. VOLUNTARY PERMANENCY PLANNING

A. *National Trends: Making Alternate Arrangements for Child Custody and Care*

Permanency planning, "the notion that every child is entitled to a safe, stable, and secure living environment as a foundation for healthy development," is an important consideration for parents living with HIV/AIDS.¹⁵³ In 1994, some 7,300 children and adolescents lost their parents to HIV/AIDS; by the year 2000,

151. *Bush v. Gore*, 531 U.S. 98 (2000).

152. *See, e.g.*, *Jim C. v. Arkansas Dep't of Educ.*, 197 F.3d 958 (8th Cir. 2000) (en banc) (affirming the district court holding that section 504 of the Rehabilitation Act of 1973 was a valid exercise of congressional spending and that suits brought under the Act could not be dismissed due to state immunity since the state accepted federal funds).

153. Jeffrey Selbin and Carolyn McAllaster, *Issues in Family Law for People with HIV*, in *AIDS AND THE LAW* 321 (3d ed. 1998 & Supp. 2000).

experts projected that the number of motherless children and adolescents due to HIV/AIDS could range from 80,000 to as high as 125,000 in the United States.¹⁵⁴ On a global scale, there are approximately eleven million children who have been left parentless by HIV/AIDS.¹⁵⁵

While it is certainly a parent's duty to make provisions for a child's care, if or when the parent is not available, parents with HIV/AIDS face some specific challenges when making choices for alternative custody or guardianship arrangements. Planning often involves disclosure of health status to family, which may lead to conflicts based on particular belief systems or personal prejudices.¹⁵⁶ Non-custodial parents may present legal disputes and other family members might battle for the role of kinship caregiver.¹⁵⁷ A parent must also find a suitable caregiver if the other parent is not available or fit, and make a legal plan while at the same time coming to terms with a devastating disease.¹⁵⁸ In cases where the child welfare system has become involved in the family there are additional concerns about the parent's control of decision-making for the child.¹⁵⁹ The permanency planning process, therefore, can sometimes represent a painful and stressful ordeal for many parents with HIV/AIDS. They know planning is necessary, but the thought of leaving a child behind is sometimes too much to bear. A presentation at the 1998 International AIDS Conference demonstrates this fact: Mothers made legal custody arrangements in only 25% of the cases, and the majority of the children (91%) resided with a family member, usually grandparents.¹⁶⁰ Nonetheless, children need their parents to plan because they need to have some certainty about will happen to

154. The National Abandoned Infants Assistance Resource Center, *Legal Permanency Planning for HIV-Affected Families: The Need to Plan, Current Legal Options, and Future Direction*, THE SOURCE at 1 (Fall 2000) (quotation omitted)[hereinafter *Legal Permanency Planning*].

155. The Henry J. Kaiser Family Foundation, *AIDS Orphans: 11 Million Children Parentless Due to AIDS*, KAISER DAILY HIV/AIDS REPORT, at <http://report.kff.org/archive/aids/1999/12/kh991201.4.html> (Dec. 1, 1999).

156. *Legal Permanency Planning*, *supra* note 154.

157. *Id.*

158. *Id.*

159. *Id.*

160. R. Forehand, J. et. al., *Orphans of the AIDS Epidemic in the United States: Transition-related Characteristics and Psychosocial Adjustment at 6 Months After Mother's Death*, AIDS CARE (1999) at 715-22. (quoting A.M. Boxer, *Child Care Arrangements of Children Whose Mothers Have Died of AIDS*, Paper presented at the International AIDS Conference, Geneva, Switzerland (1998)).

them if something happens to their parents. Too much can go wrong, and too much is at stake, to avoid planning.

Standby guardianship statutes and their equivalents were largely created as a response to the HIV/AIDS epidemic.¹⁶¹ In 1992, New York became the first state to codify voluntary permanency planning standards, and the motivation for legislative action came from “the AIDS epidemic and its special impact on mothers, particularly single mothers.”¹⁶² The New York law, which served as the model for many other states to follow, was created for parents with “progressively chronic illness” or “an irreversibly fatal disease” to designate a stand-by guardian.¹⁶³

The 1997 Adoption and Safe Families Act (ASFA) set forth parameters and goals for permanency planning in child protection settings and also included a “sense of congress” directed at voluntary custody placements.¹⁶⁴ The Act declared that states should:

effect laws and procedures that permit any parent who is chronically ill or near death, *without surrendering parental rights*, to designate a standby guardian for the parent’s minor children, whose authority would take effect upon: (1) the death of the parent; (2) the mental incapacity of the parent; or (3) the physical debilitation and consent of the parent.¹⁶⁵

This position was echoed by *Adoption 2002: The President’s Initiative on Adoption and Foster Care Guidelines for Public Policy and State Legislation Governing Permanence for Children* and both the American Bar Association¹⁶⁶ and American Academy of Pediatrics have come forward with support for planning methods.¹⁶⁷ These

161. *Id.*

162. *Id.* (quoting N.Y. SURR. CT. PROC. ACT. LAW §1726(3)(a)-(b) (McKinney 1996 & Supp. 1999)).

163. See Selbin & McAllaster, *supra* note 153, at 329 (quoting N.Y. SURR. CT. PRAC. ACT LAW at § 1726(3)(a)-(b)).

164. Adoption and Safe Families Act of 1997, Publ. L. No. 105-89, 111 Stat. 2115 (codified as amended throughout 42 U.S.C.).

165. *Id.*

166. The ABA accomplished this goal through an amendment to the Uniform Guardianship and Protective Proceedings Act. approved by the ABA’s house of Delegates in 1998. Selbin & McAllaster, *supra* note 153, at 332. Section 5-202 of the Act allows for designation of stand-by guardian if the parent “will likely become unable to care for the child within two years.” UNIF. PROBATE CODE § 5-202(b), 8 U.L.A. 333-34 (1998); see Selbin & McAllaster, *supra* note 153, at 332.

167. Abandoned Infants Assistance Resource Center, *AIA Fact Sheet: Standby Guardianship*, Aug. 2000 (on file with author).

laws and procedures for planning have become known as stand-by guardianship laws. Nearly twenty states, including Minnesota, have enacted these laws, representing legal recourse for “two-thirds of all adults and almost four out of every five children living with AIDS in the United States” included in their populations.¹⁶⁸ Designating a stand-by guardian is a means of formalizing parental wishes and avoiding familial conflicts after the parent passes away and is no longer able to explain his or her decisions.

Stand-by guardianships augment the tools already available to parents in assuring a stable future for their children. These tools include powers of attorney, testamentary guardianships, temporary and short-term guardianships, and designations of parental authority. Stand-by guardianships are valuable because they bridge the time

between a child’s care during a disabled parent’s lifetime, and the child’s life after the parent dies. The ideal standby guardian law permits a parent to choose a competent, trusted person to ‘wait in the wings,’ stepping in to help care for the child only if the parent becomes seriously

168. See Selbin & McAllaster, *supra* note 153, at 331 (quoting CENTERS FOR DISEASE CONTROL, HIV/AIDS SURVEILLANCE REPORT 7 (year-end ed., Dec. 1998)). Selbin & McAllaster also explain that:

[o]f the 10 states with the highest number of adults and children living with AIDS, only Texas and Georgia have failed to enact stand-by guardianship laws or their equivalents . . . Two other jurisdictions in the United States with large numbers of parents and children with AIDS—District of Columbia and Puerto Rico—also lack the stand-by guardianship option.

Selbin & McAllaster, *supra* note 153, at 331 n.161. The states with stand-by guardianship or equivalent laws are: Arkansas (ARK. CODE ANN., § 28-65-221 (1987)), California (CAL. PROB CODE, § 2105 (1991)), Connecticut (CONN. GEN. STAT. ANN., § 45a-624(a)-(g) (1993)), Florida (FLA. STAT. ANN. § 744.304; 744.3046 (1993)), Illinois (ILL. COMP. STAT. ANN. 5/11-5.3 (1993)), Iowa (IOWA CODE ANN. § 633.560; 633.591A (1992)), Maryland (MD. CODE ANN. § 13-901 through § 13-907(y)), Massachusetts (MASS. GEN. LAWS ANN. § 201-2B through 201-2G (1990)), Minnesota (MINN. STAT. § 257B (2000)), Nebraska (NEB. REV. STAT. ANN. §§ 30-2601, 30-2611, 30-2613, 30-2601, 30-2611, 30-2613, 30-2614 (1983)), New Jersey (N.J. STAT. ANN. §§ 3B:12-72 through 3B:12-77 (1983)), New York (N.Y. SURR. CT. PROC. ACT LAW, § 1726 (McKinney 1996 & Supp. 1999)), North Carolina (N.C. GEN. STAT. §§ 35A-1370 through 35A-1382 (1999)), Ohio (OHIO REV. CODE ANN. §§ 1337.09(b), 2111.02, 2111.042, 2111.12, 2111.121, 2111.13 (1993)), Pennsylvania (23 PA. CONS. STAT. ANN. §§ 23-5602, 23-5611, 23-5612, 23-5613, 23-5614 (1991)), Virginia (VA. CODE ANN. §§ 16.1-349 through 16.1-354 (1999)), West Virginia (W. VA. CODE ANN. §§ 44A-5-1 through 44A-5-8 (1997)), Wisconsin (WIS. STAT. ANN. § 48.978 (1997)), Wyoming (WYO. STAT. ANN. §§ 3-2-101; 3-2-104; 3-2-108, 3-2-201, 3-3-201 through 3-3-305 (2001)).

disabled, and taking over child rearing if the parent dies.¹⁶⁹

Ideally, stand-by guardianships give parents with HIV/AIDS the opportunity to care for their children while maintaining their own health priorities.¹⁷⁰ A successful stand-by arrangement presents a winning situation: a parent or legal custodian is not deprived of their duty to care for their children and the children remain with the parent until incapacity, incompetence or death occurs.¹⁷¹ In addition, the children enjoy the benefit of having another caregiver in their lives who understands the parent's values and wishes for the children. The stand-by guardian is empowered by all the duties necessary for giving a child appropriate and thorough care, although most states recognize the stand-by guardian's authority as concurrent with, rather than replacing that, of a parent or legal custodian.¹⁷² In a family law system that places the highest priority on the best interests of the child, stand-by guardianships provide voluntary permanency planning options that can help keep families together and assure continuity in uncertain times.

B. Minnesota Perspective: The New Stand-by Custody Law

On April 15, 2000, Governor Jesse Ventura signed Minnesota's first Stand-by Custody bill into law.¹⁷³ Minnesota was unique among the other states because it already had a Designated Caregiver Agreement statute in place.¹⁷⁴ A parent with legal custody could name an adult to care for a minor for a specified period of time, in

169. Judith Larsen, *Standby Guardianship Training and Technical Assistance Packet: A Guide for Legislators, Lawyers, and Child Welfare Professionals*, prepared by Circle Solutions, Inc. and the American Bar Association for the U.S. Department of Health and Human Services, Administration for Children and Families and Children's Bureau (2000) at I-1.

170. See Selbin & McAllaster, *supra* note 153, at 328-29.

171. *Id.*

172. See *id.* at 344. Minnesota law allows for co-custodians who act "as custodian along with the parents and share physical or legal custody of the children, or both, due to the occurrence of a triggering event. MINN. STAT. § 257B.01 subd. 4 (2000).

173. MINN. STAT. §§ 257B.01-257B.10 (2000). The bill was supported by a coalition of legal service and private attorneys, including representatives from MAP, Minnesota Justice Foundation, Minnesota Kinship Caregivers Association, and Legal Aid Society. Coalition supporters included Chrysalis Center for Women, Women's Cancer Resource Center, AARP, the Minnesota State Bar Association's Family Law Section, and the American Bar Association's Center for Children and the Law.

174. MINN. STAT. § 257A.01(1998), *repealed by* MINN. STAT. § 257B (2000).

the event of an emergency, but for no longer than one year.¹⁷⁵ The designation itself was valid for four years but could only go into effect when a parent became incapacitated.¹⁷⁶ The Designated Caregiver Agreement was not successful because it was not well-publicized and many parents objected to the requirement that the caregiver contact the local social services agency if the child stayed in the caregiver's home over thirty days.¹⁷⁷ Parents feared that their children would be placed in child protective services or foster care solely because the parent was ill and unable to parent at that time. Parents with HIV/AIDS were all the more concerned because of the potential need to disclose health status. And finally, the Designated Caregiver Agreement did not extend beyond a parent's death, so parents still needed to use other legal tools to address permanent placements.¹⁷⁸ In sum, the Designative Caregiver Agreement presented only a partial solution at best, and may have created a barrier to some parents' planning because of potential involvement by child protection.

The intent behind the Minnesota stand-by custody law, as in other states, was to create a comprehensive planning tool while also respecting the fact that a parent or legal custodian knows what is best for his or her children. This includes the ability to make a stand-by custodianship extend beyond death, eliminating potential conflicts about custodianship that could occur in the probate context rather than family court where they are more appropriately settled. A stand-by custodianship, alone, can never deprive a parent of his or her right to parent.¹⁷⁹ Minnesota differs from other states in that it placed its law in the domestic relations rather than the probate code, hence the term "stand-by custody" rather than the more commonly used "stand-by guardianship." Minnesota is also unique from many states because it gives legal custodians the ability to make stand-by designations as well as parents.¹⁸⁰

175. *Id.*; see also THE LEGAL AID SOCIETY OF MINNEAPOLIS AND LUTHERAN SOCIAL SERVICE OF MINNESOTA, KINSHIP CAREGIVER RESOURCE MANUAL 6 (June 1998). A one-time extension of the time period (up to one year) was allowed by the statute. MINN. STAT. § 257A.08 *repealed by* MINN. STAT. § 257B.

176. MINN. STAT. § 257A.04, *repealed by* MINN. STAT. § 257B. The Designated Caregiver Agreement differed from a Delegation of Parental Authority in that the DOPA is valid from the time it was signed for a period of six months and is used generally for short planned absences.

177. MINN. STAT. § 257A.09, *repealed by* MINN. STAT. § 257B.

178. MINN. STAT. § 257A.04, *repealed by* MINN. STAT. § 257B.

179. MINN. STAT. § 257B.02 (2000).

180. MINN. STAT. § 257B.03(a).

The application of the Minnesota law is similar to that of other states, particularly in the requirement that the parent or legal custodian have a debilitating or incapacitating illness.¹⁸¹ The parent or legal custodian identifies “triggering events”¹⁸² such as incapacitation, extended hospitalization or death when the stand-by custodian will have the power to act.¹⁸³ Notice to the court is required after the triggering event occurs and the court must ultimately approve all designations.¹⁸⁴ Minnesota gives the parent or legal custodian some discretion in naming a stand-by custodian, however if the child has another legal parent whose parental rights have not been terminated, whose whereabouts are known, and who is willing and able to carry out the daily care of the child, the designating party must demonstrate that either the other legal parent has consented to the designation or is not fit to parent (through a hearing where the best interests of the child standard is applied by the court).¹⁸⁵

The hearing process is an important tool for custodial parents who wish to exclude a non-custodial parent from a stand-by designation. This is particularly useful in cases where domestic violence or child abuse has occurred, and is also valuable when a noncustodial parent derides the custodial parent for his or her HIV/AIDS status. Another benefit is that custodial parents or legal custodians have an opportunity to go before the court and place on the record the reasons why another parent is not fit to care for the child. This record could prove particularly valuable if a custody contest between the non-custodial parent and the stand-by custodian occurs after the parent passes away. During a proceeding for judicial confirmation of a stand-by custodian a presumption is made that the designated custodian is capable of caring for the child, and in cases where the other parent has passed away, has given consent or lost parental rights, the presumption is extended so that confirmation of a stand-by custodianship is in the best

181. MINN. STAT. §§ 257B.01, subds. 6, 11 and 257B.06, subd. 1 (2000). Some states, however, including Connecticut, Florida, Illinois, Massachusetts, and Pennsylvania, do not link stand-by guardianships to the health status of a parent or legal custodian. See Selbin & McAllaster, *supra* note 153, at 333-36 (discussing state rules for eligibility).

182. MINN. STAT. § 257B.01, subd. 14 (2000).

183. MINN. STAT. §§ 257B.01, subd. 14, 257B.04, subd. 1(2000).

184. MINN. STAT. § 257B.05, subds. 1, 2, 5, 6 (2000).

185. *Id.* at §§ 257B.03(a)-(b), 257B.05, subds. 5-6 (2000).

interests of the child.¹⁸⁶

Minnesota's stand-by custody law is not a cure-all for everyone. There are times when parents or legal custodians may find that a stand-by custodianship is not the best option, especially if there is no suitable person available for a designation. Conflicts may exist between stand-by custody and other laws affecting a family. Some family situations are constantly in flux and it is impossible to keep up with all the changes through legal documents. And families under Juvenile Court jurisdiction will not be able to avail themselves of stand-by custody so long as a county agency is pursuing its own permanency plan or termination of parental rights proceedings.¹⁸⁷ Nonetheless, the adoption of this law represents a positive response to the needs of parents living with HIV/AIDS. It "create[s] a presumption of permanency because the court ordinarily will not appoint a different guardian when the parent dies, unless there are compelling reasons to do so."¹⁸⁸ With plans in place, a parent with HIV/AIDS can direct his or her energy toward living and enjoying life with his or her children, and concentrate on doing the things necessary to manage good health.

VI. CONCLUSION

A. *"The lasting scar of AIDS is that which is not here."*¹⁸⁹

HIV/AIDS has changed all aspects of our lives. It has inspired opinions, exposed stereotypes, revealed new biases, altered behaviors, and opened our eyes. It reminds us of our mortality, because so often it robs so many of their potential. It teaches us that an epidemic is not monolithic, that individuals with hopes and dreams cannot be boiled down to statistics, that no one is to blame for the epidemic, but all of us are responsible for its containment. Hope persists, thanks to new scientific discoveries, but until a cure is found, and even beyond that joyous day, society needs to aggressively address and protect the rights of people living with HIV/AIDS through its laws.

186. *Id.* at § 257B.06.

187. *See* MINN. STAT. §§ 260C.213, 260C.301-328 (2000).

188. *See* Larsen, *supra* note 168, at I-14.

189. Jennifer Steinhauer, *AIDS Altered the Fabric of New York in Ways Subtle and Vast*, N.Y. TIMES, June 4, 2001 (quoting Ronald G. Bayer, professor of public health at Columbia University).

This essay has explored changes in the laws that will affect people with HIV/AIDS across the nation and in Minnesota. Some are positive, such as the new privacy rules mandated by HIPAA and a ruling by the Third Circuit Court of Appeals prohibiting bans on placing foster children with families containing an HIV-positive member¹⁹⁰; others are negative, such as the Supreme Court's *Garrett* decision.¹⁹¹ The law changes constantly and it is possible to find a relationship to HIV/AIDS within many of these changes. In January 2000, for example, the United States Supreme Court let stand a ruling allowing an insurance company to place a cap on AIDS-related illnesses despite offering more coverage for other conditions under the same policy.¹⁹² The Court also ruled over a year later that medical marijuana distribution is illegal, barring the use of a therapeutic drug for people with HIV/AIDS coping with extreme pain or requiring an appetite stimulant to combat severe weight loss.¹⁹³ Finally, bans on blood donations from gay men remain intact, reinforcing the stereotype that they are the sole source of the infection.¹⁹⁴

Minnesota has seen some positive movement in its laws and policy over the past year. For instance, State District Court Judge Delila F. Pierce struck down the state's sodomy law, which had been on the books since the nineteenth century.¹⁹⁵ Although her ruling applies initially only to the eight plaintiffs in the case before her, the decision has achieved class action status and will ideally pave

190. *Doe v. County of Centre*, 242 F.3d 437, 447 (3d Cir. 2001). The court determined that the direct-threat exception under the ADA does not apply in certain foster care situations. *Id.* at 451. The County adopted a policy providing that foster families whose members have a serious infectious disease may care only care for children with the same disease. The court held that the trial court did not conduct the appropriate inquiry and that the county's reliance on statistics indicating that 12% of foster children have histories of perpetuating sexual abuse was not sufficient to show a significant risk, especially since the definition of sexual abuse was too broad and contained activities that did not carry a risk of HIV transmission. *Id.*

191. *Garrett*, 531 U.S. at 356.

192. *Doe v. Mutual of Omaha Ins. Co.*, 179 F.3d 557 (7th Cir. 1999) *cert. denied.*, Jan. 11, 2000.

193. *United States v. Oakland Cannabis Buyers' Cooperative*, 121 S.Ct. 1711 (2001) (U.S. citation unavailable at date of publishing).

194. *See, e.g.*, The Henry J. Kaiser Family Foundation, *Blood Donation: Advisory Panel Votes in Favor of Barring Gay Donors*, KAISER DAILY HIV/AIDS REPORT, at <http://report.kff.org/archive/aids/2000/09/kh000915.1.htm> (Sept. 15, 2000).

195. Pam Louwagie, *District Judge Finds Sodomy Law Unconstitutional*, STAR-TRIBUNE (Minneapolis), May 22, 2001, at 1A.

the way for legislative action repealing the law altogether.¹⁹⁶ Sodomy laws and other laws that attempt to codify private behavior force people to conceal important facts about their lives. Honesty is a critical piece in prevention of HIV/AIDS and laws that regulate privacy only encourage concealment of behavior, shame, fear, and discrimination.¹⁹⁷

The actions of the Bush administration will be determinative of the direction HIV/AIDS takes in the new century. Federal commitment to funding, education, treatment, and law enforcement must be total to ensure success. Unfortunately such commitment has not yet revealed itself, and the administration's budget advocated cuts in healthcare that will inevitably affect programs essential for people living with HIV/AIDS.¹⁹⁸ If our response to HIV/AIDS becomes complacent the epidemic will not end. Laws can only do so much. Our losses are real, and they are irretrievable. But so long as the legal system continues to respond it can provide many critical weapons in the war against HIV/AIDS so that in the future we may count among us more gains than losses.

196. *Id.*

197. Minnesota AIDS Project Public Policy Center, *Repealing MN's Bedroom Laws*, at http://www.mnaidsproject.org/html/bedroom_laws.htm (last visited June 2, 2001).

198. AIDS Action/Legislative Action Center, *AIDS Action Asks President Bush: Where's Your Commitment to AIDS?*, at <http://capwiz.com/aac/issues/alert/?altertid=28> (Mar. 1, 2001); *see also* The Henry J. Kaiser Family Foundation, *Thompson Vows U.S. Commitment to Fighting AIDS*, KAISER DAILY HIV/AIDS REPORT at http://www.kaisernetwork.org/daily_reports/rep_hiv.cfm (June 6, 2001) HHS Secretary Tommy Thompson announced that the Bush administration will propose a 7.2% increase in the federal health department's funding of prevention, research and treatment, including vaccine research. However, he has also stated that the administration will not overturn the ban on needle-exchange programs and has not addressed, to date, the administration's silence regarding increased funding for the Ryan White Care Act. *Id.*