# Falling Through The Cracks: The Unique Circumstances of HIV Disease Under Recent Americans With Disabilities Act Caselaw and Emerging Privacy Policies

Caroline Palmer and Lynn Mickelson\*

### Introduction

Most acts of discrimination begin with a breach of confidentiality, a betrayal of trust, or an opinion informed by nothing more than stereotype or bias. Discrimination is usually intentional. It is a conscious choice to undermine the perceived other through unwanted exposure. Fictions are contrived as fact to suit dishonorable purposes. The perpetrator is self-serving, yet rationalizes discriminatory acts as benefits to the common good — a flawed utilitarian approach. Inner frustration and hatred are directed outward, yet are rarely satisfied. Discrimination is part of an ugly cycle that infects the culture as a whole.

At times, however, discrimination may be the result of negligence – the mislaid document, a slip of the lip. What

<sup>\*</sup> Caroline Palmer, J.D. 1998, Hamline University School of Law, Staff Attorney at the Minnesota AIDS Project (MAP), and Lynn Mickelson, J.D. 1983, William Mitchell College of Law, Legal Services Manager at MAP. The authors thank Bob Tracy, MAP Director of Community Affairs, and Dan Kelly, MAP Legal Services Assistant, for their input.

The Minnesota AIDS Project (MAP) envisions a world free of AIDS. MAP leads Minnesota's fight to stop HIV and enhance the well-being of those affected. Founded in 1983, MAP is a statewide, nonprofit agency committed to enhancing the lives of people living with HIV, providing prevention education for those at risk for HIV, and advocating for the rights of all affected by HIV. From community outreach and legal consultation to emergency assistance, MAP is a leader in the fight against HIV. In partnership with more than 1,400 volunteers, MAP provides compassionate, confidential, and non-discriminatory services, including practical, emotional, and social support. Nearly half of the approximately 4,500 Minnesotans living with HIV use services provided by MAP. MAP Legal Services assists clients with a variety of civil issues including confidentiality, discrimination, employment, family, estate planning, civil liberties, and benefits access, and also provides resources for HIV-related criminal cases. For further information visit MAP's website at www.mnaidsproject.org.

<sup>1.</sup> See generally David Benjamin Oppenheimer, Negligent Discrimination, 141 U.

happens after the lapse in judgment, however, is critical. Remedial action might not rectify the mistake entirely, but demonstrates good faith and a willingness to learn. Further negligence — taking advantage of the situation for personal gain through gossip or coercion — is discrimination. One *chooses* to break the cycle. It is a moral choice.

Morality and discrimination are important issues in the context of HIV disease.<sup>2</sup> The epidemic is now entering its third decade, and great strides have been made in managing its impact.<sup>3</sup>

HIV destroys a certain kind of blood cells – CD4+ T cells (helper cells) – which are crucial to the normal function of the human immune system. In fact, loss of these cells in people with HIV is an extremely powerful predictor of the development of AIDS .... [R]ecently developed sensitive tests have shown a strong connection between the amount of HIV in the blood and decline in CD4+ T cell numbers and the development of AIDS. Reducing the amount of virus in the body with anti-HIV drugs can slow this immune destruction.

Centers for Disease Control National Center for HIV, STD and TB Prevention, Questions and Answers: HIV is the Cause of AIDS, at http://www.cdc.gov/hiv/pubs/cause.htm (last updated Feb. 27, 2002).

3. AIDS is no longer among the fifteen leading causes of death in the United States. Sheryl Gay Stolberg, After 20 Years, AIDS is Woven into America's Fabric, STAR-TRIB. (Minneapolis), June 3, 2001, at A3. In the United States, highly active antiretroviral therapy, i.e. protease inhibitors, "helped transform HIV disease into a chronic but manageable condition." Bob Adams, Is the Act Up?, HIV PLUS, June/July 2002, at 14. AIDS is, however, the fourth leading cause of death worldwide. The Henry J. Kaiser Family Foundation, HIV/AIDS POLICY FACT SHEET: THE GLOBAL HIV/AIDS EPIDEMIC 1 (July 2002), available at http://www.kff.org/content/2002/3030-02/Global\_Factsheet.pdf [hereinafter GLOBAL FACT SHEET]. Not everyone responds favorably to new treatments and some treatments have debilitating side effects. See The Henry J. Kaiser Family Foundation, HIV/AIDS POLICY FACT SHEET: THE HIV/AIDS EPIDEMIC IN THE UNITED STATES, (July 2002), available at http://www.kff.org/content/2002/3029-02/US\_Fact\_Sheet.pdf [hereinafter U.S. FACT SHEET]. Side effects include, but are not limited to, diarrhea, nausea, changes in body composition and fat distribution (lipoatrophy and lipodeposition), anemia, muscle weakness, fatigue, neuropathy, headaches, and pancreatis. Webcast moderated by Anquoinette Crosby with participants Richard Elion, M.D. (George Washington University School of Medicine) and Brian A. Boyle, M.D. (New York Presbyterian Hospital-Cornell University Medical Center), HIVTreatmentSide http://www.managinghiv.com (last visited Jan. 2, 2003) [hereinafter Webcast].

 $PA.\ L.\ REV.\ 899,\ 902\ (1993)$  (describing the phenomena of unconscious discrimination).

<sup>2.</sup> In this Article, "HIV disease" refers to both HIV and AIDS. The Human Immunodeficiency Virus (HIV) causes Acquired Immune Deficiency Syndrome (AIDS). The virus 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. The Kaiser Family Foundation Capital Hill Briefing Series on HIV/AIDS, The State of the HIV/AIDS Epidemic in America, 2, 3 (Apr. 2000), available at http://www.kff.org/content/2000/1581/stateofepi.pdf. HIV is transmitted from one individual to another through sexual contact and blood-to-blood contact (i.e. sharing needles). Id.

Stigma, prejudice, and fear still persist because HIV disease involves complicated social and politically-charged issues, specifically drugs, class, race, politics, religion, disability, poverty, sex, and sexual orientation.<sup>4</sup> 77 percent of all Americans believe people with HIV disease are treated unfairly.<sup>5</sup> This belief is evidenced by the everyday reality of discrimination occurring in venues ranging from the workplace to schools, treatment centers, nursing homes, medical clinics, housing, airlines, and government service providers.<sup>6</sup> It takes the form of words or actions. Sometimes threats and actual violence occur.<sup>7</sup>

In instances of racial or gender discrimination, the target traits are generally visible. Individuals with HIV disease are not readily identifiable. While some refuse to keep their health a secret, no matter the consequence, others carefully select confidantes, in hopes of avoiding negative repercussions that can accompany the act of disclosing HIV status. Shared values,

<sup>4.</sup> See David I. Schulman, AIDS Workplace Law and Policy, 9 St. LOUIS U. PUB. L. REV. 543, 547 (1990). "Because of the threat they pose to life itself, epidemics threaten the social fabric. A primal human response to such threats has been ritual acts of purification and scapegoating." Id. See also Erika L. Greenfield, Maintaining Employees' Privacy of HIV and AIDS Information in the Workplace, 15 HOFSTRA LAB. & EMP. L.J. 277, 278 (1997) (noting that "[t]his negative reputation is the result of American 'cultural, religious, moral, and ethical taboos' which commonly prevent AIDS from being freely discussed"). See also Stolberg, supranote 3, at A3 (noting the disparate impact of AIDS on the poor and minorities).

<sup>5.</sup> MINNESOTA AIDS PROJECT, 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. Feb. 5 & 6, 2001), at cover.

<sup>6.</sup> See generally Montalvo v. Radcliffe, 167 F.3d 873, 874-79 (4th Cir. 1999) (discussing discrimination in schools); Doe v. New York City, 825 F. Supp. 36, 37-38 (S.D.N.Y. 1999) (discussing discrimination on airlines); W.G.A. v. Priority Pharmacy, Inc., 184 F.R.D. 616, 616-17 (E.D. Mo. 1999) (discussing discrimination in the workplace, schools, social settings, and public accommodations); Howe v. Hull, 873 F.Supp. 72, 78 (N.D. Ohio 1994) (discussing discrimination in hospitals); Stewart B. McKinney Found., Inc. v. Town Plan & Zoning Comm'n of Town of Fairfield, 790 F.Supp. 1197, 1201-22 (D. Conn. 1992) (discussing discrimination in zoning); Doe v. Borough of Barrington, 729 F.Supp. 376, 378-91 (D.N.J. 1990) (discussing discrimination by government service providers namely law enforcement); Marcus Garvey Nursing Home, Inc. v. New York State Div. of Human Rights, 209 A.D.2d 619, 619-20 (N.Y. App. Div. 1994) (discussing discrimination in nursing homes).

<sup>7.</sup> See Doe v. Delie, 257 F.3d 309, 331 (3rd Cir. 2000).

<sup>8.</sup> See Know HIV/AIDS, Get the Facts , at www.knowhivaids.org/prev\_getfacts.html (last visited March 25, 2003); iVillage, Visible Signs of HIV Infection?, at www.Ivillagehealth.com/experts/infectious/qas/0,,417599\_173978,00.html (last visited March 25, 2003).

<sup>9.</sup> See The Cost of Stigma, AIDSLINE BRIEF (Minnesota AIDS Project), Mar. 2001, at 5 [hereinafter The Cost of Stigma].

personal beliefs, and trust play key roles in this decision-making process. Unfortunately trust is sometimes abused. When "outed" through intentional or negligent disclosures, people with HIV disease must face consequences involving family, friends, career, faith, and community. Fear of disclosure and recrimination can lead to isolation, anxiety, depression, high-risk behavior, even a refusal to seek necessary medical treatment. Moral judgments, whether self-imposed or constructed by society, are powerful determinants in individual actions.

The law is continually evolving in its response to the moral challenges presented by HIV disease.<sup>12</sup> However, law cannot take the place of morality.<sup>13</sup> It provides only principles – the individual must make distinctions based on instilled beliefs.<sup>14</sup> Nonetheless, the law is the arbiter when personal moralities clash, and HIV

10. See Schulman, supra note 3, at 551.

The law strictly regulates disclosure of such information because of the powerful potential for social stigma of wrongful disclosures. Such disclosures can result in violations of constitutional rights, statutory confidentiality protections, discrimination, invasion of privacy, and actions alleging intentional or negligent infliction of emotional discress. Significant consequential damage can result from wrongful disclosures because of the special capacity of HIV information to lead to wrongful terminations, loss of insurance, evictions, and even the loss of friends and family.

Id.

11. See generally The Cost of Stigma, supra note 9, at 5 (noting the fears of disclosing HIV status).

12. See Caroline Palmer & Lynn Mickelson, Many Rivers to Cross: Evolving and Emerging Legal Issues in the Third Decade of the HIV/AIDS Epidemic, 28 WM. MITCHELL L. REV. 455 (2001).

13. See Frank J. Cavico, Invasion of Privacy in the Private Employment Sector: Tortious and Ethical Aspects, 30 HOUS. L. REV. 1263, 1332-33 (1993).

Equating legality with morality, however, is a flawed ethical approach. One's moral duty may demand conduct above and beyond what the law requires. One's moral beliefs may also require condemnation and disobedience of an "unjust" law. There is no guarantee, moreover, that the moral views of society are accurately reflected in its law. Not everything immoral can be made illegal.

Id.

14. Id. at 1333.

The law influences and shapes moral standards. In return, it reflects the moral beliefs of a society, thereby providing criteria for right or wrong conduct. Moral standards and their ethical framework, therefore, are important in decision-making as an analytic system from legal standards. Why do people then retreat to the positive expression of the law as a norm for morality and ignore the underlying moral issues?

Id. See also Schulman, supra note 3. "[L]aw now has evolved requirements for treating others fairly, even during such times of social turmoil – particularly during such times. As we struggle today, law can guide us past our primal impulses to blame and victimize, and contribute to alleviating the stress and pain of the epidemic." Id. at 560.

disease inhabits a realm where conflict is constant.15

This Article limits its scope to two especially contentious legal concerns and their relationship to HIV disease: disability determinations under the Americans with Disabilities Act of 1990 (ADA)<sup>16</sup> and privacy law on both the state and federal levels. Section I is a brief report on the state of HIV disease internationally, nationally, and in Minnesota.<sup>17</sup> Section II explores two ADA decisions released by the United States Supreme Court during the 2001-02 term and their potential impact on the treatment of individuals with HIV disease under disability law. 18 Section III reviews emerging privacy policies and their current and potential impact on HIV disease, particularly in the context of workplace disclosure.<sup>19</sup> A discussion of a medical records privacy bill, first proposed during the 2002 Minnesota State Legislature session and reintroduced during the 2003 session, advocates the passage of a new law in Minnesota to deter confidentiality breaches.<sup>20</sup> Newly enacted medical information state database collection rules will also be discussed in this context.21

This Article concludes that although the nature of HIV disease has changed significantly in the United States, stigma persists because of the complicated moral issues engendered by the circumstances, stereotypes, and misinformation surrounding the disease. Education helps, yet without a corresponding shift in global attitude, it falls short of the hoped-for panacea. Still, the goal of realizing a society where individuals are not judged, threatened or ostracized on the basis of their health status is attainable. Placing HIV disease within the greater context of protections afforded all individuals in the United States will help us reach that goal.

## I. HIV Disease in the Twenty-First Century

In 1982, after nearly a year of tracking a series of rare infections among members of the gay men's community, the United States Centers for Disease Control and Prevention (CDC) named the health phenomenon Acquired Immune Deficiency

<sup>15.</sup> See infra notes 148-166 and accompanying text.

<sup>16.</sup> Americans with Disabilities Act, 42 U.S.C. §§ 12101-12213 (2000).

<sup>17.</sup> See infra notes 22-48 and accompanying text.

<sup>18.</sup> See infra notes 54-166 and accompanying text.

<sup>19.</sup> See infra notes 166-277 and accompanying text.

<sup>20.</sup> See infra notes 265-277 and accompanying text.

<sup>21.</sup> See infra notes 265-277 and accompanying text.

Syndrome (AIDS) and identified several high-risk groups.<sup>22</sup> In the twenty years since the CDC released an identifier and definition for the new disease, a fast-moving global epidemic has emerged that affects men, women, and children of all sexual orientations, races, ethnicities, and economic classes, although some groups have been affected disproportionately.<sup>23</sup> In 2000, the World Bank declared HIV disease a developmental crisis.<sup>24</sup> Shortly thereafter, the United States and the United Nations Security Council identified HIV disease as a world security threat.<sup>25</sup>

AIDS is now the fourth leading cause of death worldwide.<sup>26</sup> Recent statistics show that forty million people in the world are currently living with HIV or AIDS, and approximately three million die people died of AIDS in 2001.<sup>27</sup> This year alone, five million people will become infected, and fourteen million children will lose one or both parents to AIDS.<sup>28</sup> Since 1982, over twenty million lives have been claimed by HIV disease.<sup>29</sup> As home to 71 percent (28.5 million) of the world's infected persons, sub-Saharan Africa has experienced the most devastation to its population.<sup>30</sup> The predominant route of transmission is through heterosexual sex, but men who have sex with men, injecting drug users, and sex industry workers are also among the primary affected groups.<sup>31</sup> After Sub-Saharan Africa, Eastern Europe and Central Asia are

<sup>22.</sup> The Henry J. Kaiser Family Foundation, The AIDS Epidemic at 20 Years: Selected Milestones (June 2001) 4, available at http://www.kff.org/content/2001/3026/aids20\_timeline.pdf [hereinafter Milestones]; Laurie Garrett, AIDS at 20: Legacy of Hope and Despair, NEWSDAY, May 29, 2001, at A4. The high-risk behaviors at the time included sexual activity between men and intravenous drug use. Milestones, supra. High risk traits included Hemophilia A and Haitian origin. Id. In 1983, the CDC added female partners of men with HIV/AIDS to the list. Id.

<sup>23.</sup> See Palmer & Mickelson, supra note 12, at 456-69 (discussing the epidemic history and disproportionate impact on communities of color and poor communities). HIV disease has been described as occurring in two "worlds," "a rich world' where 500,000 people with HIV have access to ARVs (anti-retrovirals) and 25,000 die of AIDS each year, and a 'poor world,' where in sub-Sarahan Africa alone, 30,000 people out of 30 million with HIV receive treatment, and where 2.2 million died of AIDS last year." Joe Larson, International AIDS Conference Highlights, THE ALIVELINE, Aug. 2002, at 1.

<sup>24.</sup> See GLOBAL FACT SHEET, supra note 3, at 1.

<sup>25.</sup> See Milestones, supra note 22.

<sup>26.</sup> See GLOBAL FACT SHEET, supra note 3, at 1.

<sup>27.</sup> See UNAIDS, REPORT ON THE GLOBAL HIV/AIDS EPIDEMIC 8, UNAIDS/02.26E (2002).

Id.

<sup>29.</sup> See GLOBAL FACT SHEET, supra note 3, at 1.

<sup>30.</sup> See id. South Africa, with approximately five million infected persons, has the world's highest population of persons living with HIV disease. Id.

<sup>31.</sup> Id.

the fastest growing regions for HIV disease due largely to intravenous drug use.<sup>32</sup>

The failure of the world's wealthiest economies to contribute proportional amounts to the overall relief effort is a contributing factor to the global AIDS epidemic.<sup>33</sup> Access to treatment, education, and prevention efforts have made a significant difference in mortality rates in the United States.<sup>34</sup> Few in the HIV community, however, would agree that the United States sufficiently funds the battle against HIV disease on either the foreign or domestic fronts.<sup>35</sup>

It is estimated that up to 950,000 Americans are living with HIV disease, including more than 300,000 diagnosed with AIDS.<sup>36</sup> Forty thousand new infections occur each year.<sup>37</sup> Sexual transmission and intravenous drug use are the main modes of transmission, and men having sex with men account for the

<sup>32.</sup> Id.

<sup>33.</sup> See GLOBAL AIDS ALLIANCE, FILLING THE FUNDING GAP TO SAVE LIVES 3, 6 2002). available http://globalaidsalliance.org/Filling the Funding Gap 09Oct02.pdf. UNAIDS has estimated that at least seven to ten billion dollars is needed on an annual basis to effectively respond to the epidemic. Id. The Global AIDS Alliance (GAA), a nonprofit dedicated to stopping AIDS worldwide, recently announced that its Global Fund needs 4.25 billion dollars in 2003 but only 650 million dollars has been pledged. Id. The United States, according to GAA, should provide a "fair-share contribution" of 1.488 billion dollars, which is "about [seven] times what President Bush has pledged to provide." Id. See also Gay Men's Health Crisis Press Release, GMHC Exposes Bush AIDS Funding Shell Game (Feb. 5, 2003), at http://www.gmhc.org/aboutus/press\_030205.html. Although President Bush announced a fifteen billion dollar aid package for global HIV prevention, only two billion dollars will be allocated in fiscal year 2004. Id. Further, the administration only targeted one billion dollars to the Global Fund to Fight AIDS, Tuberculosis and Malaria over a five-year period (200 million dollars per year). Id.

<sup>34.</sup> See U.S. FACT SHEET, supra note 3, at 1.

<sup>35.</sup> See Denial Here at Home, WASH. POST, Dec. 23, 2002, at A18. Low funding for AIDS relief by the Bush administration may contribute to three million deaths a year, a fact the editorial writer refers to as "murder by complacency." Id. A five billion dollar pledge for AIDS relief, as compared to 200 billion dollars for war against Iraq, would make a significant difference and save lives. Id. See also David Brown, HHS Reviews Funding to AIDS Groups After Protest, WASH. POST, Aug. 19, 2002, at A1. Health and Human Services Secretary Tommy Thompson was heckled at the International AIDS Conference in Barcelona by protestors stating that the United States does not do enough to address the treatment and care of persons with HIV in poor countries. Id. In retaliation, HHS, by request of twelve members of Congress, began investigating more than a dozen AIDS service organizations whose members joined in the protests. Id. This action could potentially affect funding and produce a chilling result on organizations protesting the government's lack of commitment to AIDS relief. Id.

<sup>36.</sup> See U.S. FACT SHEET, supra note 3, at 1.

<sup>37.</sup> Id.

largest population affected.<sup>38</sup> The number of HIV infected women continues to grow and it is now estimated that women account for 30 percent of all new HIV infections.<sup>39</sup> Racial and ethnic minorities in all gender categories are disproportionately represented in HIV disease statistics and now comprise the majority of all new AIDS cases in the United States.<sup>40</sup> The rising numbers of HIV disease diagnoses among young people signal a need for more aggressive prevention programs that emphasize total health, including sex education, and do not rely solely on abstinence messages.<sup>41</sup>

Many of the national trends for populations affected and disproportional results are reflected in Minnesota's HIV disease statistics. Over 6,660 cases of HIV disease have been recorded in Minnesota since the beginning of the epidemic.<sup>42</sup> Currently, 4,331 individuals are living with HIV or AIDS in the state.<sup>43</sup> AIDS has claimed over 2300 lives since the beginning of the epidemic.<sup>44</sup> The primary mode of transmission is sex (male to male among men, male to female among women).<sup>45</sup> African American and African-

<sup>38.</sup> Id. 46 percent of all reported adult/adolescent AIDS cases have been linked to sex between men. Id. Men who have sex with men account for 42 percent of all new infections. Id.

<sup>39.</sup> Id. at 2. Infection among women is due primarily to heterosexual sex (75 percent) followed by intravenous drug use (25 percent). Id. Women of color are disproportionately affected: African American women currently account for 64 percent of new AIDS cases among women. Id. Latina women account for 17 percent of new AIDS cases among women. Id.

<sup>40.</sup> Id. African Americans and Latinos represent only 12 percent and 14 percent of the United States population respectively. Id. However, they account for 47 percent and 19 percent of newly reported cases in 2000. Id. HIV is the leading cause of death for African Americans between the ages of 25 to 44 and third for Latinos in the same age group. Id. See Stohlberg, supra note 3, at A3. "AIDS in this country is increasingly an epidemic of the poor, which means it is increasingly an epidemic of minorities." Id.

<sup>41.</sup> See, e.g., U.S. FACT SHEET, supra note 3, at 5 (noting the rising number of HIV/AIDS cases among young people). Abstinence-only education programs using government money to promote religion have experienced judicial rebuke despite the Bush Administration's attempts to increase funds to federal abstinence programs and other faith-based initiatives. See, e.g., Ceci Connolly, Judge Orders Changes in Abstinence Program; Louisiana Group Found to Be Promoting Religion, WASH. POST, July 26, 2002, at A3 (noting a successful American Civil Liberties Union (ACLU) challenge to the Louisiana's Governor's Program on Abstinence by demonstrating a violation of the First Amendment's separation between church and state requirement).

<sup>42.</sup> Minnesota Department of Health, HIV Surveillance Report, 2001, 2001 HIV/AIDS IN MINNESOTA: ANNUAL REVIEW 7, available at http://www.health.state.mn.us/divs/dpc/aids-std/inc\_2001.pdf (last visited Feb. 18, 2003).

<sup>43.</sup> Id. at 8.

<sup>44.</sup> Id.

<sup>45.</sup> Id. at 29, 31.

born women are disproportionately represented, making up 66 percent of all cases among women.<sup>46</sup>

HIV disease has changed the world in countless ways. For example, Presidential Commissions have been established to create recommended protocols to aid employers, schools, and communities while they are creating policies that affect the rights of persons with AIDS and HIV disease.<sup>47</sup> Non-profit AIDS service organizations exist throughout the country that provide services to affected populations and raise awareness through educational efforts and fundraising activities.<sup>48</sup> Young people do not know a world without AIDS. Significantly, different cultures have been forced to confront deep-seated beliefs about sexuality, sexual orientation, chemical dependency, delivery of medical services, residential and hospice care, race, and many other complicated social constructs.<sup>49</sup> Rigid morality simply cannot overcome the awesome scope of this health crisis.

# II. Recent Americans with Disabilities Act Cases: A New Interpretation of Legislative Intent in the United States Supreme Court and the Potential Implications for Individuals with HIV Disease

# A. Setting the Stage: Bragdon v. Abbott

The ADA<sup>50</sup> prohibits discrimination based on disability in employment (Title I),<sup>51</sup> public services (Title II),<sup>52</sup> public accommodations (Title III),<sup>53</sup> and miscellaneous venues (Title V).<sup>54</sup> The law created "a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities ... [by providing] clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities."<sup>55</sup> Congress defined disability as a "physical or mental"

<sup>46.</sup> Id. at 19.

<sup>47.</sup> See Schulman, supra note 3, at 543.

<sup>48.</sup> For a listing of services (i.e. AIDS hotlines and service organizations), see http://www.thebody.com/hotlines.html (last visited Feb. 12, 2003).

<sup>49.</sup> See UNAIDS, MEN, CULTURE & HIV / AIDS 1, 1-2, available at http://www.unaids.org/wac/2001/Campaigndocs/culture.pdf (last visited March 25, 2003).

<sup>50.</sup> Americans With Disabilities Act, 42 U.S.C. §§ 12101-12213 (2000).

<sup>51. 42</sup> U.S.C. §§ 12111-12117.

<sup>52. 42</sup> U.S.C. §§ 12131-12150.

<sup>53. 42</sup> U.S.C. §§ 12181-12189.

<sup>54. 42</sup> U.S.C. §§ 12201-12213.

<sup>55. 42</sup> U.S.C. § 12101(b)(1)-(2). The ADA expanded upon the Rehabilitation Act

impairment that substantially limits one or more of the major life activities."<sup>56</sup> ADA claimants must also show that their condition is widely perceived as disabling and that they either have a record of being disabled, an actual disability, or are regarded as being disabled, whether or not the conditions associated with the disability currently exist.<sup>57</sup> This definition has proven confusing for the courts, particularly because Congress did not include a list of impairments or specify what a "major life activity" might be.<sup>58</sup> A wide variety of judicial interpretations paved the way for Bragdon v. Abbott<sup>59</sup> in 1998.<sup>60</sup> Bragdon represents the first time the United States Supreme Court considered HIV disease in the

of 1973, which provided protections in the context of federal government employment, programs receiving federal aid, or government contractors. See 29 U.S.C. § 794 (1999). The ADA drafters "lifted" the disability definition from section 504 of the Rehabilitation Act. See William C. Smith, Drawing Boundaries, A.B.A. J., Aug. 2002, 48, 50. Arlene Mayerson, lawyer with the Disability Rights Education Fund in Berkeley, California, explained that the three-prong approach would "cover all the important bases" when litigating the definition of "legal disability":

Prong one incorporates a functional approach that looks to the characteristics of the individual. The second and third prongs — "record of" and "regarded as" — incorporate a social relations approach that looks to the negative reactions to an impairment rather than the extent of the impairment itself. Thus, even if workers or job applicants were not substantially limited by their disabilities, they still should be protected from adverse treatment in the workplace because of their real or perceived impairments.

Id.

- 56. 42 U.S.C. § 12102(2)(A). The Rehabilitation Act regulations issued by the Department of Health, Education and Welfare in 1977 provide a list of "major life activities" including: "walking, seeing, hearing" and "performing manual tasks." 45 C.F.R. § 84.3(j)(2)(ii) (2001). The Equal Employment Opportunity Commission (EEOC) has created a definition of "substantially limits" for ADA purposes: "[u]nable to perform a major life activity that the average person in the general population can perform" or "[s]ignificantly restricted as to the condition, manner or duration under which an individual can perform a particular major life activity as compared to the condition, manner or duration under which the average person in the general population can perform that same major life activity." 29 C.F.R. § 1630.2(j) (2001). The Regulations also list the following factors to determine whether a person is substantially limited in a major activity: "[t]he nature and severity of the impairment; [the] duration or expected duration of the impairment; and [t]he permanent or long-term impact, or the expected permanent or long-term impact of or resulting from the impairment." Id. at §§ 1630.2(j)(2)(i)-(iii).
  - 57. 42 U.S.C. § 12102(2)(B)-(C).
- 58. See Sherena Shawrieh, Bragdon v. Abbott: Expanding the Reach of the Americans with Disabilities Act, DEF. COUNS. J., Jan. 2000, at 107. See also Denise DeCell, Bragdon v. Abbott: A Case of HIV as a Perceived Disability Under the Americans with Disabilities Act, 73 St. John's L. Rev. 933, 940 (1999) (noting that the statute "does not explicitly define impairment with regard to disability").
  - 59. 524 U.S. 624 (1998).
- 60. See, e.g., Runnebaum v. Nationsbank of Md., 123 F.3d 156, 170 (4th Cir. 1997) (holding that the plaintiffs "asymptomatic HIV infection" was not a disability under the ADA).

context of an ADA decision.61

Bragdon Court interpreted the ADA disability determination to include people with asymptomatic HIV or AIDS. or people in the early stages of HIV disease. 62 Sidney Abbott, a woman with asymptomatic HIV at the start of the case, went to see her dentist, Dr. Randon Bragdon, for a filling, 63 Although Bragdon did not refuse to treat Abbott, he stated that he would only perform the procedure in a hospital because she was HIVpositive.<sup>64</sup> He offered his services at the hospital for no extra charge, but explained Abbott would be responsible for any hospital costs.65 Abbott filed a discrimination suit under Title III of the ADA, which prohibits discrimination in public accommodations.66 Abbott argued that she had a "physical or mental impairment that substantially" limited one or more of her "major life activities" reproduction.<sup>67</sup> The district court granted her motion for summary judgment and the First Circuit affirmed.68 The Supreme Court granted certiorari to resolve the questions of whether reproduction could be considered a major life activity, whether an asymptomatic individual with HIV disease is disabled, and whether a health care provider must perform an invasive procedure on an infectious patient in his office.69

The Court used a three-step analysis to determine whether Abbott was disabled.<sup>70</sup> First, the Court examined Congressional

<sup>61.</sup> Bragdon, 524 U.S. at 644-48. The Court discussed prior agency and judicial interpretations which did not have the guidance of Supreme Court opinions on the matter. *Id.* 

<sup>62.</sup> Id. at 641. The difference between symptomatic and asymptomatic depends on an individual's CD4 count and viral load at any given time. See NEW MEXICO AIDS INFONET, ACUTE HIV INFECTION 1 (Aug. 5, 2002), at http://www.thebody.com/nmai/pdfs/acute\_infection.pdf.

<sup>63.</sup> Bragdon, 524 U.S. at 628-29.

<sup>64.</sup> Id. at 629.

<sup>65.</sup> Id.

<sup>66.</sup> Id. Title III states, "[N]o individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any person who ... operates a place of public accommodation." 42 U.S.C. § 12182(a) (1994). "Public accommodation" includes the "professional office of a health care provider." 42 U.S.C. § 12181(7)(F) (1994).

<sup>67.</sup> Bragdon, 524 U.S. at 637. The first prong of the ADA definition for disability states: "a physical or mental impairment that substantially limits one or more of the major life activities of such individual." 42 U.S.C. § 12102(2)(A) (1994).

<sup>68.</sup> See Abbott v. Bragdon, 912 F.Supp. 580, 584 (D.Me. 1995), aff'd, 107 F.2d 934, 949 (1st Cir. 1997).

<sup>69.</sup> Bragdon, 524 U.S. at 628, 648.

<sup>70.</sup> Id. at 631.

intent and agency interpretation of the ADA.<sup>71</sup> Next, using regulations promulgated under the Rehabilitation Act and extensive medical analysis of HIV disease, the Court concluded that during an asymptomatic phase the virus actively attacks white blood cells and lymph nodes.<sup>72</sup> The Court therefore concluded that asymptomatic HIV is a physical impairment within the meaning of the ADA.<sup>73</sup> The Court further decided that reproduction was a "major life activity" because it was "central to the life process itself."<sup>74</sup>

Finally, the Court stated that Abbott satisfied the third step of the disability test because HIV disease limited her ability to reproduce to two ways: in order to conceive Abbott would risk exposing her partner to infection, and if she conceived, she would risk passing the infection to the child during pregnancy and birth. Abbott met the ADA disability test because, although she could still conceive and give birth, the dangers associated with these activities created a substantial limitation in her life choices. Thus, the Court held Abbott disabled under the ADA definition.

The Court further held that a defendant would not be liable for discrimination under the ADA if the plaintiff's treatment

<sup>71.</sup> Id. According to the rules of statutory construction, defined terms imply that they correspond with regulatory interpretations already in existence. Id. at 631-33. Established administrative and judicial interpretations further inform meaning. Id. at 646-47. Because Congress relied extensively on the Rehabilitation Act and its jurisprudence to define disability, the Court concluded that the decision making of agencies implementing a statute "constitute a body of experience and informed judgment to which courts and litigants may properly resort for guidance." Id. at 642. See, e.g., Sch. Bd. of Nassau County v. Arline, 480 U.S. 273, 285-86 (1987) (holding that employees with infectious diseases were considered disabled under the Rehabilitation Act, 29 U.S.C. § 790 et seq.).

<sup>72.</sup> Bragdon, 524 U.S. at 637.

<sup>73.</sup> Id. The Rehabilitation Act defined "physical impairment" as "any physiological disorder or condition ... affecting one or more of the following body systems: ... hemic and lymphatic." Id. at 632 (citing 45 C.F.R. § 84.3 (j)(2)(i) (1997)). This definition is virtually the same as the one adopted by the ADA and the EEOC for purposes of implementing the ADA. Bragdon, 524 U.S. at 631.

<sup>74.</sup> Id. at 638. Mr. Bragdon argued that Congress intended the ADA to only apply to an individual's public or economic activities but the Court found nothing in the statutory interpretation to support this contention. Id. The Court looked to the Rehabilitation Act regulations, which included a list of "major life functions." Id. The list included "caring for one's self [and] performing manual tasks." Id. at 638-39. The Court concluded that these activities are neither public nor economic, further bolstering its conclusion that Congress did not intend to limit the definition in such a way. Id.

<sup>75.</sup> Id. at 639-40.

<sup>76.</sup> Id. at 641.

<sup>77.</sup> Id. at 641-42.

"pose[d] a direct threat to the health or safety of others." A direct threat under the ADA is "a significant risk to the health or safety of others that cannot be eliminated by a modification of policies, practices, or procedures, or by the provisions of auxiliary aids or services."79 Referring again to legislative intent, the Court explained that Congress included direct threat language in order discrimination based on irrational misinformation.80 This was an important distinction to make in the context of an HIV-based disability claim because the Court recognized that stigma plays a role in the perception and treatment of individuals with HIV disease.81 The Court sent a needed signal that HIV-positive "much Americans substantially limited only in the manner in which they are treated by the uninformed and frightened."82

Despite the clarification of disability definitions and direct threat analysis, the Court left several questions unanswered in Bragdon. For example, how would the decision affect HIV-positive people who do not plan to reproduce, or who plan to use nontraditional methods for conception, or seniors with HIV disease who are beyond their reproductive years?83 Ultimately the Bragdon decision is very limited in scope, leaving the door open for further disagreement on HIV disability determinations. Because the Court narrowly tailored its analysis to an asymptomatic woman of reproductive age and ability, leaving open some discussion as to the impact of AIDS on other life activities yet ultimately failing to elaborate on how the ADA might apply in

<sup>78.</sup> Id. at 648 (quoting 42 U.S.C. § 12182(b)(3) (1994)).

<sup>79. 42</sup> U.S.C. § 12182(b)(3).

In determining whether an individual poses a direct threat to the health or safety of others, a public accommodation must make an individualized assessment, based on reasonable judgment that relies on current medical knowledge or on the best available objective evidence, to ascertain: the nature, duration, and severity of the risk; the probability that the potential injury will actually occur; and whether reasonable modifications of policies, practices or procedures will mitigate the risk.

Abbott v. Bragdon, 107 F.2d 934, 943 (1st Cir. 1997). Evidence is confined to the medical evidence available at the time a service provider refuses treatment. See id. at 944. Chevron U.S.A. Inc. v. Echazabal, 122 S. Ct. 2045 (2002), discussed infra notes 121-147 and accompanying text, expands upon the definition of direct threat to include the disabled person as well. Id.

<sup>80.</sup> Bragdon, 524 U.S. at 649.

<sup>81.</sup> Id. The court concluded that "few, if any, activities in life, are risk free." Id. This statement indicated that there is a critical difference between a belief, unfounded in evidence, and a substantiated fact. Id. See also DeCell, supra note 58, at 944-50 (discussing the "direct threat exception" to the ADA).

<sup>82.</sup> DeCell, supra note 58, at 950.

<sup>83.</sup> See Adams, supra note 2, at 15; Shawrieh, supra note 58, at 111-12.

those instances, it is likely that individuals who fail to fit such criteria will not be able to utilize *Bragdon* as sole precedent.<sup>84</sup> The next section examines this assertion in more detail by reviewing recent ADA decisions by the Court.

- B. Landmark Changes in the Supreme Court's 2001-02 Term
- i. Toyota Manufacturing Kentucky, Inc. v. Williams

On March 14, 2002, Justice Sandra Day O'Connor gave a speech at the Georgetown University Law Center.<sup>85</sup> She stated that the ADA is "an example of what happens when sponsors are so eager to get something passed that what passes hasn't been as carefully written as a group of law professors might put together.<sup>86</sup> So it leaves lots of ambiguities and gaps and things for courts to figure out."<sup>87</sup> In the years since *Bragdon*, the Supreme Court appears to be addressing conflicts within the Act. Simultaneously,

84. See Shawrieh, supra note 58, at 111. Shawrieh points out that even though one of the most likely groups of plaintiffs is gay males,

[b]y definition they cannot conceive through sexual activity with their partners. The plaintiff in the pre-Bragdon Fourth Circuit, Runnebaum v. Nationsbank of Maryland, would most likely lose now as he lost originally. Runnebaum was an asymptomatic HIV-positive male bank employee who was fired after two shipments of AZT addressed to him arrived at the bank and were mistakenly opened by other bank employees. He claimed he was fired because of his HIV status .... The Fourth Circuit held that asymptomatic HIV does not "substantially limit procreation or intimate sexual relations" for purposes of the ADA, and it went on to state in dictum that even if procreation were a major life activity that Runnebaum "forewent having children" because of his HIV status.

Id. at 111 (citations omitted). However, Shawrieh goes on to explain that Hernandez v. Prudential Insurance Co., 977 F. Supp. 1160 (M.D. Fla. 1997) produced a different result. Id. An HIV-positive gay male who wanted to have children since a very young age but had not done so prior to his HIV diagnosis was substantially limited in this major life activity. Id. at 1164-65. Shawrieh concludes that there can be no predictable result for gay men under the Bragdon decision. Shawrieh. supra note 58, at 111.

In a recent case, Blanks v. Southwestern Bell Communications, Inc., 310 F.3d 398, 402 (5th Cir. 2002), the Fifth Circuit held, in part, that Blanks, although HIV-positive, did not qualify as disabled under the ADA because he was not "regarded" as disabled by his employer, Southwestern Bell. Id. Blanks could only be excluded from a narrow range of jobs (two or less) and did not demonstrate substantial limitation in a major life activity, namely reproduction. Id. Blanks' wife underwent a procedure to prevent her from having more children long before the alleged discrimination took place. Id. at 401. Blanks did not want to have more children, and therefore there was no substantial limitation of the sort found in Bragdon. Id.

<sup>85.</sup> Smith, supra note 55, at 49.

<sup>86.</sup> Id.

<sup>87.</sup> Id.

the Court is changing the definition of disability and narrowing the application of the law, to the detriment of many who would otherwise benefit from its protections.<sup>88</sup>

In June 1999, the Court released three employment decisions further restricting the definition of disability under the ADA. Commonly known as the *Sutton* trilogy, the cases signaled the Court's turn toward strict formalism with respect to disability cases.<sup>89</sup> The Court reshaped legislative history and intent to limit application of the Act.<sup>90</sup> As a result, all claims are to be evaluated on a case-by-case basis, and anything that might remedy or mitigate a disability's impact, such as medical treatment or corrective devices (but not invasive treatments), must be taken into account when making a determination.<sup>91</sup>

During the 2001-02 session, the Court solidified its commitment to formalism in four landmark cases, beginning with Toyota Motor Manufacturing, Kentucky, Inc. v. Williams. 22 Ella Williams, an automobile plant worker, worked on an engine fabrication assembly line where she used pneumatic tools. 33 The tools caused pain in her hands, wrists, and arms that was diagnosed as bilateral carpal tunnel syndrome and bilateral tendonitis. 4 Williams personal physician placed her on permanent work restrictions, and she asked her employer, Toyota,

<sup>88.</sup> This Article will focus on two of the four ADA cases considered by the Supreme Court during the 2001-02 term: Chevron U.S.A. Inc. v. Echazabal, 122 S. Ct. 2045 (2002) and Toyota Motor Manufacturing., Kentucky, Inc. v. Williams, 122 S. Ct. 681 (2002). The other cases are U.S. Airways v. Barnett, 122 S. Ct. 1516, 1525 (2002), where the Court determined that ADA protections of disabled workers rarely trump seniority rights of co-workers and Barnes v. Gorman, 122 S. Ct. 2097, 2102-03 (2002), where the Court held that municipalities are not subject to punitive damages in private ADA cases.

<sup>89.</sup> The three cases comprising the Sutton trilogy are: Sutton v. United Airlines, 527 U.S. 471 (1999); Murphy v. United Parcel Service, 527 U.S. 516 (1999); and Albertson's, Inc. v. Kirkinburg, 527 U.S. 555 (1999).

<sup>90.</sup> See infra notes 148-166 and accompanying text for a discussion of the new ADA interpretations.

<sup>91.</sup> See Smith, supra note 55, at 50-51. In Sutton v. United Airlines, the Court rejected twin sisters' claims of discrimination because they were not hired as commercial airline pilots. 527 U.S. at 471. The sisters were both nearsighted and the court concluded that corrective lenses would remedy their situation while opening the door to some pilot positions, satisfying their career aspirations. Id. at 493. Similarly, a truck driver in Murphy v. United Parcel Service could, in the Court's view, control hypertension with medication. 527 U.S. at 516. In Albertson's, Inc. v. Kirkinburg, another truck driver had means of compensating for his monocular vision. 527 U.S. at 555. In these decisions the Court seems to be acknowledging the human body's natural ability to compensate for disability.

<sup>92. 122</sup> S. Ct. 681 (2002).

<sup>93.</sup> Id. at 686.

<sup>94.</sup> Id.

to modify her job duties.<sup>95</sup> She then missed work for medical leave and filed a claim under the Kentucky Worker's Compensation Act.<sup>96</sup> The claim was eventually settled, and Williams returned to work; however, she was not satisfied with Toyota's accommodation efforts and she filed suit, claiming that her employer had violated the ADA.<sup>97</sup>

Having settled, Williams returned to work once again, at first with satisfactory accommodations.98 Her work assignment changed, however, and Williams began to experience pain in her neck and shoulders.99 The in-house medical service diagnosed her with myotendonitis bilateral periscapular (inflammation of the muscles and tendons around her shoulder blades); myotendonitis and myositis bilateral forearms with nerve compression causing median nerve irritation; and thoracic outlet compression, a painful nerve condition in the upper extremities. 100 Williams asked Toyota to accommodate her medical condition but she claimed they refused her request. 101 Toyota countered that Williams regularly missed work.<sup>102</sup> On December 6, 1996, Williams' last day at the plant, her physicians placed her on a "no-work-of-any-kind restriction," and on January 27, 1997, Toyota sent Williams a letter terminating her employment because of "her poor attendance record."103 Williams sued Toyota once again, citing their failure to reasonably accommodate her disability and unfair termination. 104 Williams stated that she was "disabled" under the ADA because her "physical impairments substantially limited her in (1) manual tasks; (2) housework; (3) gardening; (4) playing with her children; (5) lifting; and (6) working, all of which, she argued. constituted major life activities under the Act."105 The District Court granted Toyota's summary judgment motion, and the Court of Appeals reversed the lower court's ruling that Williams was disabled at the time she sought an accommodation but affirmed the rulings on Williams' Family and Medical Leave Act (FMLA)

<sup>95.</sup> Id.

<sup>96.</sup> Id.

<sup>97.</sup> Id.

<sup>98.</sup> Id. at 687.

<sup>99.</sup> Id.

<sup>100.</sup> Id. at 684.

<sup>101.</sup> Id.

<sup>102.</sup> Id.

<sup>103.</sup> Id. at 687.

<sup>104.</sup> Id. Respondent amended her complaint to include a violation of the Family and Medical Leave Act of 1993, 29 U.S.C. § 2601 et seq. See Williams, 122 S. Ct. at 687.

<sup>105.</sup> Williams, 122 S. Ct. at 687.

and wrongful termination claims.<sup>106</sup> The Supreme Court granted certiorari "to consider the proper standard for assessing whether an individual is substantially limited in performing manual tasks."<sup>107</sup>

The Court began its analysis by stating that the ADA requires private employers to provide "reasonable accommodations" to the known physical or mental limitations of an otherwise qualified individual with a disability who is an applicant or employee, unless such covered entity can demonstrate that accommodation would impose an undue hardship" and by reciting the ADA definition for disability. 108 The Court noted that the Equal Employment Opportunity Commission (EEOC) created its own definitions for "substantial limitation" and "major life activity."109 The Court, after parsing out the meanings of each word in the disability definition, focused on "substantial," stating that it "clearly precludes impairments in only a minor way with tasks performance of manual from qualifying disabilities."110 The Court went on to interpret the phrase "major life activities" as those which "are of central importance to daily life."111 In order for manual tasks to qualify as major life activities they must "be central to daily life.112

After studying the disability definition, the Court stated that all terms should be subjected to strict interpretation so as "to create a demanding standard for qualifying as disabled" under the ADA. 113 The Court surmised that Congress must not have intended too broad a meaning so as to avoid an untenable number

<sup>106.</sup> Id. at 687-88.

<sup>107.</sup> Id. at 689.

<sup>108.</sup> Id. (citing 42 U.S.C. §§ 12112(b)(5)(A), 12102(2) (2000)). Additionally, the Court referred to the Rehabilitation Act of 1973, 29 U.S.C. § 706(8)(B) (1988), and previous decisions, including Bragdon for appropriate statutory construction, and the Sutton trilogy for regulatory authority to interpret the term "disability." Id. at 689-90.

<sup>109.</sup> Id. at 690 (citing 29 C.F.R. § 1630.2(j) (2001)). Under the EEOC regulations, "substantially limit[ed]" means "unable to perform a major life activity that the average person in the general population can perform"; or "[s]ignificantly restricted as to the condition, manner or duration under which an individual can perform a particular major life activity as compared to the condition, manner or duration under which the average person in the general population can perform that same major life activity." Id.

<sup>110.</sup> Id. at 691.

<sup>111.</sup> *Id*.

<sup>112.</sup> Id.

<sup>113.</sup> Id.

of Americans qualifying under the Act. 114 The Court concluded that an individual who is substantially limited in manual tasks must be able to demonstrate how he or she is prevented or severely restricted from performing activities central to daily life. 115 Further, "the impairment's impact must also be permanent or long-term."116 Medical evidence in the form of a diagnosis is not enough to prove one's case: an "individualized assessment" is critical because symptoms differ from person to person. 117 Finally, the Court determined that the Act and previous decisions did not indicate that the impairment should only be analyzed in the context of workplace activities. 118 The ADA applies to many venues aside from employment, demonstrating a broad reach (but still a narrow definition of disability), and restrictions on manual tasks specific to the workplace are not sufficient to show substantial limitation under the ADA. 119 Williams' claim failed to meet the standards set forth by the Court. 120

### ii. Chevron U.S.A. Inc. v. Echazabal

The Williams decision set a stern, no-nonsense tone with regard to ADA cases. By the time the Court rendered its decision in Chevron U.S. Inc. v. Echazabal, its move toward strict

When it enacted the ADA in 1990, Congress found that "some 43,000,000 Americans have one or more physical or mental disabilities." If Congress intended everyone with a physical impairment that precluded the performance of some isolated, unimportant, or particularly difficult manual task to qualify as disabled, the number of disabled Americans would surely have been much higher. Cf. Sutton v. United Air Lines, Inc., 527 U.S. at 487 (finding that because more than 100 million people need corrective lenses to see properly, "[h]ad Congress intended to include all persons with corrected physical limitations among those covered by the Act, it undoubtedly would have cited a much higher number than 43 million disabled persons in the findings").

Id. (citations omitted).

Carpal tunnel syndrome, one of the respondent's impairments, is just such a condition. While cases of severe carpal tunnel syndrome are characterized by muscle atrophy and extreme sensory deficits, mild cases generally do not have either of these effects and create only intermittent symptoms of numbness and tingling. Studies have further shown that, even without surgical treatment, one quarter of carpel tunnel cases resolve in one month, but in 22 percent of the cases, symptoms last for eight years or longer.

Id. at 692 (citations omitted).

<sup>114.</sup> Id.

<sup>115.</sup> Id.

<sup>116.</sup> Id.

<sup>117.</sup> Id. at 691-92.

<sup>118.</sup> Id. at 693.

<sup>119.</sup> Id.

<sup>120.</sup> Id. at 694.

interpretation, and away from a more liberal legislative intent, was complete.<sup>121</sup>

Mario Echazabal began working for independent contractors at an oil refinery owned by Chevron in 1972.122 He applied for a job with Chevron on two occasions and was informed that he had to pass a company physical examination before hiring. 123 Both exams revealed liver abnormality or damage and Echazabal was eventually diagnosed with Hepatitis C.124 Chevron's doctors contended that Echazabal's medical condition would exacerbated by continued exposure to the toxins present in the refinery. 125 Echazabal was denied a job on each occasion. 126 Further, Chevron requested that the independent contractor reassign Echazabal to jobs either free of toxic exposure or outside the refinery altogether. 127 The contractor laid off Echazabal in 1996. 128 Echazabal filed suit claiming that Chevron violated the ADA in refusing to hire him or allow him to work in the refinery because of his Hepatitis C diagnosis. 129 Chevron countered that the EEOC permitted the direct threat defense, stating that Echazabal's disability presented a direct threat to his health on the job. 130 The District Court granted Chevron's motion for summary judgment, and the Ninth Circuit reversed. 131 Supreme Court granted certiorari because the Ninth Circuit decision conflicted with two other decisions in the Eleventh and Seventh Circuits. 132

The court began its analysis with the statement that the ADA prohibits "discrimina[tion] against a qualified individual with a disability because of the disability ... in regard to" several

<sup>121. 122</sup> S. Ct. 2045, 2050-51 (2002).

<sup>122.</sup> Id. at 2047-48.

<sup>123.</sup> Id. at 2048.

<sup>124.</sup> Id.

<sup>125.</sup> Id.

<sup>126.</sup> Id.

<sup>127.</sup> Id.

<sup>128.</sup> Id.

<sup>129.</sup> Id.

<sup>130.</sup> Id. (citing 29 C.F.R. § 1630.15(b)(2) (2001)). See also Bragdon v. Abbott, 524 U.S. 624, 648 (1998) (holding that petitioner could refuse to treat respondent if respondent's infectious condition posed a direct threat to the safety or health of others)

<sup>131.</sup> See Echazabal v. Cheveron U.S.A. Inc., 226 F.3d 1063, 1072 (9th Cir. 2000). The parties submitted briefs to the Ninth Circuit on the question of direct threat defense. Id. at 1066 n.3.

<sup>132.</sup> Echazabal, 122 S. Ct. at 2048 (citing Moses v. American Nonwovens, Inc., 97 F.3d 446, 447 (1996) and Koshinski v. Decatur Foundry, Inc., 177 F.3d 599, 603 (1999)).

employer actions, including hiring.<sup>133</sup> Qualification standards that "screen out or tend to screen out an individual with a disability" are discriminatory.<sup>134</sup> The standard may also include "a requirement that an individual shall not pose a direct threat to the health or safety of other individuals in the workplace"<sup>135</sup> if the individual cannot safely perform the job with accommodation.<sup>136</sup> The EEOC expands the definition, allowing the employer to screen for risks to third parties and to the worker as well.<sup>137</sup>

Chevron claimed that the refinery job posed a direct threat to Echazabal's health and that the EEOC regulation precluded the ADA. 138 The Court sided with Chevron, stating that Congress intended the "harm-to-others provision as an example of legitimate qualifications that are 'job-related and consistent with business necessity."139 The Court further stated that these "are spacious defensive categories, which seem to give an agency (or in the absence of agency action, a court) a good deal of discretion in setting the limits of permissible qualification standards."140 Also, the ADA itself does not expressly exclude "extrastatutory" interpretation. 141 The Court concluded that the omission could not reasonably have indicated Congressional intent to consider only the health of others in the workplace and not that of that of the employee. 142 Chevron could rely on the EEOC standard "so long as it makes sense of the statutory defense for qualifications standards that are 'job-related and consistent with business necessity."143 The Court viewed Chevron's reasons as legitimate, including the avoidance of "time lost to sickness, excessive

<sup>133.</sup> Id. (citing 42 U.S.C. § 12112(a) (2001)).

<sup>134.</sup> Id. at 2048-49 (citing 42 U.S.C. § 12112(b)(6)). However, the ADA provides an affirmative defense for use of a qualification standard if the standard is "shown to be job-related for the position in question and ... consistent with business necessity. Id. at 2049 (citing 42 U.S.C. § 12113(b)).

<sup>135.</sup> Id. (citing 42 U.S.C. § 12113(b)).

<sup>136.</sup> Id. (citing 42 U.S.C. § 12113(a)).

<sup>137.</sup> Id. (citing 29 C.F.R. § 1630.15(b)(2) (2001)). "The term 'qualification standard' may include a requirement that an individual shall not pose a direct threat to the health or safety of the individual or others in the workplace." 29 C.F.R. § 1630.15(b)(2).

<sup>138.</sup> Echazabal, 122 S. Ct. at 2049. Chevron argued that "nothing in the statute unambiguously precludes such a defense, while the regulation was adopted under authority explicitly delegated by Congress, 42 U.S.C. § 12116, and after notice-and-comment rulemaking." Id.

<sup>139.</sup> Id. at 2050.

<sup>140.</sup> Id.

<sup>141.</sup> Id.

<sup>142.</sup> Id.

<sup>143.</sup> Id. at 2052 (quoting 42 U.S.C. § 12113(a) (2001)).

turnover from medical retirement or death, litigation under state tort law, and the risk of violating the Occupational Safety and Health Act of 1970."<sup>144</sup>

The Court noted that the EEOC definition was not an example of "the kind of workplace paternalism the ADA was meant to outlaw" because the standard was not aimed at whole classes of disabled people who were denied work on the basis of "untested and pretextual stereotypes." By requiring a specific inquiry, the EEOC provided an opportunity for a detailed exploration of potential harms an employee might face, fulfilling the requirements of the direct threat defense. 147

# C. HIV Disease Under the New ADA Interpretations

The Williams and Echazabal decisions have engendered much speculation and trepidation about the future of the ADA. Maryland Representative Steny H. Hoyer, one of the early shapers of the ADA, believes the Court is taking too rigid an approach. The legislation was intended to be broadly interpreted so that it would apply "not only to people who had genuine trouble functioning normally but [to] people whose employers might wrongly perceive them as being substantially impaired." Others believe the Court, through its conservative approach, may be favoring employers and leaving employees in the difficult position of not being considered disabled until they are too disabled to actually work, a result completely contrary to the ADA's purpose of making American society more accessible to people with disabilities. 150

<sup>144.</sup> Echazabal, 122 S. Ct. at 2052.

<sup>145.</sup> Id.

<sup>146.</sup> Id.

<sup>147.</sup> Id. at 2052-53.

<sup>148.</sup> Smith, supra note 55, at 50, n.40.

<sup>149.</sup> Id. at 50 (quoting Maryland. Representative Steny H. Hoyer).

<sup>150.</sup> See id. The Court "is trying to conform the ADA to a model of civil rights legislation [by] protecting a defined minority group from outright discrimination without inflicting undue harm on others." Id. (quoting Mark C. Rahdert, law professor at Temple University in Philadelphia). According to the American Bar Association (ABA) Commission on Mental and Physical Disability Law, in 2001 employers prevailed in 95.7 percent of the federal court cases that reached the merits of employee claims. Smith, supra note 55, at 50.

The ADA has been condemned for the difficulty employees have in pursuing claims. It is said that fewer than 10 percent of all claims are successful under the act. The meager track record stems from the "catch-22" aspect of the law. It requires that an employee have significant "impairment" of normal life activities in order to be qualified for coverage under the law, yet also dictates that he or she be able to perform "the essential functions" of the job in order to be protected under the statute.

The recent ADA decisions will certainly inspire discourse about treatment of HIV disease under the Act. The Sutton trilogy is troubling because one could argue that individuals with HIV disease can manage with proper drug therapies, thereby mitigating the disability and potentially undermining the Bragdon Williams could prove helpful because its essential holding requires that the impairment suffered by an employee must extend beyond the limitations of workplace duties. 152 While some may argue quite persuasively that carpal tunnel syndrome does extend into all aspects of life, there can be no denying that HIV disease is always present, even when an individual is asymptomatic. 153 However, it is more likely that the Williams decision will prove burdensome because the new emphasis on individual evaluation will require greater reliance on medical evidence, analysis of potential mitigating factors, the severity of the alleged impairments, and impact of the disability on daily life.154 Thorough research will be critical to the success of an ADA case. 155 There is voluminous medical evidence about HIV disease Although it affects everyone differently, the one available. common factor of HIV disease is lack of a cure. 156 Asymptomatic individuals are still experiencing, on a cellular level, significant changes because of the virus. 157 If litigants want to overcome the Williams burdens, they will have to prove that these changes are significant, ongoing, and unique. Litigation, therefore, could be extensive and expensive because of the necessary reliance on expert medical evidence and testimony.

Echazabal presents the biggest concern for individuals with HIV disease. The decision gives employers considerable power in deciding when working conditions pose a direct threat to the employee. Medical information manipulated in such a manner

Thus, the employee needs to be quite afflicted in order to be qualified, but the affliction must not be so great that it impedes the employee's work abilities. Consequently only a small number of employees are able to prevail under the statute and its state counterparts.

Marshall H. Tanick, Privacy of Medical Records in Minnesota: Hippocrates or Hyprocrisy?, The Hennepin Lawyer, May 2001, 10, 25.

<sup>151.</sup> Bragdon v. Abbott, 524 U.S. 624 (1998).

<sup>152.</sup> Toyota Motor Mfg., Ky., Inc. v. Williams, 122 S. Ct. 681, 681 (2002).

<sup>153.</sup> See Bragdon, 524 U.S. at 637 (concluding that even during an asymptomatic phase the virus still actively attacks white blood cells and lymph nodes).

<sup>154.</sup> Smith, supra note 55, at 51.

<sup>155.</sup> Id.

<sup>156.</sup> Bragdon, 524 U.S. at 637.

<sup>157.</sup> Id.

<sup>158.</sup> Chevron U.S.A. Inc. v. Echazabal, 122 S. Ct. 2045, 2049-53 (2002).

as to support an employer's belief could become a pretextual tool for discrimination. According to Ronda Goldfein, Executive Director of the AIDS Law Project of Pennsylvania, "all you need is some bad science to say there's a threat to the person, and you can essentially tell them, 'you don't have enough sense to protect yourself, so we're going to do it for you." Individuals with HIV disease have reason to distrust such a paternalistic scenario because similar arguments have already been used to deny services and opportunities that HIV-negative persons would automatically expect to receive, including organ transplants, plastic surgery, and pregnancy. Health care workers with HIV could be denied employment because of possible exposure to infections, as could teachers who spend hours a day with children carrying a host of contagions, or police officers and firefighters who experience high stress and physical demands on the job. 161

Taken to the extreme, *Echazabal* gives an employer license to place an HIV-positive employee in the least demanding dead-end position, rationalizing it as an "accommodation." The potential for discrimination, even by a well-intentioned employer, has been raised by the *Echazabal* decision. The decision creates a disincentive for employees with HIV disease to disclose their health status to employers or submit to qualifying physical exams for fear of triggering a chain of events similar to that experienced by Mario Echazabal. This distrust could keep many qualified individuals with HIV disease from pursuing work. Few will have the resources to actually gather all of the extensive documentation available, and now necessary, to mount a successful ADA claim if discrimination occurs. The HIV community is correct in viewing this ruling with considerable skepticism. 166

<sup>159.</sup> Adams, supra note 3, at 19.

<sup>160.</sup> Id

<sup>&</sup>quot;People with HIV have been turned away for years when they needed liver transplants under the argument that their compromised immune system makes it not likely for them to survive. They've been denied cosmetic surgery under that claims that it wouldn't be good for them. HIV-positive women are discouraged from becoming pregnant. There's a whole range of things that HIV-positive people are regularly denied because it's supposed to be for their own good."

Id. (quoting Catherine Hanssens, Director of Lambda Legal Defense and Education Fund's AIDS Project).

<sup>161.</sup> Adams, supra note 3, at 19.

<sup>162.</sup> Id. at 19-20.

<sup>163.</sup> Id.

<sup>164.</sup> Id. at 15-20.

<sup>165.</sup> Id. See also supra notes 3-11 (noting the many consequences of disclosure).

<sup>166.</sup> See, e.g., Adams, supra note 3, at 19 (noting the thin divide between actual

# III. Emerging Privacy Policies and Their Impact on HIV Disease

# A. HIV and the Workplace: Employee Expectations of Accommodation and Privacy

As the recent Supreme Court cases indicate, employment presents one of the most complicated contexts for accommodating individuals with disabilities. Employees with HIV disease encounter many obstacles in the workplace. Therefore, advocates need to pay particular attention to the nuances of disclosure, confidentiality, medical records protection, and accommodation in employment settings when handling HIV-related claims. The CDC has estimated that every United States company will, at some point, have at least one employee with HIV disease on the payroll. Yet many problems arise because employers are often ill-prepared when it comes to protecting the privacy rights and accommodating the needs of employees with HIV disease. 169

Privacy is a primary concern for HIV-positive employees. The problems of stigma and social ostracism associated with HIV disease are as compelling in the workplace as any other setting. <sup>170</sup> Further, confusion abounds regarding the direct threat defense under the ADA, and courts are constantly faced with the problem of balancing employee rights with employer interests. <sup>171</sup> Although

concern for an employee's well-being and discrimination).

<sup>167.</sup> See supra note 88 and accompanying text.

<sup>168.</sup> Bless S. Young & Kimberly R. Wells, Managing AIDS in the Workplace, 41 PRAC. LAW., Apr. 1995, 41, 42. The information referenced in this section was compiled by Heather C. Sawyer, Senior Staff Attorney, LAMBDA Legal Defense (http://www.lambdalegal.org (last visited Jan. 17, 2003)), and Lynn Mickelson, for a presentation at the Hennepin County Bar Association entitled Reasonable Accommodation and Privacy Concerns for Employees with HIV and AIDS on Feb. 22, 2002.

<sup>169.</sup> Young & Wells, *supra* note 168, at 42. Most AIDS-related problems in the workplace arise because many employers are unaware of how to deal with AIDS. *Id.* They are unaware of legal issues and how that impacts on medical and social security benefits. *Id.* They are uninformed about the medical aspects of this issue. *Id.* 

<sup>170.</sup> Greenfield, *supra* note 4, at 278-79. "Disclosure of an employee's AIDS status will usually result in emotional harm to the employee and may also result in actual or threatened physical harm. This is due largely to the fact that stereotypes continue to exist, despite the abundance of AIDS-related information available." *Id.* at 281.

<sup>171.</sup> See, e.g., Toyota Motor Manufacturing, Kentucky, Inc. v. Williams, 122 S. Ct. 681, 694 (2002) (finding employee's medical condition did not meet ADA requirements); Chevron, U.S.A., Inc. v. Echazabal, 122 S. Ct. 2045, 2045-46 (2002) (holding that an employer can make decisions about an employee's ability to do job based on disability and job requirements during the hiring process). See also

substantial medical evidence shows that HIV disease is not readily transmitted in workplace settings, employers remain concerned about exposure as well as the perception of the HIV-positive employee by other employees, customers or clients.<sup>172</sup> Such concern can easily turn into discriminatory action, especially if the HIV-positive employee is fired, demoted, forced to resign, harassed, or not reasonably accommodated.<sup>173</sup>

An employee's voluntary disclosure of health status usually accompanies a request for accommodation. Many persons with HIV disease suffer disruptive side effects from medications. They must also adhere to regimented diets and mealtimes to

Cavico, supra note 13, at 1345:

The employee's right to privacy, however, is a relative right. It requires a balance between the contending interests of the employee's personal privacy expectations and the employer's traditional interests in quality, performance and productivity. Courts customarily balance the conflicting interests of employers and employees through the common law of torts.

Id. In Cronan v. New England Telephone, Co., 41 Fair Empl. Prac. Cas. (BNA) 1273, 1274 (Mass. Super. Ct. Sept. 16, 1986), a supervisor published an employee's health status to other employees. Id. The employee received many threatening phone calls and letters and did not return to work because he feared for his life. Some of his coworkers threatened to lynch him. Id. The case settled out of court, presumably because the employer could not show how publication of the employee's health information could have furthered any legitimate business purpose. Greenfield, supra note 3, at 295. The employer's motion to dismiss was denied by the court. Cronan, 41 Fair Empl. Prac. Cas. at 1279.

172. See, e.g., Laura Pincus, The Americans with Disabilities Act: Employers New Responsibilities to HIV-Positive Employees, 21 HOFSTRA L. REV. 561, 562 (1993) (noting that despite extensive evidence showing that in most cases HIV-positive employees are able to perform at the same level as other employees and without risk of contagion, employers still harbor concerns about whether their business will be adversely affected by an employee's HIV-positive status).

173. Young & Wells, supra note 168, at 52. Under the ADA, discrimination is defined to include an employer's failure to make "reasonable accommodations to the known physical or mental limitations of an otherwise qualified individual with a disability, who is an applicant or employee, unless such covered entity can demonstrate that the accommodations would impose an undue hardship on the operation of the business of such covered entity." 42 U.S.C. § 12112(b)(5)(Å) (2001). Examples of reasonable accommodation in the statute include "job restructuring, part-time or modified work schedules, [and / or] reassignment to a vacant position." 42 U.S.C. § 12111(9). See also 29 C.F.R. § 1630.2(o) (2002) (providing a nonexhaustive list of potential reasonable accommodations). The Appendix to Part 1630 - Interpretive Guidance on Title I of the ADA - also includes use of accrued paid leave or allowing additional unpaid leave (note that there may be some overlap with the employer's obligation under the Family and Medical Leave Act, which provides up to 12 weeks unpaid leave if certain criteria are met). 29 C.F.R. The appendix explains that job restructuring only requires restructuring of marginal job functions - an employer is not required to reallocate essential job functions, which are those functions the employee would have to perform, with or without reasonable accommodation, to be considered qualified. Id. 174. See Webcast, supra note 3.

satisfy rigorous medication schedules.<sup>175</sup> Impairments that are characteristic manifestations of an underlying disability are considered part of the underlying disability and therefore must be accommodated.<sup>176</sup> Accommodations for employees with HIV can range from flexible break time; relocation of the work area closer to a restroom; flexible start and end times; light duty, reassignment to a different, equivalent position; and intermittent leave.<sup>177</sup>

In *Prilliman v. United Air Lines, Inc.*, <sup>178</sup> a group of HIV-positive airline pilots alleged that the employer had a duty to help them find other positions with the airline. <sup>179</sup> The court held that an employer who knows of a disability has an affirmative duty to inform the employee of other suitable job opportunities and to determine whether the employee is interested in and qualified for those positions. <sup>180</sup> This obligation exists so long as no undue hardship is placed on the employer or if the employer has a similar policy for other (non-disabled) employees. <sup>181</sup>

An employer must accommodate the "known physical or mental limitations" of an employee. 182 Some courts have interpreted this to require employees to request help or assistance in accommodating his or her disability, but some have required the employer to share the burden as well. 183 The employee need not,

<sup>175.</sup> See HIV Education Prison Project (HEPP), HIV 101: Summary of Antiretroviral Agents, Dosing and Administration Recommendations, available at http://www.thebody.com/hivatis/pdfs/adult\_guidelines.pdf (last visited Feb. 8, 2003). Schedules vary depending on an individual's type and combination of medications. Id at 45-50. Each medication has different requirements. Id. For example, the protease inhibitor, Indinavir (Crixivan), must be taken either one hour before or two hours after a meal, while another protease inhibitor Amprenavir (Agenevase) can be taken with or without food but high fat meals should be avoided. Id. The Non-Nucleoside Reverse Transcriptase Inhibitor Efavirenz (Sustiva) is also affected by high fat meals. Id. The Nucleoside Reverse Transcriptase Inhibitor Abacavir (ABC, Ziagen) is affected by alcohol. Id.

<sup>176.</sup> See, e.g., Vande Zande v. Wis. Dep't of Admin., 44 F.3d 538, 544 (7th Cir. 1995) (holding that paraplegic employee's pressure ulcers are part of her disability and therefore part of what employer must accommodate).

<sup>177.</sup> See supra note 176 and accompanying text.

<sup>178. 53</sup> Cal. App. 4th 935 (Cal. App. 2 Dist. 1997).

<sup>179.</sup> Id at 944.

<sup>180.</sup> Id at 947-48.

<sup>181.</sup> Id. The ADA requires reasonable accommodation unless an employer can establish that the accommodation would impose an "undue hardship." 42 U.S.C. § 12112(b)(5)(A) (2001).

<sup>182. 42</sup> U.S.C. § 12112(b)(5)(A).

<sup>183.</sup> See, e.g., Phelps v. Field Real Estate Co., 991 F.2d 645, 649-50 (10th Cir. 1993) (recognizing defendant employer's lack of knowledge of employee's HIV infection as a successful defense in employment discrimination action). See also Reed v. LePage Bakeries, Inc., 244 F.3d 254, 260-62 (1st Cir. 2001) (holding

however, invoke the exact statutory terms to satisfy this burden; plain English is sufficient. 184 The EEOC requires an "interactive process" for the accommodation request. 185 The "interactive process" is used "[to] identify the precise limitations resulting from the disability and potential reasonable accommodations that could overcome those limitations." 186 The EEOC guidance identifies four steps: (1) analyze the job and determine essential functions; (2) consult with the employee to determine precise job-related and how to overcome those with accommodation; (3) consult with the employee to identify potential accommodations and their effectiveness: (4) consider the employee's preference (although employer is not bound by the employee's choice) and select the accommodation most appropriate for the employee and employer. 187 Even though the EEOC places the burden of compliance primarily on the employer, courts have found that employees share this burden and must engage in open communication with the employer. 188

Reasonable accommodation has been an issue in cases involving health care workers terminated after their employer learns of their diagnosis. 189 In many cases, employers have argued

employee's request must be "sufficiently direct and specific" and provide notice of specific accommodation).

<sup>184.</sup> See, e.g., Miller v. Illinois Dep't of Corr., 107 F.3d 483, 486-87 (7th Cir. 1997) (holding an injured employee's statement that "I want to keep working for you – do you have any suggestions?" was sufficient to trigger employer's duty to accommodate).

<sup>185. 29</sup> C.F.R. § 1630.2(o)(3) (2002).

<sup>186.</sup> Id.

<sup>187.</sup> See 29 C.F.R. app. pt. 1630.

<sup>188.</sup> See Vawser v. Fred Meyer, Inc., No. 00-36081, 2001 WL 1174084, at \*2 (9th Cir. Oct. 4, 2001) (finding that employer was not liable for failure to accommodate employee with HIV where employee's doctor failed to respond to employer's request for clarification of requested accommodation). The Eighth Circuit set out a fourpart test for plaintiffs to prove that an employer failed to engage in the interactive process in good faith:

<sup>(1)</sup> the employer knew about the employee's disability; (2) the employee requested accommodations or assistance for his or her disability; (3) the employer did not make a good faith effort to assist the employee in seeking accommodations; and (4) the employee could have been reasonably accommodated but for the employer's lack of good faith.

Fjellestad v. Pizza Hut of Am., Inc., 188 F.3d 944, 952 (8th Cir. 1999).

<sup>189.</sup> See, e.g., Bradley v. Univ. of Tex., 3 F.3d 922, 924-25 (5th Cir. 1993) (holding that HIV-positive surgical technician could not perform essential function of being in operative field); Estate of Mauro v. Borgess Med. Ctr., 137 F.3d 398, 403-07 (6th Cir. 1998) (determining that employer was not required to accommodate HIV-positive operating room technician by providing assistance for team where he was required to place hand in or about incisions to help doctor view); Waddell v. Valley Forge Dental Assoc., 276 F.3d 1275, 1283-84 (11th Cir. 2001) (finding that a dental hygienist posed a "significant risk" to patients "even though the risk [of

that health care workers with HIV disease pose a direct threat to themselves and others, and that no reasonable accommodation can reduce this threat to a level that would enable HIV-positive employees to perform their jobs. 190 Employers have been successful in convincing courts that any accommodation would be unreasonable because employers would have to hire "full-time" assistants to perform the essential functions of HIV-positive employees' jobs. 191

Minnesota laws<sup>192</sup> and federal laws<sup>193</sup> require all medical records be kept confidential and separate from other personnel records.<sup>194</sup> The Minnesota Human Rights Act (MHRA)<sup>195</sup> and the

transmission] is small and such an event never before has occurred"). But see Parks v. Female Health Care Assoc., 96-C7133, 1997 WL 285870, at \*5 (N.D. Ill. May 23, 1997) (rejecting an employer-hospital's argument that, as a matter of law, an HIV-positive surgeon or surgical technician is a direct threat and not otherwise qualified as a factual inquiry could prove "reasonable accommodations" would enable the employee "to carry out her essential job functions").

- 190. See supra note 189.
- 191. See supra note 189 and accompanying text.
- 192. MINN. STAT. § 363.02. subd. 1(9)(i)(d) (2002).
- 193. 42 U.S.C. § 12112(d)(3)-(4) (2002); 29 C.F.R. § 1630.14(c)(1) (2002).

194. See MINN. STAT. § 144.335, subd. 3a(a) (2002). The Health Records and Reports Act applies to anyone who has received health care services. Id. It prohibits the divulging of health records "without a signed and dated consent from the patient or the patient's legally authorized representative." Id. Under the ADA, information regarding medical condition or history must be "collected and maintained on separate forms and in separate medical files and ... treated as a confidential medical record." 42 U.S.C. § 12112(d)(3)(B). Exceptions are made in limited circumstances, including for restrictions on work, accommodations or in emergencies when first aid personnel require information. Id.

The common law right of privacy, recently recognized in Minnesota, has not had an impact on medical record confidentiality decisions. See Lake v. Wal-Mart Stores, Inc., 582 N.W.2d 231, 232-36 (Minn. 1998). The Minnesota Supreme Court held that a woman's photograph of two nude friends in shower developed at Wal-Mart and distributed to members of the community without consent was an actionable tort. Id. at 235. The court stated:

Today we join the majority of jurisdictions and recognize the tort of invasion of privacy. The right of privacy is an integral part of our humanity; one has a public persona, exposed and active, and a private persona, guarded and preserved. The heart of our liberty is choosing which parts of our lives shall become public, and which parts we shall hold close.

Id. The court declared "[an] [i]ntrusion upon seclusion occurs when one intentionally intrudes, physically or otherwise, upon the solitude or seclusion of another or his private affairs or concerns ... if the intrusion would be highly offensive to a reasonable person." Id. (quoting RESTATEMENT (SECOND) OF TORTS § 652B (1977)). Highly offensive conduct cannot be merely "callous" or "petty" and must be considered in the context of the entire course of conduct. This is a fact-specific analysis. See Bauer v. Ford Motor Credit Co., 140 F.Supp.2d 1019, 1024-25 (D. Minn. 2001). See also Bauer v. Ford Motor Credit Co., 149 F.Supp.2d 1106, 1111 (D. Minn. 2001) (holding credit company's repossession efforts despite plaintiff's statement that he was not the correct target of the repossession were

ADA cover medical information obtained in the course of a post-offer/pre-employment medical examination, inquiries into the ability of employees to perform job-related functions, and examinations that are job-related and consistent with business necessity. The ADA's confidentiality provision is broad, covering both disabled and non-disabled employees. For example, supervisors and managers may receive medical information only in cases where necessary work restrictions or

"offensive to a reasonable person" and amounted to an intrusion upon the plaintiffs right to seclusion); C.L.D. v. Wal-Mart Stores, Inc., 79 F.Supp.2d 1080, 1087-88 (D. Minn. 1999) (deciding against an employee who alleged her pregnancy and abortion were improperly disclosed by a supervisor to one of the employee's co-workers because the publication of the information was not sufficiently widespread); Walker v. Minnesota Mining & Mfg., Co., 2000 WL 520254, at \*1, \*6-8 (Minn. Ct. App. May 2, 2000) (holding even though caseworker's behavior was "petty and totally unworthy of a professional," it was not a sufficient intrusion into the employee's privacy where an injured employee sued his employer because the worker's compensation case manager obtained his medical records, shared the information with the employer and accompanied the employee to medical appointments). See generally Neal T. Buethe, Things to Come in Minnesota: Ways in Which the Privacy Tort Has Affected Employment Law in Other States, 23 HAMLINE L. REV. 38 (1999); Nicholas D. Bieter, Minnesota's Right of Privacy Torts: Expanding Common Law Beyond Its Reasonable Constitutional Bounds in Lake v. Wal-Mart Stores, Inc., 20 HAMLINE J. PUB. L. & POLY 177 (1999); Joseph Schmitt, Courts and Employers Struggle Over Privacy Issues Since Lake, THE HENNEPIN LAWYER, Feb. 2002, at 10; Marshall H. Tanick, Reflections on Lake: The State of the Right to Privacy in Minnesota, Bench & Bar, Oct. 2000, at 41; Karin Peterson & Mary Setter, Minnesota Recognizes the Common Law Tort of Invasion of Privacy, THE HENNEPIN LAWYER, Dec. 1998, at 4.

195. MINN. STAT. ch. 363 (2002).

196. See id. See also 42 U.S.C. § 12112(d)(3)(B) (2002) (requiring that medical information must kept in separate files). See generally Schmitt, supra note 194, at 10-11 (discussing the laws governing medical information).

197. See Cossette v. Minnesota Power & Light, 188 F.3d 964, 969 (8th Cir. 1999). In analyzing the ADA's medical record confidentiality provisions, the court stated:

The plain language of subsections (d)(3) and (d)(4) speaks of "employees" and "applicants" – suggesting that Cossette need not be disabled in order to recover. This language stands in stark contrast to the ADA's general prohibition of disability discrimination, which provides that employers shall not "discriminate against a qualified individual with a disability." 42 U.S.C. § 12112(a) (1994). Although subsection (d)(1) provides that subsection (a)'s general prohibition against discrimination shall include discrimination on the basis of medical examinations and inquiries, that provision is only one of several protections afforded by subsection (d), and it is only discrimination itself (and not illegal disclosure) that requires a showing of disability.

Id. (emphasis omitted). Some courts have found that medical information provided voluntarily by an employee, not in pursuit of accommodation, and not requested by the employer, is not protected by the ADA. In Rohan v. Networks Presentation LLC, 175 F.Supp.2d 806 (D. Md. 2001), the court held that an employee who provided a "voluntary medical history" when she discussed her disability with her managers was not protected because she did not provide the information as part of an "employee health program" at the work site. Id. at 814.

accommodations are required. 198

Cossette v. Minnesota Power & Light 199 is a recent example of a medical records case in which actual disability is not equated with the employee's right to confidentiality about medical history.<sup>200</sup> In Cossette, an employee with a back injury requiring lifting restrictions, sought a new job.<sup>201</sup> Her supervisor learned of the employee's job search and informed the prospective employer, without the employee's consent, about the employee's injury and work restrictions.<sup>202</sup> When the employee was turned down for the job because of the breach in confidentiality about her medical condition, she sued her employer under the ADA.203 The court determined that she was not disabled because her injury did not sufficiently impair her daily activities.<sup>204</sup> Nonetheless, the court held that the unauthorized disclosure of her medical information was a violation of the ADA.<sup>205</sup> Even though she was not disabled under the Act. 206 Cossette could still demonstrate that her employer's violation caused some sort of tangible injury 207 Summary judgment in favor of the employer was reversed, and the case was eventually settled in favor of the employee. 208

State and federal regulations, as well as developing case law, indicate that employees with HIV disease will face significant challenges in accommodation and breach of confidentiality cases.<sup>209</sup> Insurance is an additional consideration.<sup>210</sup> Many HIV-

<sup>198. 42</sup> U.S.C. § 12112(d)(3)(B). First aid and safety personnel may have access to the information during emergency situations and government officials may have access for purposes of compliance efforts. 42 U.S.C. § 12112(d)(3)(B)(i)-(iii).

<sup>199. 188</sup> F.3d 964.

<sup>200.</sup> Id. at 969.

<sup>201.</sup> Id. at 966-68.

<sup>202.</sup> Id. at 967-68.

<sup>203.</sup> Id. at 969-70.

<sup>204.</sup> Id. at 970-71.

<sup>205.</sup> Id. at 971.

<sup>206.</sup> See id. at 969-70 (citing Fredenburg v. Contra Costa County Dep't of Health Serv., 172 F.3d 1176, 1181-82 (9th Cir. 1999) and Griffin v. Steeltek, Inc., 160 F.3d, 591, 593-94 (10th Cir. 1998), and holding a "plaintiff need not be disabled to state a claim for the unauthorized gathering or disclosure of confidential medical information").

<sup>207.</sup> Id. at 970 (citing Griffin, 160 F.3d at 594-95, and Armstrong v. Turner Indus., Inc., 141 F.3d 554, 562 (5th Cir. 1998) (assuming without deciding that non-disabled plaintiff may proceed under subsection (d)(2), applicant must show "some cognizable injury in fact of which the violation is a legal and proximate cause for damages to arise from a single violation")).

<sup>208.</sup> Id. at 964.

<sup>209.</sup> See generally Greenfield, supra note 4, at 282-87 (highlighting a host of difficulties employees face in bringing breach of confidentiality suits).

<sup>210.</sup> See generally Joel L. Hodes, Corporate America's Response to the AIDS

positive employees have health insurance provided by the employer.<sup>211</sup> Some employers, however, in order to avoid rising costs, have placed limits or caps on existing health insurance benefits or excluded certain conditions from coverage.<sup>212</sup> Except for pre-existing conditions, universal limits or exclusions, and coverage limitations on treatments not exclusive to a particular disability, the EEOC has determined some of these disabilities-based measures are discriminatory.<sup>213</sup>

# B. Privacy and Discrimination Protection in the Public and Private Sectors

# i. Minnesota Government Data Practices Act: Public Protection

The remainder of this Article will summarize existing Minnesota privacy law and new federal privacy guidelines with the goal of proposing a state law that will provide additional protections to individuals with HIV disease in light of the stigma associated with the health condition.

Minnesota has been a trailblazer in state privacy protections. Its comprehensive data privacy law, now known as the Minnesota Government Data Practices Act (MGDPA), was the first of its kind in the United States.<sup>214</sup> The Legislature enacted the MGDPA in 1973, but the 1979 revisions created the "presumption that government data are public and are accessible by the public for both inspection and copying unless there is a federal law, a state statute, or a temporary classification of data that provides that

Crisis: What Price Glory?, 61 ALB. L. REV. 1091, 1092 (1998) (showing the large number of HIV infected persons in America's work force).

<sup>211.</sup> See, e.g., id. at 1092-94 (discussing the role corporate health care plays in providing for HIV-positive individuals).

<sup>212.</sup> See, e.g., Mason Tenders Dist. Council Welfare Fund v. Donaghey, No. 93-1154, 1993 WL 944580, at \*1-2 (S.D.N.Y. Nov. 19, 1996) (holding a union health plan excluding AIDS-related claims violated the ADA).

<sup>213.</sup> See 42 U.S.C. § 12112(a) (2002); 29 C.F.R. § 1630.4(f) (2002). See also Robert E. Stein, The Rights of Employees with AIDS: The Conflict Between the Need for Adequate Insurance Coverage and Individual Privacy in the Workplace, 10 St. John's J. Legal Comment. 557, 559 (1995) (discussing conditions that are or should be covered from discriminatory actions); Catherine Hanssens, Healthcare Insurance, AIDS and the ADA, 10 St. John's J. Legal Comment. 567, 568-71 (1995) (discussing prohibited employer actions that result in altering benefit schemes created by ERISA).

<sup>214.</sup> See Mike Mosedale, Data Man, CITY PAGES, Jan. 9, 2002, available at http://www.citypages.com/databank/23/110/article10061.asp. The MGDPA is codified under Chapter 13 of the Minnesota Statutes. See MINN. STAT. ch. 13 (2002).

certain data are not public."<sup>215</sup> The MGDPA protects the privacy of medical information collected by state agencies, political subdivisions, or statewide systems (i.e., the state welfare system).<sup>216</sup> Subjects may request copies of their MGDPA data.<sup>217</sup> Information can be released without consent subject to court order, emergency situation, or statutory obligation for mandatory reporting.<sup>218</sup> Persons harmed by unauthorized releases of publicly collected data are entitled to damages up to \$10,000 per violation, plus costs and attorneys fees.<sup>219</sup>

Use of information collected in the context of government practices is of great concern to persons with HIV disease. A recent family law case at Minnesota AIDS Project (MAP) involved a parenting time evaluation conducted by a county court services office.<sup>220</sup> Although the evaluator obtained a consent form from the client to verify her health condition, the client, as well as her attorney and the presiding judicial officer, were shocked to discover that the evaluator had gathered voluminous documents about the client's pregnancy with a child who was not even the subject of the family court case. From the beginning of his investigation, the evaluator had expressed inordinate interest in the fact that the client became pregnant after her HIV diagnosis. Although the client explained that many women, with proper medical care and specific medications, are able to give birth to children free of HIV disease.<sup>221</sup> the evaluator remained skeptical. The collected medical documents were irrelevant to the case and indicated that the evaluator, who had mentioned the term "child endangerment" in relation to the client's pregnancy, had a discriminatory motive. The file was available to the child's father, who had been abusive to the client in the past. The client and the child's father were no longer involved. Fortunately, he did not view the records. The judicial officer ordered that the records be

<sup>215.</sup> MINN. STAT. § 13.01, subd. 3.

<sup>216.</sup> MINN. STAT. § 13.02, subd. 12. See also Minnesota Medical Records Act, MINN. STAT. § 144.335 (2002).

<sup>217.</sup> MINN. STAT. §§ 13.03-.04.

<sup>218.</sup> MINN. STAT. §§ 13.07-.08, 13.43.

<sup>219.</sup> MINN. STAT § 13.08, subd. 1.

<sup>220.</sup> For reasons evident in the subject matter of this Article, the author wishes to keep details of cases which MAP has provided assistance confidential. For more information, please contact MAP Legal Services at (612) 341-2060.

<sup>221.</sup> See, e.g., Public Health Service Task Force, Recommendations for Use of Antiretroviral Drugs in Pregnant HIV-1-Infected Women for Maternal Health and Interventions to Reduce Perinatal HIV-1 Transmission in the United States 2 (Aug. 30, 2002), available at http://www.aidsinfo.nih.gov/guidelines/perinatal/Perinatal.pdf.

removed from the investigator's file and returned to the client, who was embarrassed by the many private details disclosed about her obstetric history and gynecological health. Complaints were made to the county court services office and chief family law judge, but it is unknown whether the evaluator experienced any consequences for his actions. The county did not accept an offer of a free training from MAP.

The actions of the court evaluator indicated an abuse of government authority and a failure to protect private information. Under the MGDPA, the responsible authority has a duty to "(1) establish procedures to assure all data on individuals is accurate, complete, and current for the purposes for which it was collected; and (2) establish appropriate security safeguards for all records containing data on individuals." The episode demonstrated that the county had not provided sufficient education about HIV and pregnancy to workers investigating family law cases, and failed to adequately protect the information collected. 223

As the case described above illustrates, the MGDPA provides important protections in the public context. Public trust cannot be maintained without such safeguards. Government has a duty, to use and protect personal information. If it fails in this duty then the public cannot cooperate with the government in activities designed to better the individual and society.

# ii. Title VII and the Minnesota Human Rights Act: Private Protection

As in the case of the MGDPA, Minnesota has been a leader in adopting human rights protections. The federal Civil Rights Act of 1964 was actually preceded by the MHRA, which was passed in 1955.<sup>224</sup> Today, employment discrimination cases in Minnesota are considered in the context of the MHRA, the ADA, and Title VII.<sup>225</sup> The MHRA also includes prohibitions on discrimination

<sup>222.</sup> MINN. STAT. § 13.05, subd. 5.

<sup>223.</sup> Education is important in the context of family law actions. Opposing parties, for instance, are quick to use HIV as evidence of poor moral character on the part of the positive parent and proffer this evidence as reason for denying custody or access based on the best interests of the child. Such arguments fail, for the most part, because under Minnesota law the disability of a parent or legal custodian is not "determinative of the custody of the child, unless the proposed custodial arrangement is not in the best interest of the child." MINN. STAT. § 518.17, subd. 1(a)(9) (2002). A parent's HIV status, in other words, would prove relevant only if the parent was so debilitated that he or she could not care for the child.

<sup>224.</sup> MINN. STAT. ch. 363, §§ 363.01-.20 (2002).

<sup>225.</sup> See 42 U.S.C. § 2000e-2(a)(1) (2002) (prohibiting discrimination in the terms

based on disability and sexual orientation.<sup>226</sup>

Title VII and the MHRA differ in many respects, which has led to some conflicts in application and practice.<sup>227</sup> Compared to the MHRA, the standard for establishing discrimination under Title VII is very rigorous.<sup>228</sup> Title VII litigants have to prove that the alleged discrimination was unwelcome, perpetuated because of protected status, and severe enough to affect the plaintiff's working conditions and create an abusive working environment.<sup>229</sup> Administrative remedies, such as filing a charge with the EEOC, must be exhausted before a Title VII claim can be filed in the court system.<sup>230</sup> MHRA claimants, on the other hand, may file suit in court and pursue charges of discrimination with the Department of Human Rights (DHR) after a showing of probable cause is made through a DHR investigation.<sup>231</sup> Further, Title VII narrowly defines liability: only employers, as defined by the statute, can be liable for discrimination.<sup>232</sup> Supervisors, however, are not considered employers.<sup>233</sup> The MHRA extends liability to any person who directly or indirectly attempts to "aid, abet, incite, compel, or coerce a person" to engage in unlawful discrimination as defined by the statute.<sup>234</sup> Under the MHRA, the employer is

and conditions of employment based on race, color religion, sex, or national origin). See also Sheila Engelmeier & Jonathan J. Hegre, The Deepening Divide: Minnesota and Federal Employment Laws, BENCH & BAR, Apr. 2001, at 21 (providing an overview of the evolving federal and state laws with a particular emphasis on changes at the federal level that affect the interplay between the two systems in employment cases).

<sup>226.</sup> MINN. STAT. § 363.01, subds. 13, 41a.

<sup>227.</sup> See Engelmeier & Hegre, supra note 225, at 22.

<sup>228.</sup> See id. at 21-24 (highlighting the growing divide between the ADA and the MHRA as courts are more strictly interpreting the ADA).

<sup>229.</sup> See Faragher v. City of Boca Raton, 524 U.S. 775, 786-90 (1998); Burlington Indus., Inc. v. Ellerth, 524 U.S. 742, 754 (1998) (discussing the elements which must be proven for a Title VII claim to be successful).

<sup>230.</sup> See 42 U.S.C. § 2000e-5 (2002) (governing enforcement provisions).

<sup>231.</sup> MINN. STAT. § 363.06, subd. 1. Claimants under the MHRA have one year from when the discriminatory act was committed to commence suit or file a charge with MHRA. MINN. STAT. § 363.06, subd. 3. Depending on how the suit is commenced, claimants under Title VII have either one hundred eighty to three hundred days to file a charge. 42 U.S.C. § 2000(e)-5(e)(1).

<sup>232.</sup> See 42 U.S.C. § 2000(e)-2(a). An employer is "a person engaged in an industry affecting commerce who has fifteen or more employees for each working day in each of twenty or more calendar weeks in the current or preceding calendar year, and any agent of such person." 42 U.S.C. § 2000(e)(b). The MHRA protects employees no matter the size of the employer. MINN. STAT. § 363.03, subd. 1(2); MINN. STAT. § 363.01, subd. 17.

<sup>233.</sup> See Bonomolo-Hagen v. Clay Central-Everly Cmty. Sch. Dist., 121 F.3d 446, 447 (8th Cir. 1997).

<sup>234.</sup> MINN. STAT. § 363.03, subd. 6.

also vicariously liable when it "knows or should know of the existence of the harassment and fails to take timely appropriate action." Finally, Title VII and the MHRA differ with respect to compensatory and punitive damages. Title VII caps awards in federal discrimination cases in accordance with the size of the employer's workforce. The MHRA, however, places no limit on compensatory damages but caps punitive damages. 237

Employment discrimination cases are common in the MAP legal program. For example, an employee at a fast-food chain reported a supervisor informing a co-worker, in the employee's presence and without his consent, about the employee's HIV status. The co-worker then told other employees and customers, creating a hostile working environment for the HIV-positive worker. In another case, an employee of an overnight delivery carrier was denied accommodation and subsequently harassed for disclosing his status. An assistant to housebound individuals lost work hours once she informed her employer of her medical condition. A security guard told his supervisor and was subsequently terminated on a false claim that he was sleeping on the job.

What separates HIV-related employment cases from other cases is the significance of disclosure. Often an employee with HIV disease need not tell anyone of his or her condition. Even accommodation requests can be based on a doctor's recommendation describing a chronic illness requiring certain work restrictions. Only certain jobs, usually in the health care

<sup>235.</sup> MINN. STAT. § 363.03, subd. 6(2). Courts have imputed liability to an employer in sexual harassment actions. See, e.g., Guiliani v. Stuart Corp., 512 N.W.2d 589, 595 (Minn. App. 1994) (noting the relationship between a manager and employer, and imputing liability on an agency theory); Kay v. Peter Motor Co., Inc., 483 N.W.2d 481, 484-85 (Minn. App. 1992) (finding liability when an employer should have known of the manager's conduct). But see Weaver v. Minnesota Valley Labs, Inc., 470 N.W.2d 131, 134-35 (Minn. App. 1991) (refusing to impute liability when an employer had specific procedures in place to report harassment and such procedures were not followed); Heaser v. Lerch, Bates & Assocs., 467 N.W.2d 833, 835 (Minn. App. 1991) (finding no imputed liability when the employer has implemented an objectionable behavior policy that includes a clear procedure for reporting harassment on the job).

<sup>236. 42</sup> U.S.C. § 1981a(b)(3) (2001).

<sup>237.</sup> MINN. STAT.  $\S$  363.071, subd. 2. Claimants can receive up to "three times the actual damages sustained" in compensatory damages and up to \$8,500 per incident in punitive damages. *Id.* 

<sup>238.</sup> See supra note 62 and accompanying text.

<sup>239.</sup> See supra text accompanying note 175. Accommodation requests involve disclosure of "precise limitations resulting from the disability," not disclosure of the precise nature of the illness.

field, require full disclosure.<sup>240</sup> A breach in confidentiality not only creates a potentially hostile work environment but also negatively affects the employee's health because of the associated stress.<sup>241</sup> Sharing information without consent, inquiring after a person's HIV status, or taking an unauthorized HIV test would be considered "highly offensive to a reasonable person" under the invasion of privacy law "because it would provide knowledge of the most vivid details of one's present health and in some cases allow inferences about one's intimate behavior."<sup>242</sup> The dangers associated with such knowledge require additional vigilance and caution in fashioning discrimination and privacy laws with respect to HIV disease.<sup>243</sup>

# iii. Proposed Medical Records Privacy Act Amendments: The Need for Expansive Policy in Minnesota

Many people are concerned about medical information privacy and wonder how effective protections designed to guard their health records really are.<sup>244</sup> In 1996, Congress passed the Health Insurance Portability and Accountability Act (HIPAA), a sweeping measure designed to improve access to health insurance by updating medical privacy protections for people who move from one job to another, are self-employed, or have pre-existing medical conditions.<sup>245</sup> HIPAA required the Clinton Administration to

<sup>240.</sup> Minn. Stat. § 214.19. subds. 1, 2 (2002) (requiring mandatory reporting of infectious disease for certain licensed health care workers).

<sup>241.</sup> See generally Dr. Jeffrey M. Leiphart, AIDS Survival Project: Survival News (Nov. 2000), at http://www.thebody.com/asp/nov00/stress\_hiv.html (noting that "[s]ustained stress erodes immune function and hastens the onset of AIDS").

<sup>242.</sup> Greenfield, supra note 3, at 291. See also Lake v. Wal-Mart Stores, Inc., 582 N.W.2d 231, 236 (Minn. 1998) (holding that a person's liberty interest includes choosing what personal information will be private or public). If inquiry is for purposes of support, there is likely no improper disclosure. Cf. McNemar v. Disney Store, Inc., 91 F.3d 610, 622 (3rd Cir. 1996) (finding that a district manager's approaching of an employee to determine whether rumors about the employee's health status were true was not an intrusion because it was a statement of support, he did not have to reply, and the conduct was not highly offensive to a reasonable person).

<sup>243.</sup> See supra note 242.

<sup>244. &</sup>quot;One in five American adults believes that a health care provider, insurance plan, government agency or employer has improperly disclosed personal medical information. Half of these people believe that it resulted in personal embarrassment or harm." Health Privacy Project, Health Privacy Polling Data 1 (Jan. 1999), available at http://www.healthprivacy.org/usr\_doc/PollingData901.pdf (citing a January 1999 survey conducted by Princeton Survey Research Associates).

<sup>245.</sup> Health Insurance Portability and Accountability Act, Pub. L. No. 104-191 (1996). The laws became effective April 14, 2001; most health plans and health care providers must be in compliance by April 2003. See Peter A. Winn, Confidentiality In Cyberspace: The HIPAA Privacy Rules and the Common Law, 33

adopt rules protecting the privacy of health information.<sup>246</sup> After an extensive notice period over which some 52,000 comments were submitted, the new rules were issued in December, 2000.<sup>247</sup> The Bush Administration re-opened the comment period for thirty days on February 28, 2001 in order to address concerns raised by health care companies.<sup>248</sup> The Health and Human Services Administration (HHS) under Secretary Tommy Thompson then proposed changes including the elimination of a prior consent requirement before health care providers use or disclose health care information.<sup>249</sup>

RUTGERS L.J. 617, 640-41 (2002). "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. Palmer & Mickelson, supra note 7, at 473. In fact, medical records were not as protected as credit reports or even video rental records." Id. See also Mary K. Martin, Some Things Old, Some Things New: The HIPAA Health Information Privacy Regulations, BENCH & BAR, May / June 2002, at 32 (providing an overview of HIPAA and Minnesota Medical Records Act).

246. See Winn, supra note 198, at 639-40.

247. Id. at 640.

248. See Robert Pear, Democrats Say Bush Revisions Ruin Medical Privacy Rules, N.Y. TIMES, Apr. 17, 2002, at A16.

249. U.S. Department of Health and Human Services, HHS Proposes Changes that Protect Privacy, Access to Care, HHS NEWS (Mar. 21, 2002), at http://www.hhs.gov/news/press/2002pres/20020321a.html [hereinafter HHS Fact Sheet].

This proposal to eliminate the consent requirement strikes at the very heart of the Privacy Rule and takes away a core privacy protection for consumers. The Privacy Rule's consent requirement is intended to bolster patient trust and confidence in providers and in health care organizations by respecting the patient's central role in making health care decisions. The Department's proposal ... will undermine trust in the health care system.

Health Privacy Project, Comments On Proposed Modifications to Federal Standards for Privacy of Individually Identifiable Health Information, Apr. 26, 2002, available at http://www.healthprivacy.org/usr\_doc/NPRM\_HPPComments.pdf [hereinafter Comments]. HHS claimed that the proposal "would promote access to care by removing the consent requirements that would potentially interfere with the efficient delivery of health care, while strengthening requirements for providers to notify patients about their privacy rights and practices." Supra, HHS Fact Sheet.

Another troubling proposal was a change undermining the ability of minors to seek confidential treatment without notification of their parents or guardians. *Id.* One favorable proposal included tighter provisions regulating the use of health care information for marketing purposes. *Id. See also* Health Privacy Project, *HHS Proposals Both Undermine and Enhance Privacy*, Mar. 21, 2002, available at http://www.healthprivacy.org/usr\_doc/press\_release.pdf.

The Clinton rules required doctors, hospitals, and other health care providers to obtain written consent from patients before using personal health information in treatment, reimbursement, health care operations, or administrative activities. 45 C.F.R. § 164.506 (2002). A "minimum necessary" standard on all disclosures by health care providers existed in the Clinton rules, making mandatory only disclosures to the individual and HHS for purposes of enforcement; HHS does preserve this standard. 45 C.F.R. §§ 164.502(b), 164.514(d). See also supra HHS Fact Sheet.

HHS also proposed an amendment to the definition of "protected health information."<sup>250</sup> It explicitly excluded "employment records," referred to in the preamble as "individually identifiable health information ... held by a covered entity in its role as employer."<sup>251</sup> According to the Health Privacy Project

[t]he plain language of the proposed text appears to move outside of the Privacy Rule any use or disclosure of employee's health plan records, as well as information shared with an employer's on-site clinic where that clinic is a covered provider under the current Privacy Rule. This is especially dangerous because of the legitimate concern people have that employers will use protected health information, including genetic information, inappropriately to make employment-related decisions (such as deciding which employees to promote or fire). 252

Further, the proposed HHS changes did not appear limited to covered entities but potentially included all employers.<sup>253</sup> The Health Privacy Project observed that "[t]he exclusion for 'employment records' could be interpreted to apply to the health information created or received through employer-sponsored health plans, thus moving the health plan claims of every working American (and their dependents) outside the scope of the Privacy Rule."<sup>254</sup> This was a troubling development from the perspective of HIV-positive employees, a group already vulnerable to discrimination on the basis of privacy breaches. Further, the HHS amendment potentially conflicted with the ADA protections for medical information, specifically the requirement that medical records be kept separate from employment files.<sup>255</sup>

On August 9, 2002, HHS issued the new rules and amendments created through its expanded comment period. 256

<sup>250. 67</sup> C.F.R. § 14804 (2002).

<sup>251.</sup> Id.

<sup>252.</sup> Comments, supra note 249, at 37.

<sup>253.</sup> Id. at 38. 6

<sup>254</sup> Id.

<sup>255.</sup> Id. at 39.

The proposed term "employment records" is not only dangerously broad, but it is confusing given the backdrop of federal employment laws. The Americans with Disabilities Act (as well as other federal laws) requires that medical information obtained by an employer be collected in separate forms and kept in confidential medical files, separate from personnel or other employment-related records. These laws distinguish between medical information and other types of employment records compiled by employers. Thus, it is especially confusing for the Department to propose the use of the term "employment records" as a way of referring to certain medical records compiled by employers.

Id. See 42 U.S.C. § 12112(d)(3)(B).

<sup>256.</sup> U.S. Department of Health and Human Services, HHS Issues First Major

The new federal regulations go into effect on April 14, 2003, and covered entities must be in compliance by that date with the exception of small health plans, which have until April 14, 2004.<sup>257</sup> The regulations, as expected, eliminate the patient consent requirement and allow records to be accessed for marketing purposes under certain conditions.<sup>258</sup> Employee health records are not covered under HIPAA's protected information rule.<sup>259</sup>

HIPAA sets a minimum standard for privacy protections, but it does not preempt or override stronger state law.<sup>260</sup> Minnesota's medical records privacy laws<sup>261</sup> should build upon HIPAA<sup>262</sup> in order to provide the best possible privacy protections, especially in the employment context where HIPAA offers no assistance to employees.<sup>263</sup> The Minnesota State Legislature should take advantage of the lack of preemption in this area of the federal regulations and promulgate laws creating higher standards for

<sup>258.</sup> Press Release, Health Privacy Project, HHS Releases Final Modifications to Regulation. Aug. 2002. available http://www.healthprivacv.org/usr\_doc/press\_release802.pdf Thereinafter Health Privacy Project Press Release]. HHS will now "merely require that providers ask patients to acknowledge receipt of a privacy notice. Notice alone does not provide a comparable opportunity for dialogue or understanding," Id. Marketing is narrowly defined in the new regulations, and therefore many companies and manufacturers will be able to circumvent the requirements and obtain patient information to send targeted mailings about new drugs or the like. Id. Marketing is defined as "a communication about a product or service that encourages the recipient to purchase or use the product or service." 45 C.F.R. §§ 164.501, 164.508(a)(3) (2002). Pharmacies do not have any opportunity to obtain prior consent from a patient about the use of their health information for commercial purposes. Health Privacy Project Press Release, supra, at 2. Pharmacies do not have to inform patients that a drug company will be sending them letters. Id. These regulations seem to contradict recent court actions upholding patient privacy, including a recent settlement agreement in which a chain drug store, Eckerd's, used signatures from customers when they picked up their prescriptions as "authorization" to release their information for marketing purposes. Id. After the Florida Attorney General began an investigation, Eckerd's agreed to change its policy and give customers the chance to "opt-in" to the use of their information for marketing. Linda Kleindienst, Eckerd Settles Customer Privacy Case, Pharmacy Forum (July 11, 2002), at http://www.pharmacyforum.com/eckerd\_settles\_customer\_privacy.htm.

<sup>259. 45</sup> C.F.R. §§ 160.102-.103, 164.500.

<sup>260. 45</sup> C.F.R. §§ 160.203-.205. The Regulations allow more protective state laws to contradict federal law. *Id.* According to the Health Privacy Project, "a state law is more stringent when it prohibits or restricts a use or disclosure that would be permitted under the regulation." Health Privacy Project, *Summary of HIPAA Privacy Rule*, 34, Sept. 13, 2002, available at http://www.healthprivacy.org/usr\_doc/RegSummary2002.pdf.

<sup>261.</sup> MINN. STAT. § 144.335 (2002).

<sup>262. 45</sup> C.F.R. § 160 et seq.

<sup>263.</sup> See id.

confidentiality of patient and employee health information. The Legislature should also address the recent approval of the Minnesota Health Department database designed to collect patient names, addresses, and medical conditions from health departments and insurers for service quality and cost analysis.<sup>264</sup> The legislature should pass laws to protect patient information from unauthorized uses.

During the 2002 legislative session, MAP introduced a medical records privacy bill to provide better confidentiality the state of protections and stronger civil penalties in Minnesota 265 The measure was MAP's response to several compelling cases in the Project's legal program.<sup>266</sup> For example, a health insurer sent an employer information on health care costs for the group, which included the specific names of the prescription drugs the employees were using. While the report did not give individual names of employees, the information was grouped in such a way that it was easy for the small business to know who in the company was using which drugs. Because an employee with HIV disease who is taking medication generally requires a large quantity of different drugs that are recognizable in their purpose, such information could easily "out" an employee who has not disclosed his or her health status to an employer. In another case, an HIV-positive construction worker told his boss

<sup>264.</sup> See Maura Lerner, Judge Ok's State Health Database, STAR-TRIB. (Minneapolis), Dec. 3, 2002, at A1. The Health Department (MDH) claimed that it needed the information to research health care quality and costs, and promised to encrypt all information using several layers of codes. Id. Critics, including the Minnesota Civil Liberties Union (MCLU) and the Citizen's Council on Health Care (CCHC), objected, stating that MDH did not establish specific public health goals or minimize the privacy impact on individuals as required under Minnesota Statute section 62J. See Press Release, Minn. Civil Liberties Union, MCLU Weighs In on Intrusive Medical Records Reporting Rules, Oct. 25, 2002 (on file with Law and Inequality). The MCLU added that the rule could "have adverse public health effects by deterring patients from seeking treatment for sensitive medical issues out of privacy concerns." Id. CCHC noted that there were over 1,000 comments in opposition to the rule, and that "only a few commentators, mostly health officials and public health researchers, have expressed support for the rule without reservation." CCHC, Public Response to Minnesota's Proposed Rule, 26, 27, Nov. 2002, available at http://www.cchconline.org/pdf/data\_rules.pdf. A bill has been introduced in the Minnesota House of Representatives that would require patient consent before health care data could be shared with MDH. H.F. 164, 83rd Leg. (Minn. 2003-2004).

<sup>265.</sup> The legislature placed the proposed bill on hold until the 2003 session for further development and research. The discussion here centers on actions proposed by the bill as it currently stands that are likely to be revisited during the 2003 legislative session. The Senate version is S.F. 3074 (Minn. 2001-02) and the House version is H.F. 3601 (Minn. 2001-02).

<sup>266.</sup> See supra note 220.

about his health status because of the potential adverse effects of his medications. The next day he learned that his boss told all of his coworkers. The resulting stigmatizing behaviors of his coworkers forced him to quit his job. Finally, two employees, one with HIV disease, the other with cancer, were terminated not, they believe, because of job performance but rather due to escalating health care premiums. Neither employee had ever released health information to the employer.

These cases, and many others affecting individuals with HIV disease and other stigmatizing diseases or high-cost conditions, prove that the medical records privacy laws should strengthened through new legislation. Currently, insurers and may maintenance organizations (HMOs) release employers for confidential health information to Current law does not prohibit disclosure of an nurnoses.267 individual's confidential health information when employers, HMOs, drug companies, or corporations hold medical records.<sup>268</sup> Further, penalties are extremely limited if an employer or provider releases health information with the patient's permission.<sup>269</sup> It is unclear whether the current statute covers health information that an employee discloses verbally with an employer.<sup>270</sup>

HMOs and other insurers should not be able to release confidential health information to employers. While it is understandable that a purchaser of health care – the employer – would want data on how much it is spending on health care costs, this data should not, in any way, personally identify an employee. At a time when health care costs continue to escalate, an employer's knowledge of an employee's health care costs could adversely affect personnel decisions.

Employers, pharmaceutical companies, and health plans that hold medical records should not be able to disclose the information without patient consent. Currently, Minnesota's medical records laws apply only to providers such as pharmacists, doctors, and nurses.<sup>271</sup> Minnesota law, under this limited application, does not cover an employer, a health plan, or a corporation that owns a pharmacy that has access to medical records.<sup>272</sup> Thus, the law does not prohibit entities from disclosing a patient's personal

<sup>267.</sup> MINN. STAT. § 62D.145, subd. 2(a)(6) (2002).

<sup>268.</sup> MINN. STAT. § 144.335, subd. 3(a) (2002).

<sup>269.</sup> MINN. STAT. § 144.335, subd. 6.

<sup>270.</sup> See id.

<sup>271.</sup> MINN. STAT. § 144.335.

<sup>272.</sup> Id.

health information for marketing and fundraising purposes.

Current law does not define what constitutes a medical record outside of the context of the medical provider system. This lack of definition creates problems when medical information is brought into the workplace, especially when the information is not in the form of a medical record. Often information is shared verbally between employer and employee. The bill proposed by MAP provides a definition for health and medical information: "information of a medical nature about a continuing medical condition that is provided by the subject of the information and that relates to a request for, or the potential need for, medical leave or a reasonable or necessary accommodation."273 definition provides a necessary framework and is inclusive of verbal communications, thereby eliminating any doubt about confidentiality breaches. The employer's only obligation under the proposed bill is to inform the employee that medical information could be protected at the employee's request:274 the employee still has to take affirmative action to request that the information remain confidential.275

Finally, the medical records privacy bill outlines stronger civil penalties for breaches of confidentiality. Stricter enforcement mechanisms can deter improper disclosure from happening in the first place. The proposed law makes those who negligently or intentionally release a health record or medical information without consent liable for general damages and compensatory damages for harm caused by the unauthorized release, plus costs and reasonable attorneys fees. General damages based on unwarranted release would be easier to demonstrate than the current standard of having to prove harm, reinforcing the deterrent aspects of the law and placing less of a burden to litigation on the employee.

Today, people with HIV are living longer. As a result, issues of privacy and confidentiality are becoming increasingly important, especially in the workplace where employers and

<sup>273.</sup> S.F. 3074, 2nd Eng., 82nd Leg. (Minn. 2001-02). The definition was narrowly tailored through the use of the terms "continuing medical condition," "medical leave" and "reasonable or necessary accommodation" so as to avoid situations such as the common cold or flu.

<sup>274.</sup> See id. at subd. 3.

<sup>275.</sup> See id

<sup>276.</sup> See id. at § 1, subd. 4: "An employer who negligently or intentionally violates Subd. 2 [employee consent to disclosure] is liable to the employee for damages, plus costs and reasonable attorney fees." Id.

<sup>277.</sup> See H.F. 3601, 82nd Leg. (Minn. 2001-02).

employees alike may be unaware of their obligations and rights regarding health care information. The Bush Administration's changes to HIPAA set an ominous precedent for employee privacy protection. Minnesota should take this opportunity to strengthen its laws and make a commitment to privacy worthy of the precedents it set with regard to human rights and government data privacy protections.

### Conclusion

HIV is a complicated disease, varied in form, unpredictable in result, and still incurable. Many individuals diagnosed early in the epidemic continue to thrive, enjoying relatively normal lives, while others endure painful infections, frequent hospitalizations, and short life spans. The capricious nature of the disease contributes to the general misunderstanding that surrounds it. The unknown tends to breed fear, and fear, in turn, breeds stigma. History shows us, repeatedly, that human nature tends to favor self-preservation, no matter how irrational, before compassion.

This Article discusses the many changes in discrimination and privacy laws that have occurred in recent years. These laws seem to grow more complicated with the passage of time as courts, policymakers, and advocates attempt to fit unique situations into general legal frameworks. Such complications, however, are necessary. So long as HIV remains a flashpoint for discrimination, the laws must provide broad protections that take into account all of the medical and social complexities associated with the disease. However, if the Supreme Court further narrows the ADA's application, and privacy laws fail to deter invasion, the legal system will inadequately serve HIV-positive individuals.

Now that we are more than twenty years into the epidemic, it is time to realize a new chapter in the fight for the rights of HIV-positive individuals. We celebrate the victories of longer lives and progress made. The third decade represents an opportunity for focusing the law in an attempt to eradicate, once and for all, the stigma, hate, and fear individuals with HIV disease do not deserve and should not have to endure.