

## FROM THE STREETS OF PHILADELPHIA: THE AIDS LAW PROJECT OF PENNSYLVANIA'S HOW-TO PRIMER ON MITIGATING HEALTH DISPARITIES

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Joe Miller (DENZEL WASHINGTON): What do you love about the law, Andrew?

Andrew Beckett (TOM HANKS): I...many things...uh...uh...What I love the most about the law?

Joe Miller: Yeah.

Andrew Beckett: It's that every now and again—not often, but occasionally—you get to be a part of justice being done. That really is quite a thrill when that happens.<sup>1</sup>

- DIALOGUE IN THE MOVIE "PHILADELPHIA" (1993)

### I. INTRODUCTION

In the mid-1980s, a time when there was no hope of treatment and the public was rampant with AIDS hysteria, concerned citizens carried on a spirited public discourse about the services that people with HIV/AIDS needed to survive: health care, case management, home-delivered meals, even pet care.<sup>2</sup> But few recognized how large of a role legal services could play in helping people with HIV/AIDS get the care they needed. It was difficult to understand that people with AIDS often needed a lawyer to get to a doctor.

All types of AIDS service organizations were created during this period, but funding and support for legal services remained limited.<sup>3</sup> Despite the scarcity of resources, several legal-services organizations dedicated exclusively to the unique

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1. PHILADELPHIA (TriStar Pictures 1993).

2. See, e.g., Bob Port, *Rules Drive Up Cost of AIDS Treatment*, ST. PETERSBURG TIMES, May 23, 1989, at 10A (discussing health care and other services necessary for AIDS patients); Marsha Kay Seff, *AIDS Patients Helped with Pets*, SAN DIEGO UNION-TRIBUNE, Mar. 6, 1989, at E2 (describing services available to AIDS patients in need of pet care).

3. See, e.g., Susan Duerksen, *City's AIDS Response Dismays the Experts*, SAN DIEGO UNION-TRIBUNE, Dec. 15, 1987, at A1 (discussing lack of funding for AIDS programs, including legal services).

legal needs of people with HIV/AIDS developed throughout the nation.<sup>4</sup> Over the years, these firms have seen first-hand how legal services can positively impact a client's health outcome.

Decades after the discussions of the importance of legal services in an AIDS-care continuum, the connection between dedicated legal services and mitigating health disparities has become the foundation for medical-legal partnerships. These partnerships and the development of "public-health legal services" have been analyzed in many fine articles.<sup>5</sup>

This Article, written from a practitioner's perspective, will describe how the AIDS Law Project of Pennsylvania responded to Philadelphia's AIDS epidemic. Parts II and III of the Article provide a brief background of the health disparities that have persisted throughout the AIDS epidemic. Parts IV and V compare the services requested by clients seeking assistance from the AIDS Law Project of Pennsylvania with the epidemiological data of those infected with HIV. Parts VI and VII identify the various models of HIV legal-services providers.

All lawyers seek justice for their clients, but certain vulnerable populations need more than just legal justice. Populations that have endured animus, inequality, or indifference have a need for social justice, greater than what can be accomplished in a courthouse or by a contract. The need for social justice, as a path to mitigating health disparities, is the impetus for dedicated, holistic legal services like those offered by the AIDS Law Project of Pennsylvania. The authors hope this Article can serve as a guide for any lawyer seeking to replicate these services and "be a part of justice being done."

## II. BACKGROUND

### A. *AIDS in the Early Days of the Epidemic*

To better understand the unique role that legal service providers have played in addressing the barriers faced by people living with HIV/AIDS, it is important to examine the history of the disease in the United States.

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4. See, e.g., AIDS COORDINATION PROJECT, AM. BAR ASS'N, DIRECTORY OF LEGAL RESOURCES FOR PEOPLE WITH HIV/AIDS 3-221 (3d ed. 2006), available at <http://www.abanet.org/AIDS/publications/aidsdirectory.pdf> (providing information about HIV/AIDS legal resources available by state, as well as resources available in American Samoa, Guam, Puerto Rico, Virgin Islands, and Washington, D.C.).

5. See, e.g., David I. Schulman et al., *Public Health Legal Services: A New Vision*, 15 GEO. J. ON POVERTY L. & POL'Y 729, 731-70 (2008) (discussing origins of legal-medical partnerships); Elizabeth Tobin Tyler, *Allies Not Adversaries: Teaching Collaboration to the Next Generation of Doctors and Lawyers to Address Social Inequality*, 11 J. HEALTH CARE L. & POL'Y 249, 253-56 (2008) (discussing benefits of medical-legal partnerships); Jane R. Wettach, *The Law School Clinic as a Partner in a Medical-Legal Partnership*, 75 TENN. L. REV. 305, 310-13 (2008) (describing benefits to law students of housing medical-legal partnership in law school clinic setting); Deborah Rhode, *Access to Justice: Connecting Principles to Practice*, 17 GEO. J. LEGAL ETHICS 369, 392-97 (2004) (proposing suggestions for successful legal service partnerships and noting successful examples of such partnerships); Pamela Tames et al., Commentary, *The Lawyer Is In: Why Some Doctors Are Prescribing Legal Remedies for Their Patients, and How the Legal Profession Can Support This Effort*, 12 B.U. PUB. INT. L.J. 505, 510-27 (2003) (discussing benefits and limitations of multidisciplinary practice).

Acquired immunodeficiency syndrome (“AIDS”) was first recognized as a new disease in the United States in 1981, when practitioners in New York, Los Angeles, and San Francisco began to see young, homosexual men with unusual diseases for young adults not known to have suppressed immune systems.<sup>6</sup> In mid-1982, the Centers for Disease Control and Prevention (“CDC”) published a report of thirty-four cases of opportunistic infections and Kaposi’s Sarcoma among Haitians living in several different states in the United States, none of whom reported homosexual behavior.<sup>7</sup> One week later, the CDC reported similar symptoms among persons with hemophilia, and the first case in a transfusion recipient was reported from San Francisco in an infant in late 1982.<sup>8</sup> For a short time, the new disease was called gay-related immunodeficiency syndrome (“GRIDS”), but by September of 1982, the CDC had published a case definition, using the designation of acquired immune deficiency syndrome or AIDS, in print, and it was rapidly adopted by researchers.<sup>9</sup>

The incidence of the new disease grew rapidly across the country over the next fifteen years. While only 100 AIDS cases had been reported to the CDC by the fall of 1981, 1,000 cases had been reported two years later, by February 1983.<sup>10</sup> By the end of the 1980s, every state had reported new cases of AIDS to the CDC.<sup>11</sup> New diagnoses peaked in 1992, when the CDC reported an estimated 78,000 AIDS cases that year.<sup>12</sup> By October 1995, over half a million AIDS cases had been reported in the United States.<sup>13</sup>

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6. See, e.g., Ctrs. for Disease Control & Prevention, *Kaposi’s Sarcoma and Pneumocystis Pneumonia Among Homosexual Men—New York City and California*, 30 MORBIDITY & MORTALITY WKLY. REP. 305, 305–07 (1981) (describing twenty-six homosexual men in New York and San Francisco); Ctrs. for Disease Control & Prevention, *Pneumocystis Pneumonia—Los Angeles*, 30 MORBIDITY & MORTALITY WKLY. REP. 250, 250–51 (1981) (describing five young, homosexual men in Los Angeles); Henry Masur et al., *An Outbreak of Community-Acquired Pneumocystis Carinii Pneumonia: Initial Manifestation of Cellular Immune Dysfunction*, 305 NEW ENG. J. MED. 1431, 1431 (1981) (reporting similar syndrome in drug users). All of these individuals shared a profound immunodeficiency, the hallmark of which was a depletion of CD4-positive, or T-helper, lymphocytes.

7. Ctrs. for Disease Control & Prevention, *Opportunistic Infections and Kaposi’s Sarcoma Among Haitians in the United States*, 31 MORBIDITY & MORTALITY WKLY. REP. 353 (1982).

8. See Ctrs. for Disease Control & Prevention, *Update on Acquired Immune Deficiency Syndrome (AIDS) Among Patients with Hemophilia A*, 31 MORBIDITY & MORTALITY WKLY. REP. 644, 644 (1982) (reporting on several cases of hemophilia A patients diagnosed with AIDS); Ctrs. for Disease Control & Prevention, *Update on Acquired Immune Deficiency Syndrome (AIDS)—United States*, 31 MORBIDITY & MORTALITY WKLY. REP. 507, 513 (1982) (noting two cases in hemophilia A patients).

9. See Ctrs. for Disease Control & Prevention, *Update on Acquired Immune Deficiency Syndrome (AIDS)—United States*, 31 MORBIDITY & MORTALITY WKLY. REP. 507, 513 (1982).

10. Dennis H. Osmond, University of California San Francisco, *Epidemiology of HIV/AIDS in the United States* (2003), <http://hivinsite.ucsf.edu/InSite?page=kb-01-03#S1.5X>; see also Harold W. Jaffe et al., *Acquired Immune Deficiency Syndrome in the United States: The First 1,000 Cases*, 148 J. INFECTIOUS DISEASES 339, 339 (1983) (noting 1,000 cases documented by 1983).

11. Osmond, *supra* note 10.

12. Ctrs. for Disease Control & Prevention, *Epidemiology of HIV/AIDS—United States, 1981–2005*, 55 MORBIDITY & MORTALITY WKLY. REP. 589, 589 (2006).

13. Osmond, *supra* note 10.

In the 1980s and early 1990s, little or no treatment existed, and an AIDS diagnosis meant a near-certain death sentence.<sup>14</sup> By 1993, HIV infection and AIDS had become the leading cause of death among persons twenty-five to forty-four years old.<sup>15</sup> In 1994, an estimated 41,930 U.S. residents died of AIDS.<sup>16</sup> In 1994, HIV infection accounted for twenty-three percent of all deaths among men and thirty-two percent of all deaths among African American men.<sup>17</sup> It was the third highest cause of death for women twenty-five to forty-four years of age (eleven percent of deaths), but the first cause of death among African American women (twenty-two percent of deaths).<sup>18</sup>

For the individuals who received an AIDS diagnosis in those early days, their lives changed profoundly. The disease struck down mostly young men, otherwise in the prime of their lives. These men were forced to confront the prospect of early death and to make plans accordingly. In addition to their health needs, their legal needs were dramatically influenced by their illness. Many needed assistance in the financial planning of their assets and extensive estate planning, as state law created a presumption in favor of one's biological family over his or her partners or lovers.<sup>19</sup> These barriers created legal challenges both during life (in the form of health care proxies and powers of attorney) and after (in the form of will contests).<sup>20</sup>

Additionally, newly diagnosed individuals faced dramatic legal challenges related to their employment and health insurance that often required legal assistance. The onset of the epidemic, and the panic that accompanied it,<sup>21</sup> set the tone for blatant stigma and discrimination against people with HIV that persists today. People with HIV were routinely fired from their jobs, evicted from their homes, excluded from schools, shunned by family members, and threatened with

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14. Only forty-four percent of persons diagnosed with AIDS in 1981 were still living two years later. Ctrs. for Disease Control & Prevention, *supra* note 12, at 590.

15. Ctrs. for Disease Control & Prevention, *Update: Mortality Attributable to HIV Infection Among Persons Aged 25-44 Years—United States 1994*, 45 MORBIDITY & MORTALITY WKLY. REP. 121, 121 (1996).

16. *Id.*

17. *Id.*

18. *Id.*

19. See generally Jane Harris Aiken, *Striving to Teach "Justice, Fairness, and Morality,"* 4 CLINICAL L. REV. 1, 35 n.123 (1997) ("The heterosexual bias in the law is most evident in such areas as privacy, marriage and child rearing."); Jeffrey Selbin & Mark Del Monte, *A Waiting Room of Their Own: The Family Care Network as a Model for Providing Gender-Specific Legal Services to Women with HIV*, 5 DUKE J. GENDER L. & POL'Y 103, 105-08 (1998) (discussing AIDS patients' legal needs and barriers to legal representation).

20. See, e.g., *In re Guardianship of Kowalski*, 382 N.W.2d 861, 865 (Minn. App. 1986) (affirming appointment of incompetent person's father as her guardian instead of woman in spouse-like relationship with her because of preference for appointing family members); *Stewart v. Schwartz Brothers-Jeffer Memorial Chapel, Inc.*, 606 N.Y.S.2d 965, 967 (N.Y. Sup. Ct. 1993) (recognizing presumption that decedent's family had right to possession of decedent's body at death for purposes of burial despite claim by decedent's partner that family was not honoring decedent's wishes).

21. "The July 1985 cover of *Life* informed the nation in three-inch red letters that 'NOW NO ONE IS SAFE FROM AIDS,'" and featured "a seemingly typical Pennsylvania family all but one of whose members ha[d] the disease." Richard D. Mohr, *AIDS, Gays, and State Coercion*, 1 BIOETHICS 95, 98 (1987). As it turned out, all of those individuals were in high-risk groups: the father was a hemophiliac and his wife was infected through sexual conduct and passed the virus to her child through birth. *Id.*

violence.<sup>22</sup> For example, in the real-life cases that inspired the storyline of the movie *Philadelphia*, two lawyers who were fired from prominent Philadelphia law firms sued their former employers in 1988 and 1993 for terminating them after they disclosed their HIV status.<sup>23</sup> Such stories were, and continue to be, unfortunately, all too commonplace.

In addition to employment discrimination, individuals with HIV were (and are) also subject to societal stigma that can be detrimental to their health. Because HIV was primarily limited to specific, traditionally disfavored groups,<sup>24</sup> the early epidemic was used as a justification to enact homophobic policies at both the state and federal level.<sup>25</sup> Many conservative leaders moralized that gay men were getting their just deserts for their “sins.” A *Los Angeles Times* poll in December 1985 revealed that fifty-one percent of Americans were in favor of quarantining individuals with AIDS.<sup>26</sup> In March 1986, William F. Buckley, Jr. wrote in the *New York Times*: “Everyone detected with AIDS should be tattooed in the upper forearm, to protect common-needle users, and on the buttocks, to prevent the victimization of other homosexuals.”<sup>27</sup>

Once a test for the antibodies believed to cause AIDS was approved in March 1985,<sup>28</sup> it was used both to detect potential carriers of the virus and to exclude

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22. See Gregory M. Herek, *Thinking About AIDS and Stigma: A Psychologist's Perspective*, 30 J. L. MED. & ETHICS 594, 595–597 (2002) (discussing origins, causes, and examples of AIDS-related stigma).

23. See *Doe v. Kohn, Nast & Graf, P.C.*, 862 F. Supp. 1310, 1314–15 (E.D. Pa. 1994) (describing facts of lawsuit brought by HIV-positive lawyer against his former law firm); *Cain v. Hyatt*, 734 F. Supp. 671, 672–77 (E.D. Pa. 1990) (announcing findings of fact in lawsuit over law firm's termination of HIV-positive lawyer). The court in *Cain* found that “[t]he defendants, in utter disregard of [plaintiff's] rights, summarily removed the plaintiff from his position while he lay in the hospital, just days after he had honestly confided to them he had AIDS,” and awarded him \$157,888.18 in damages. *Cain*, 734 F. Supp. at 686–87. In *Doe*, the court denied defendant's motion for summary judgment in part, and the parties eventually reached a settlement. *Doe*, 862 F. Supp. at 1318, 1324–25; see also Rhonda K. Jenkins, *Square Pegs, Round Holes: HIV and the Americans with Disabilities Act*, 20 S. ILL. U. L.J. 637, 650 (1996) (describing public details of settlement).

24. See Ctrs. for Disease Control & Prevention, *Current Trends Update: Acquired Immunodeficiency Syndrome—United States*, 35 MORBIDITY & MORTALITY WKLY. REP. 17, 17–21 (1986) (noting that ninety-four percent of AIDS patients can be classified as gay or bisexual men, injection drug users, or hemophiliacs).

25. See Mohr, *supra* note 21, at 95 (discussing state-mandated discrimination against groups at risk for AIDS). As part of their justification for the proposed restrictive measures, politicians often compared AIDS to viral diseases like influenza and the common cold. *Id.* at 98.

26. *Id.* at 96 n.3.

27. William F. Buckley Jr., Op-Ed., *Crucial Steps in Combating the AIDS Epidemic: Identify All the Carriers*, N.Y. TIMES, Mar. 18, 1986, at A27; see also ARTHUR D. KAHN, AIDS, THE WINTER WAR 3 (1993) (reporting Buckley quote).

28. The test was originally used to determine the presence of HTLV-III antibodies in the blood supply, to help prevent AIDS cases in hemophiliacs and others receiving blood transfusions. See Cristine Russell, *U.S. Expected to Approve an AIDS Blood Test Today*, WASH. POST, Mar. 2, 1985, at A1 (noting that two percent of cases are linked to contaminated blood products). At the time, the “FDA and other experts stress[ed] that the new blood test [was] ‘not a test for AIDS’; rather, they reported that the test ‘measures only the presence of antibodies, but does not provide a means of predicting whether a person will become ill with AIDS in the future.’” *Id.* The CDC estimated that, of those who tested positive for the antibodies, only “10 percent may come down with the actual disease.” *Id.*

those individuals from various employment and sectors of society.<sup>29</sup> CDC researchers called for all homosexual men to take the test as a means of controlling the epidemic.<sup>30</sup> The Defense Department announced that the test would be administered to all recruits to the armed services, and those who tested positive would be barred from the military.<sup>31</sup> In the fall of 1985, the National Education Association recommended that schools be able “to screen for exposure to AIDS in students or teachers when there was ‘reasonable cause’ to believe they had been infected.”<sup>32</sup> Before passing the Americans with Disabilities Act in 1990, Congress (and many states) proposed that food handlers and health care workers should also be tested, and that restrictions should be imposed on “AIDS carriers.”<sup>33</sup> In 1992, the Aerospace Medical Association called for mandatory HIV testing of all pilots, and for grounding of those pilots who were HIV-positive.<sup>34</sup>

In response, civil rights leaders and lawyers advocated against these discriminatory policies and provided legal services for individuals who were forced to confront challenges caused by their HIV status that had nothing to do with their health.<sup>35</sup> As a result, many states introduced laws specifically protecting

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29. See, e.g., The Associated Press, *Jersey AIDS Tests Due for High-Risk Groups*, N.Y. TIMES, Mar. 11, 1985, at B3 (reporting that New Jersey Department of Health would soon offer tests to high-risk individuals “so blood banks would not be overloaded with ‘an influx of people who suspect they might have a problem’” (quoting Allen N. Koplin, deputy commissioner of the New Jersey Department of Health)); Ronald Kotulak, *Chicago Plans Special Clinics for AIDS Tests*, CHI. TRIB., Mar. 14, 1985, at A4 (reporting purpose of testing clinics was to halt donations by possibly infected people). Some leaders in the gay community recognized the stigma that an HIV-positive status carried, and questioned its usefulness so long as no treatment or protection from discrimination existed. See Michael Specter, *Blood Test Misuse to Diagnose AIDS Feared*, WASH. POST, June 10, 1985, at A1 (“As a blood test, it is clearly useful’ . . . . ‘But its implications are pernicious and profound. There is the stigma of a fatal disease, questions of confidentiality and also worries about insurance and discrimination. The test cannot tell you if you have AIDS or whether you will get it. I tell people to stay away.” (quoting Dr. Martin Wasserman, director of Arlington’s Department of Human Services)). The Gay Men’s Health Crisis coined the slogan “no test is best,” and argued that the test can be almost as devastating as the disease. See JOHN BLAKE SCOTT, *RISKY RHETORIC: AIDS AND THE CULTURAL PRACTICES OF HIV TESTING* 41 (2003) (noting that opposition to testing started before test’s approval).

30. See Harry Nelson, *Blood Tests Hold Key to Control of AIDS Epidemic, Researcher Says*, L.A. TIMES, Apr. 15, 1985, at 3 (reporting CDC’s emphasis on importance of test in reducing transmission of disease).

31. Margaret Engel, *Recruits to Receive AIDS Tests: Military to Reject Those Whose Blood Shows Viral Exposure*, WASH. POST, Aug. 31, 1985, at A1. Dr. William E. Mayer, Assistant Secretary of Defense for Health Affairs, “was ‘not confident’ that AIDS cannot be transmitted through casual contact.” *Id.* He stated, “‘I’m not confident at all that the person who has AIDS or has [the] virus in saliva and tears’ would not spread the disease ‘if he’s in an enclosed space’ such as a tank, aircraft carrier or tent.” *Id.*

32. Kenneth B. Noble, *Teacher Group Backs AIDS Tests for Some*, N.Y. TIMES, Oct. 10, 1985, at A25.

33. The Associated Press, *AIDS Rules Reject Need for Job Test*, CHI. TRIB., Nov. 14, 1985, at 17.

34. See Brian C. McCormack, Comment, *HIV Employment Discrimination in Air Transportation*, 61 J. AIR L. & COM. 287, 291–92 (1995) (noting that pilots would not volunteer medical problems).

35. Of course, people with HIV have also faced the additional barrier to accessing proper care resulting from a health care provider’s refusal to treat them. See, e.g., *Bragdon v. Abbott*, 524 U.S. 624, 649 (1998) (finding that refusal of care by dentist could comply with Americans with Disabilities Act if there is “direct threat” to health of others). This form of discrimination persists to this day. See Brad Sears, *HIV Discrimination in Health Care Services in Los Angeles County: The Results of Three Testing Studies*, 15 WASH. & LEE J. C.R. & SOC. JUST. 85, 86 (2009) (describing results of three studies measuring HIV-discrimination in health care services and finding “that 56% of skilled nursing facilities, 26% of

the rights of people with HIV.<sup>36</sup> Gradually, advocates relying upon lawyers, such as those at the AIDS Law Project of Pennsylvania, helped to ensure protection for those living and dying with AIDS in the early days.

*B. The Changing Demographics of HIV/AIDS*

With the development of antiretroviral medications and the “AIDS” cocktail in 1996,<sup>37</sup> the AIDS epidemic has changed somewhat in character, although individuals with HIV still face tremendous legal barriers that interfere with their health status. People living with HIV and AIDS can expect to live an average of 22.5 years after their diagnosis, an increase from an average of 10.5 years in 1996.<sup>38</sup> Since 1981, an estimated 1.7 million U.S. citizens have been infected with HIV, “and more than 1.1 million [are] estimated to be living with the disease today.”<sup>39</sup> Although rates of infection have stabilized since the early days, it is estimated that approximately 56,300 individuals in the United States were infected in 2006.<sup>40</sup> “AIDS cases have been reported in all 50 states, the District of Columbia,” and all United States territories, although “[t]en states account for 71% of AIDS cases reported since the beginning of the epidemic.”<sup>41</sup> Pennsylvania ranked sixth in the highest number of AIDS cases reported in 2007, as well as cumulatively.<sup>42</sup>

Of all racial and ethnic groups in the United States, HIV/AIDS has hit African Americans the hardest, especially in recent years. The proportion of new cases in African Americans has risen from twenty-five percent in 1981<sup>43</sup> to fifty-one percent in 2007, despite now accounting for only about twelve percent of the U.S.

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plastic and cosmetic surgeons, and 47% of obstetricians in Los Angeles County would not take any patient who was HIV-positive for any type of service, even when patients were asymptomatic”).

36. For example, at least fourteen states explicitly included HIV status in their nondiscrimination statutes. See Lawrence O. Gostin et al., *Disability Discrimination in America: HIV/AIDS and Other Health Conditions*, 281 JAMA 745, 749 (1999) (discussing treatment of HIV status in nondiscrimination statutes among states).

37. In 1996, for the first time since the AIDS epidemic began, the number of deaths nationwide due to AIDS fell compared to the year before. Ctrs. for Disease Control & Prevention, *Update: Trends in AIDS Incidence—United States, 1996*, 46 MORBIDITY & MORTALITY WKLY. REP. 861, 861 (1996). Although the media incorrectly trumpeted the discovery of the antiretroviral drugs as the “End of AIDS,” the discovery of these drugs marked a dramatic break from the previous era of no treatment. See, e.g., Philip A. Leider, *Domestic AIDS Vaccine Trials: Addressing the Potential for Social Harm to the Subjects of Human Experiments*, 88 CAL. L. REV. 1185, 1191 n.23 (2000) (citing newspaper articles that greeted the development of antiretroviral drugs with unbridled optimism).

38. Kathleen McDavid Harrison et al., *Life Expectancy After HIV Diagnosis Based on National HIV Surveillance Data from 25 States, United States*, 53 J. ACQUIRED IMMUNE DEFICIENCY SYNDROME 124, 125 (2010).

39. THE HENRY J. KAISER FAMILY FOUNDATION, HIV/AIDS POLICY FACT SHEET: THE HIV/AIDS EPIDEMIC IN THE UNITED STATES (Sept. 2009), available at <http://www.kff.org/hivaids/upload/3029-10.pdf>.

40. *Id.*

41. *Id.*

42. CTRS. FOR DISEASE CONTROL & PREVENTION, HIV/AIDS SURVEILLANCE REPORT: CASES OF HIV INFECTION AND AIDS IN THE UNITED STATES AND DEPENDENT AREAS, 2007, at 32 (2009), available at [www.cdc.gov/hiv/topics/surveillance/resources/reports/2007report/pdf/2007SurveillanceReport.pdf](http://www.cdc.gov/hiv/topics/surveillance/resources/reports/2007report/pdf/2007SurveillanceReport.pdf).

43. Osmond, *supra* note 10.

population.<sup>44</sup> Rates of HIV are highest amongst African American males, at 2,388 per 100,000, which is six times as high as the rate for white men.<sup>45</sup> “Black women are also severely affected. The prevalence rate for black women (1,122 per 100,000) was 18 times the rate for white women (63 per 100,000).”<sup>46</sup> Approximately sixty-four percent of all women living with HIV/AIDS are African American.<sup>47</sup> African Americans with HIV/AIDS also have shorter survival times than individuals of other races.<sup>48</sup>

HIV/AIDS also continues to affect men who engage in same-sex sexual activity, whether or not those men openly identify as gay, bisexual, or transgender. In 2007, an estimated seventy-five percent of HIV/AIDS diagnoses among men resulted from male-to-male sexual contact.<sup>49</sup>

Younger gay and bisexual men and those of color are at particularly high risk. Young men between the ages of 13 and 29 accounted for 38% of infections among gay and bisexual men, a share that was even higher among young Black men (52%). Studies have also found high HIV incidence and prevalence among gay and bisexual men in some cities, particularly Black and Latino men, many of whom did not know they were infected.<sup>50</sup>

### III. A FRAMEWORK FOR MITIGATING HEALTH DISPARITIES

Although people with HIV may not face the same level of hostility as they did in the early days of the epidemic, social stigma and other legal challenges persist, and continue to interfere with clients’ health needs.<sup>51</sup> Until very recently, people living with HIV were banned from traveling to the United States altogether.<sup>52</sup>

44. CTRS. FOR DISEASE CONTROL & PREVENTION, HIV/AIDS AMONG AFRICAN AMERICANS (2010), available at <http://www.cdc.gov/hiv/topics/aa/resources/factsheets/pdf/aa.pdf>.

45. National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, Ctrs. for Disease Control & Prevention, Health Disparities in HIV/AIDS, Viral Hepatitis, STDs, and TB (Jan. 25, 2010), <http://www.cdc.gov/nchhstp/healthdisparities/AfricanAmericans.html>.

46. *Id.*

47. National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, Ctrs. for Disease Control & Prevention, HIV/AIDS and African Americans (June 28, 2007), <http://www.cdc.gov/hiv/topics/aa/index.htm>.

48. *Id.*; see also Harrison et al., *supra* note 38, at 126 (finding that African American men diagnosed with HIV in 2005 would, on average, have a life expectancy of five years less than their white counterparts).

49. See CTRS. FOR DISEASE CONTROL & PREVENTION, *supra* note 42, at 12 (displaying data on most common means of transmitting HIV).

50. THE HENRY J. KAISER FAMILY FOUNDATION, *supra* note 39 (footnotes omitted).

51. For example, although the numbers have increased (from thirty-two percent in 1997), still only forty-four percent of individuals surveyed in 2009 answered that “they would be ‘very’ comfortable working with someone who has HIV or AIDS.” THE HENRY J. KAISER FAMILY FOUNDATION, 2009 SURVEY OF AMERICANS ON HIV/AIDS: SUMMARY OF FINDINGS ON THE DOMESTIC EPIDEMIC 19 chart 24 (Apr. 2009), available at <http://www.kff.org/kaiserpolls/upload/7889.pdf>. See generally Scott Burris, *Disease Stigma in U.S. Public Health Law*, 30 J.L. MED. & ETHICS 179, 184–86 (2002) (discussing relationship between law and public health, and its impact on day-to-day work of providing effective care and prevention services for people with and at risk of stigmatized conditions).

52. On October 30, 2009, President Obama announced the end of a twenty-two-year ban on travel to the United States for people who are HIV-positive. The new rules promulgated by the Department of



“Stigmatizing attitudes are strongly correlated with misunderstanding the mechanisms of HIV transmission and overestimating the risks of casual contact and with negative attitudes toward social groups disproportionately affected by the epidemic, especially gay men and injecting drug users.”<sup>53</sup> Studies have shown that the existence of AIDS stigma is a barrier to seeking HIV testing and treatment.<sup>54</sup> HIV-related stigmatization has also been found to be a potent stressor for HIV-positive people, and is associated with depressive symptoms, receiving psychiatric care, and poorer health status.<sup>55</sup> Such stigma is experienced more commonly among people who disclose their HIV status to a broad range of social contacts.<sup>56</sup>

Moreover, the stark racial disparities that characterize the more recent years of the epidemic reflect a continued need for legal interventions to combat the social and economic barriers that contribute to infection rates and poor health.<sup>57</sup> People with HIV face a number of economic barriers that impact their health, such as their ability to secure housing, social security benefits, or health insurance. Despite the advances in treatment and the shift of the disease from a sure death sentence to a chronic, manageable illness (for those who are able to access the treatment), HIV continues to stand as a unique disease in the ways in which it impacts so many far-reaching areas besides personal health.<sup>58</sup>

Policymakers studying disparities in health care have “identifie[d] four major arenas for policy action” that “influence health behaviors and outcomes . . . 1) Individual socioeconomic circumstances[;] 2) Physical and cultural community environment[;] 3) Personal management of health[; and] 4) Health care financing

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Health and Human Services became effective on January 4, 2010. See *Medical Examination of Aliens: Removal of Human Immunodeficiency Virus (HIV) Infection from Definition of Communicable Disease of Public Health Significance*, 74 Fed. Reg. 56547–62 (Nov. 2, 2009) (codified at 42 C.F.R. pt. 34) (eliminating HIV as reason for denying admittance of foreigners to United States).

53. Gregory M. Herek et al., *HIV-Related Stigma and Knowledge in the United States: Prevalence and Trends, 1991–1999*, 92 AM. J. PUB. HEALTH 371, 371 (2002) (footnotes omitted).

54. See, e.g., Valerian J. Derlega et al., *AIDS Stigma Among Inmates and Staff in a USA State Prison*, 19 INT'L J. STD & AIDS 259, 259 (2008) (finding AIDS stigma was barrier to treatment in prison).

55. See Peter A. Vanable et al., *Impact of HIV-Related Stigma on Health Behaviors and Psychological Adjustment Among HIV-Positive Men and Women*, 10 AIDS & BEHAVIOR 473, 474 (2006) (stating among those who are HIV-positive, stigma constitutes chronic stressor).

56. *Id.*

57. See Adaora A. Adimora et al., *Ending the Epidemic of Heterosexual HIV Transmission Among African Americans*, 37 AM. J. PREVENTATIVE MED. 468, 469 (2009) (reporting findings that social and economic environment in which many African Americans live shapes sexual network patterns and increases personal infection risk almost independently of personal behavior).

58. Some public health authorities have argued against treating HIV/AIDS differently than other medical conditions, deriding what they refer to as “AIDS exceptionalism.” See, e.g., David J. Casarett & John D. Lantos, *Have We Treated AIDS Too Well? Rationing and the Future of AIDS Exceptionalism*, 128 ANNALS INTERNAL MED. 756, 758–59 (1998) (tracing history of HIV policies and arguing against AIDS exceptionalism). *But see* Amy L. Fairchild et al., *The Myth of Exceptionalism: The History of Venereal Disease Reporting in the Twentieth Century*, 31 J.L. MED. & ETHICS 624, 624–27 (2003) (noting similarity between HIV/AIDS policy and venereal disease policy to demonstrate that AIDS policy has not been treated so differently from all other diseases). For the reasons discussed in this Article, however, we believe that the legal needs of people with HIV/AIDS are sufficiently unique so as to merit specialized attention to their care.

and delivery.”<sup>59</sup> As described in further detail in the next section, the AIDS Law Project of Pennsylvania takes a holistic approach to legal services in order to address each of these areas through targeted legal representation and promotion of equitable HIV/AIDS policy.

#### IV. THE AIDS LAW PROJECT OF PENNSYLVANIA

“The AIDS Law Project of Pennsylvania<sup>60</sup> is a public-interest law firm founded in 1988 by Temple Law School graduate David W. Webber to focus on AIDS-related discrimination cases.”<sup>61</sup> At that time, before the Americans with Disabilities Act, no laws protected people with HIV/AIDS from discrimination, so Webber relied upon “just-cause laws that prevent a worker from being terminated except in cases of incompetence or other non-AIDS related derelictions of responsibility.”<sup>62</sup>

The firm “serves all of Pennsylvania from its home base in Philadelphia,”<sup>63</sup> and has grown to include five full-time attorneys, a volunteer part-time attorney, an *of counsel* attorney, five paralegals, a full-time finance director, two full-time administrative assistants, a part-time office manager, and eight law student interns.<sup>64</sup> “In 2009, the AIDS Law Project of Pennsylvania represented 1,343 people in 1,713 legal matters.”<sup>65</sup>

This section will provide a brief overview of the firm, including its staff, eligibility criterion, and funding challenges. Section V will detail the specific services provided by the firm and analyze how those services have changed over the course of the epidemic.

##### A. Meeting People Where They Are

The firm believes that it is critically important to provide services by meeting people where they are. Each year, the AIDS Law Project of Pennsylvania makes two to three home and hospital visits per month. Two notaries on staff help to expedite paperwork. Two full-time employees (a receptionist and a paralegal) speak both English and Spanish, one lawyer speaks both English and French, and another speaks English, Tamil, and Sinhala. The firm benefits from additional

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59. KATE S.H. MEYERS, KAISER PERMANENTE INSTITUTE FOR HEALTH POLICY, RACIAL AND ETHNIC HEALTH DISPARITIES: INFLUENCES, ACTORS, AND POLICY OPPORTUNITIES 11 (2007), available at [www.kpinstituteforhealthpolicy.org/kpihp/CMS/Files/Meyers%20IHP\\_Disparities-influences%20Actors%20031907.pdf](http://www.kpinstituteforhealthpolicy.org/kpihp/CMS/Files/Meyers%20IHP_Disparities-influences%20Actors%20031907.pdf) (discussing impact of health care financing and delivery on individual behavior and health outcomes).

60. See AIDS Law Project of Pennsylvania, <http://www.aidslawpa.org> (last visited Mar. 5, 2011) (explaining brief history and purpose of organization).

61. AIDS Law Project of Pennsylvania, History, [http://www.aidslawpa.org/alpp\\_history.htm](http://www.aidslawpa.org/alpp_history.htm) (last visited Mar. 5, 2011).

62. Kent Reichert, *A Question of Rights: Issue of AIDS at Work*, PHILA. BUS. J., Oct. 31, 1988, at 10B.

63. AIDS Law Project of Pennsylvania, History, *supra* note 61.

64. See AIDS Law Project of Pennsylvania, Staff, <http://www.aidslawpa.org/staff.htm> (last visited Mar. 5, 2011) (showing current staff of AIDS Law Project of Pennsylvania).

65. AIDS Law Project of Pennsylvania, History, *supra* note 61.

written translation and oral interpretation provided free of charge by the Philadelphia Health Department.

The firm understands the need to be physically accessible to clients. The home office in Center City Philadelphia is located just a few blocks from both the state's largest HIV/AIDS social-service agency and the largest HIV/AIDS health care clinic.<sup>66</sup> This convenience allows clients to combine trips to their AIDS care providers with visits to their lawyers. The proximity also facilitates processing of paperwork.

The AIDS Law Project of Pennsylvania is also located within short walking distance of Philadelphia's City Hall, which houses the Register of Wills and the Recorder of Deeds; landlord/tenant and family courts; federal district court; bankruptcy court; and a law library. The firm is within walking distance or an easy public transportation commute of six major hospitals, enabling staff members to make hospital visits on short notice.

In addition, in order to reach clients who may not realize that they need legal assistance, the firm has long believed that it must reach out to areas where people with HIV access other services. The AIDS Law Project of Pennsylvania entered into its first medical-legal partnership in 1993, with a lawyer<sup>67</sup> rotating among three health care facilities: a Philadelphia Health Department clinic, a pediatric hospital's infectious disease clinic, and a hospital-based practice for HIV-positive pregnant women. A lawyer from the firm worked with women to make permanency plans for their children's futures, and also addressed other needs.

The partnership has had many versions over the years, including its current incarnation as an agreement with the organization Philadelphia FIGHT and its HIV-specialty-care practice, the Jonathan Lax Treatment Center.<sup>68</sup> Once a week, a legal intern under the AIDS Law Project of Pennsylvania's supervision meets with Lax Center patients and conducts intake interviews regarding their legal needs. Each intake is assessed and assigned to someone from the firm for follow-up. The firm also trains the Lax Center's medical staff regarding public benefits and legal entitlements that require medical verification and the manner in which that verification must be provided.

The firm also provides free legal services at Prevention Point Philadelphia, the city's only legal needle-exchange program.<sup>69</sup> Twice a week, a paralegal from

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66. "ActionAIDS, a Philadelphia-based organization works in partnership with people living with or affected by HIV/AIDS, to sustain and enhance their quality of life. [ActionAIDS] provide[s] a range of direct services and take[s] an active and professional approach to leadership in service, education and advocacy." ActionAIDS, ActionAIDS: Mission, <http://actionaids.org/about/mission> (last visited Mar. 5, 2011); see also Philadelphia FIGHT, The Jonathan Lax Center, <http://fight.org/section.php?cat=2&sec=27> (last visited Mar. 5, 2011) (explaining mission of and services available at Lax Center).

67. The firm's initial medical-legal partnership lawyer, Catherine Hanssens, is now Executive Director of the Center for HIV Law and Policy, which she founded after eight years as AIDS Project Director at the Lambda Legal Defense and Education Fund.

68. The Jonathan Lax Treatment Center provides comprehensive primary care to people living with HIV/AIDS. See Philadelphia FIGHT, *supra* note 66.

69. "[Prevention Point Philadelphia] is a non-profit, public health organization committed to protecting the health and welfare of drug users and sex workers. PPP works to reduce the harm associated with drug use and sex industry work by offering a safe and humane alternative to the war on

the firm does intake interviews at a Prevention Point exchange site, documenting cases of unresolved criminal records. In the late nineteen nineties, people with bench warrants or parole/probation violations were prohibited from receiving cash welfare or SSI disability benefits.<sup>70</sup> Although many of these rules have been amended,<sup>71</sup> the firm has continued the program because clients still need help in resolving criminal records.

### B. *Eligibility Criteria*

As discussed above, people with HIV face traditional barriers to legal services and health care: poverty, race, class, geographic location, and limited English proficiency. The AIDS Law Project of Pennsylvania recognizes that other barriers exist as well: stigmatization of gay and transgendered people, unsubstantiated fear of HIV transmission, and the real fear of repercussions if others discover that someone has HIV. As a result, the firm has no financial eligibility criteria for representation, and services are available to anyone in Pennsylvania living with or affected by HIV. As the AIDS epidemic has generally evolved from a short road of diagnosis-to-death into a chronic yet manageable illness, the legal needs of the firm's clients have changed. And the clients themselves are different today: more are heterosexual, more are African American, more are Latino, more are women, and more are intravenous drug users.<sup>72</sup>

### C. *Organizational Structure*

The firm works collaboratively with AIDS health care and social services organizations, bar associations, and law schools throughout Pennsylvania, but remains independent, setting its own standards for client representation, public-policy positions, and program development. Independence allows the firm to assure clients undivided loyalty, and makes it responsible for its own fundraising. The firm is independent by circumstance, not by design: In the early years of the AIDS epidemic in Philadelphia, the mid- to late-1980s, legal services were left to find funding and support alone. The AIDS Law Project of Pennsylvania began with a few startup grants from local and national organizations and a small contract from the city of Philadelphia, and today also receives federal funding and major foundation grants.

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drugs." See Prevention Point Philadelphia, About Us, <http://www.preventionpointphilly.org/about/> (last visited Mar. 5, 2011) (explaining needle exchange program).

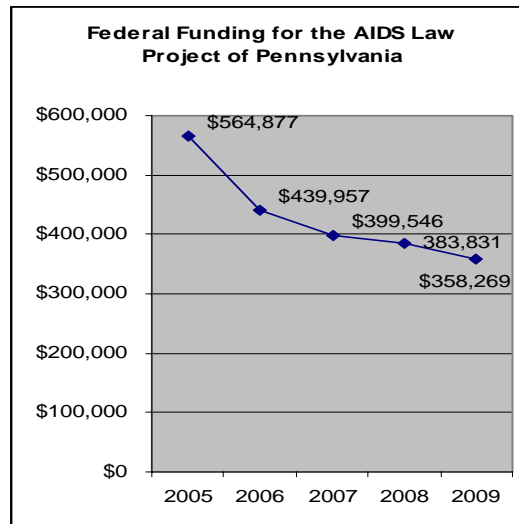
70. See Personal Responsibility and Work Opportunity Reconciliation Act of 1996, Pub. L. No. 104-193, § 202, 110 Stat. 2105, 2185-86 (codified at 42 U.S.C. § 1382(e)(4)(A)) (stating that fleeing to avoid prosecution and violation of parole or probation disqualifies a person from welfare eligibility).

71. For a full review of the "fleeing felon" rules and subsequent amendment, see 42 U.S.C. § 1382 (2006). See also *Martinez v. Astrue*, No. 08-CV-4735 CW (N.D. Cal. Aug. 11, 2009) (stipulation of settlement in class action against commissioner of social security for denying benefits to people with outstanding warrants); Gerald McIntyre, *Have You Seen a Fleeing Felon? Social Security Administration Targets SSI Recipients with Outstanding Warrants*, CLEARINGHOUSE REV., Jan.-Feb. 2003, at 474 (reviewing "fleeing felon" rules in SSI program).

72. AIDS Law Project of Pennsylvania Statistics, 1992-2009 (on file with authors).

#### D. Federal Funding

Most HIV legal services programs receive federal funding through the Ryan White HIV/AIDS Treatment Modernization Act.<sup>73</sup> This funding represents one-third of the annual budget of the AIDS Law Project of Pennsylvania. The Ryan White program is administered by the HIV/AIDS Bureau of the Health Resources and Services Administration in the U.S. Department of Health and Human Services.<sup>74</sup> Funds are awarded to a grantee, usually a health department, which then subcontracts with various service providers (i.e., outpatient and ambulatory health services, pharmaceutical programs, oral-health care, legal services, etc.).<sup>75</sup> Beginning in 2006, the Ryan White Act placed limits on grantee subcontracts, requiring that seventy-five percent of all awarded funds be spent on core medical services.<sup>76</sup> All services not defined as core medical, such as legal services, were designated as supportive and allotted the remaining twenty-five percent.<sup>77</sup> As a result, during the last three years, as the client base has remained relatively constant and clients' needs have become more complex, federal funding for the AIDS Law Project of Pennsylvania has declined steadily.



73. Ryan White HIV/AIDS Treatment Modernization Act of 2006, Pub. L. 109-415, 120 Stat. 2767 (2006) (codified at 42 U.S.C. § 300ff). "Legal services are the provision of services to individuals with respect to powers of attorney, do-not-resuscitate orders and interventions necessary to ensure access to eligible benefits, including discrimination or breach of confidentiality litigation as it relates to services eligible for funding under the Ryan White HIV/AIDS Program. It does not include any legal services that arrange for guardianship or adoption of children after the death of their normal caregiver." HIV/AIDS BUREAU, HEALTH RES. & SERVS. ADMIN., INSTRUCTIONS FOR COMPLETING THE 2008 RYAN WHITE HIV/AIDS PROGRAM ANNUAL DATA REPORT 18 (2009) (emphasis omitted).

74. Ryan White HIV/AIDS Treatment Modernization Act of 2006 § 107(a)(2).

75. *Id.* § 105.

76. *Id.*

77. *Id.*

As the chart above shows, in 2006 the firm lost twenty-three percent of its federal funding, a \$124,920 loss. In 2007, federal funding dropped another ten percent from 2005 levels to a low of \$399,546, or thirty percent below the 2005 level. Another four percent drop of \$15,715 in 2008 brought the decline to \$181,046, a thirty-two percent decrease since 2005. Finally, in 2009, federal funds dropped another \$25,562, an additional seven percent, making the cumulative percentage loss over four years thirty-seven percent, which is equal to a \$206,608 loss. To maintain the same necessary level of services, these dramatic funding cuts must be recouped through other sources.

## V. SERVICES PROVIDED

The mission of the AIDS Law Project of Pennsylvania is to provide free legal services throughout Pennsylvania to people living with HIV/AIDS and others affected by the epidemic.

The firm does this through three separate forms of advocacy: 1) offering a full complement of civil legal services through direct representation; 2) providing trainings and community education to people living with HIV, health care providers, law students, and the public; and 3) advocating for public policy at the local, state, and national levels that will both improve public health and protect the rights of those affected by HIV/AIDS.

### A. *Direct Representation*

The firm offers a variety of services to our clients that are designed to mitigate health disparities by targeting and attempting to eliminate specific barriers in people's lives that will impact their health if left unaddressed. Some services are specifically related to HIV, such as legal representation for individuals who have faced discrimination and concerns with their medical privacy. Others are related to accessing health care, such as government (Medicaid or Medicare) or private insurance enrollment and coverage disputes. The firm also provides disability-related services, such as obtaining social security disability benefits or private disability insurance, and addresses the poverty-related need for welfare and food stamps. Housing and family law services are also provided. Finally, the firm offers services to provide for estate and permanency planning, such as wills, living wills, and powers of attorney, which are recommended regardless of a client's health or income.

The firm's programs have been successful. Each year, an in-house quality-assurance review of housing and public-benefits programs finds that about eighty-five percent of clients seeking public benefits are enrolled in an appropriate public or private health-insurance program by the time their files are closed. Among clients with housing issues, a similar percentage has safe, affordable housing by the time their cases are closed.

As discussed above, the services we provide can broadly be grouped into the following categories: "1) Individual socioeconomic circumstances[;] 2) Physical

and cultural community environment[;] 3) Personal management of health[; and] 4) Health care financing and delivery.”<sup>78</sup>

#### 1. Individual Socioeconomic Circumstances

The firm helps clients who are unable to work because of deteriorating health to obtain income replacement through Social Security and private-insurance disability benefits. For some clients, Social Security disability benefits may represent a significant financial increase from a state welfare benefit,<sup>79</sup> while for others, transitioning from employment to disability can result in a loss of income. The assurance of a monthly check allows the client to build a life based on a fixed and predictable income.

For clients receiving disability benefits whose health has improved enough to make them feel ready to return to work, the firm developed a back-to-work program. Clients wanted to work but were afraid of losing their disability benefits, particularly health insurance, which had enabled them to get the health care that had made them feel well enough to work. In addition to seeking an income supplement, these clients felt alone and disconnected from society without the structure of a job. The firm helps these clients negotiate the work-incentive rules of the Social Security Administration and private disability insurers.

Illness is expensive, regardless of a person’s socio-economic status. The firm developed a program responding to the enormous health-related debt accumulated by many clients.<sup>80</sup> For some, it may involve working out payment plans with creditors to build a financial future. For others with limited resources or who are too ill to think of their futures, it may involve helping to discharge debt through loan-forgiveness programs and bankruptcy. Resolving debt goes a long way toward ameliorating the stress from harassing bill-collectors and providing peace of mind.

#### 2. Physical and Community Environment

The AIDS Law Project of Pennsylvania also seeks to intervene when individuals’ HIV status starts to impact their physical and community environment, specifically in the areas of discrimination, family law, and housing. In 2009, the AIDS Law Project responded to seventy-nine new complaints of AIDS discrimination.<sup>81</sup> Successful challenges to discrimination send the message that

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78. MEYERS, *supra* note 59, at 11; *see id.* at 16–21 (discussing each category in greater detail).

79. In Philadelphia in 2010, the general-assistance benefit for one person was \$205 a month. Pennsylvania Department of Public Welfare Cash Assistance Handbook, *available at* [http://services.dpw.state.pa.us/oimpolicymanuals/manuals/bop/ca/168/168\\_C.htm#TopOfPage](http://services.dpw.state.pa.us/oimpolicymanuals/manuals/bop/ca/168/168_C.htm#TopOfPage). The maximum federal Supplemental Security Income (“SSI”) payment amount for an eligible individual in 2010 is \$674.00 per month. SOCIAL SECURITY ADMINISTRATION, ANNUAL REPORT OF THE SUPPLEMENTAL SECURITY INCOME PROGRAM 28 tbl.IV.A2 (2009), *available at* <http://www.ssa.gov/OACT/ssir/SSI09/ssi2009.pdf>.

80. Our clients’ financial concerns fall in line with other individuals with chronic medical conditions who face debt due to their health. *See* David U. Himmelstein et al., *Medical Bankruptcy in the United States, 2007: Results of a National Study*, 122 AM. J. MED. 741, 742 (2009) (finding that 62.1% of all personal bankruptcies in 2007 were medical in nature).

81. AIDS Law Project of Pennsylvania Statistics, *supra* note 72.

people with HIV do not pose a threat, and help to reduce the stigma that fuels the AIDS epidemic. People who are stigmatized and socially excluded are less likely to seek treatment once infected or to change their behavior to reduce the risk of future transmission.<sup>82</sup>

HIV discrimination occurs in all areas of society and interferes with an individual's employment, housing, or access to medical care and other public services. The firm has represented lawyers, doctors, truck drivers, clergy, barbers, executives, food-service workers and even a gymnastics instructor in employment discrimination cases. Clients have been denied services by dentists, surgeons, bikini-waxers, tattoo parlors, funeral homes, fertility clinics, and adoption agencies. They have been excluded from high school football teams, personal-care homes, health clubs, cosmetology classes, and medical-assistance training programs.

When people living with HIV/AIDS challenge discrimination, it helps the citizenry at large. The AIDS Law Project of Pennsylvania twice sued Philadelphia's fire department because emergency medical technicians refused to treat patients with HIV.<sup>83</sup> The settlement agreement<sup>84</sup> in both cases required that all EMTs be trained on infection control—a benefit to anyone who ever has to call 911.<sup>85</sup>

In 1994, the firm sued a Philadelphia health club with a predominantly gay male clientele, after a member was ejected because of fears of HIV transmission.<sup>86</sup> The settlement in this case was not just a validation for the client and his family—although the plaintiff did not live long enough to see the resolution—but sent a clear message to the community that people with HIV need not be feared and present no risk of transmission in casual settings.

In addition to securing the place of people with HIV/AIDS in the community, the firm has worked to ensure a safe physical place for them. In the late 1990s, recognizing the impact of safe, affordable housing as an important factor in positive health outcomes, the firm began representing tenants facing eviction. A

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82. Jennifer N. Sayles et al., *The Association of Stigma with Self-Reported Access to Medical Care and Antiretroviral Therapy Adherence in Persons Living with HIV/AIDS*, 24 J. GEN. INTERNAL MED. 1101, 1103 (2009) (finding that individuals with HIV reporting high level of stigma were more likely to report poor access to care, regular source of HIV care, and ART adherence).

83. See *Smith v. City of Philadelphia*, 345 F. Supp. 2d 482, 484–85 (E.D. Pa. 2004) (noting that such claims were filed in 1994 and 2001). The first case was brought administratively with the U.S. Department of Justice. *Id.* at 485. The firm often works with outside counsel to assist with litigation. The firm was grateful to partner with Gregory L. Liacouras from the law firm of Liacouras & Smith in this case.

84. The 1994 settlement was the first with the U.S. Department of Justice based on an ADA claim. See Valerie M. Russ, *AIDS Discrimination Case Settled: City Ambulance Crew Refused to Treat Patient*, PHILA. DAILY NEWS, Mar. 22, 1994, at 6 (noting that this was first formal AIDS discrimination settlement under Americans with Disabilities Act).

85. Settlement Order at ¶ 6, *Smith v. City of Philadelphia*, 345 F. Supp. 2d 482 (E.D. Pa. 2004) (No. 03-6494), 2006 WL 38777443, available at <http://www.ada.gov/gillsmith.htm>.

86. Joseph A. Slobodzian, *Lawsuit Accuses Gym of AIDS Bias: A Center City Man Says the Owner Embarrassed then Ejected Him After Learning He Had AIDS*, PHILA. INQUIRER, Aug. 18, 1994, at B1. The plaintiff's lawyers "called the suit the first against a fitness center under the two-year-old Americans with Disabilities Act, the federal law that requires facilities that serve the public to accommodate people with disabilities, including AIDS or HIV, the AIDS virus." *Id.*



subsequent study confirmed “a significant relationship between homelessness/unstable housing and remaining outside of, or marginal to HIV medical care.”<sup>87</sup> People with HIV/AIDS who receive meaningful “housing assistance are almost four times more likely to enter into medical care . . . and they are twice as likely to enter into and continue in care that meets current clinical standards for treatment of HIV/AIDS,” the study found.<sup>88</sup> The firm’s housing program has extended to representation of homeowners facing mortgage foreclosures.

In addition, the firm has a family law program designed to maintain stability in the face of illness. It allows terminally ill parents to name a future guardian for their children in the event of incapacity or death. This process provides for a smoother transition for the surviving family, reducing the negative impact on children’s futures.

### 3. Personal Management of Health

The AIDS Law Project of Pennsylvania works to ensure that clients understand that their medical information is private and may not be shared without permission, except in certain limited circumstances.<sup>89</sup> In the absence of assurances concerning the privacy of HIV-related information, some clients will not seek health care for fear that the news of their HIV will spread, with potentially dangerous consequences. In 2009, the firm responded to seventy-three complaints of violations of HIV-specific medical privacy.<sup>90</sup>

Over the years, the firm has provided representation in a wide variety of privacy cases. These have included: corporate snooping involving a public-transportation agency employee’s review of employees’ prescription records to determine their health conditions;<sup>91</sup> a doctor yelling out a warning in a hospital hallway that a patient has HIV, just as the man’s twelve-year-old son, unaware of his father’s diagnosis, entered his hospital room; and a county child-and-youth worker showing up unannounced at a client’s home while she is entertaining a

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87. ANGELA A. AIDALA ET AL., COLUMBIA UNIV. SCH. OF PUB. HEALTH, COMMUNITY HEALTH ADVISORY & INFORMATION NETWORK REPORT 2001–10 UPDATE REPORT 41, HOUSING STATUS AND HEALTH OUTCOMES AMONG PERSONS LIVING WITH HIV/AIDS 12 (2001).

88. *Id.*

89. In Pennsylvania, an individual’s HIV status is specifically protected by the Confidentiality of HIV-Related Information Act (commonly known as “Act 148”), 35 PA. CONS. STAT. §§ 7601–7612 (2010). An individual whose HIV status has been disclosed in violation of Act 148 can bring a civil suit for compensatory damages. *Id.* § 7610. The federal Health Insurance Portability and Accountability Act (“HIPAA”), 45 C.F.R. pt. 160 (2010) also provides protection against disclosure of personal health information.

90. AIDS Law Project of Pennsylvania Statistics, *supra* note 72.

91. *See Doe v. Se. Pa. Transp. Auth.*, 886 F. Supp. 1186, 1192–93 (E.D. Pa. 1994) (finding such action to be unreasonable search); *see also* Huntly Collins, *Rite Aid Settles Over HIV Privacy*, PHILA. INQUIRER, Dec. 23, 1994, at B01 (noting settlement agreement ensured customer confidentiality in billing procedures). As part of an out-of-court settlement, Rite Aid Corp. “agreed not to divulge any AIDS-related prescription information to Pennsylvania employers.” *Id.* “The AIDS Law Project believes this case to be the first in the nation to address the very real fear that employers will use health benefit records to learn an employee’s HIV status,” said the firm’s managing attorney, Yolanda French Lollis Esq. *Id.* The firm was grateful to partner with the Law Office of Clifford Boardman in this case.

friend from church, and asking whether she is getting enough supportive services to handle her HIV. The great majority of these complaints are settled without judicial intervention because clients often fear further disclosure, even though many lawsuits have been filed using pseudonyms.

Related to the idea of privacy of medical information is the right to make one's own treatment and property decisions. In 2009, the firm prepared 173 wills, living wills, and medical and financial powers of attorney.<sup>92</sup> These documents, about twenty percent of which were prepared in clients' homes or hospital rooms, enabled them to retain a voice in their health care decisions. The firm also represents clients who are having difficulty resolving the estates of their deceased lovers or partners. In 2010, the firm secured the proceeds of a client's deceased partner's annuity contracts, after the company had originally sought out and awarded the proceeds to the deceased partner's ex-wife, whom he had divorced over twenty years prior.<sup>93</sup> These services enable our clients to take control of important decisions in their lives, and to feel confident that their wishes will be respected in both life and death.

#### 4. Health Care Financing

Finally, the AIDS Law Project of Pennsylvania works to mitigate health disparities by offering services to help individuals access health care. These services include enrolling clients in public or private health insurance programs and responding to coverage problems, such as preexisting condition exclusions, out-of-network providers, restrictive formularies, and prior authorization for services.

For example, in 2007, the firm worked to secure the health insurance of a client who had sold her life and health insurance policies to a viatical settlement company in 1994, before the discovery of antiretroviral treatment for HIV.<sup>94</sup> After comprehensive treatment became available, and it became clear that our client planned to live a long and healthy life, the viatical company informed our client that it would no longer abide by the terms of the contract, in which it had agreed to pay her health insurance premiums for the remainder of her life.<sup>95</sup> The New Jersey Superior Court found against the company, finding an anticipatory breach of contract, and the appellate court agreed.<sup>96</sup> The parties subsequently reached settlement, and our client was able to continue to access the care she needed to maintain her health.

The firm also has pursued health care-related cases that have had a positive impact on more than just the individual plaintiff. For example, the firm

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92. AIDS Law Project of Pennsylvania Statistics, *supra* note 72.

93. *See* Teachers Ins. & Annuity Ass'n of Am. v. Bernardo, No. 09-911, 2010 WL 299560, at \*6 (E.D. Pa. Jan. 26, 2010) (awarding death benefits to client as lawful beneficiary of annuity contracts). The firm was grateful to partner with the Law Office of Brian E. Appel in this case.

94. *See* Smith v. Life Partners, Inc., No. A-1151-06T1, 2007 WL 2847400, at \*18 (N.J. Super. Ct. App. Div. Oct. 3, 2007) (finding that defendant's anticipatory breach warranted judgment for plaintiff). The firm was grateful to partner with Jacob C. Cohn from the law firm of Cozen O'Connor in this case.

95. *Id.* at \*1.

96. *Id.* at \*18.

successfully represented a man with HIV who had been denied a liver transplant because the Pennsylvania Department of Welfare medical assistance office considered HIV to be a life-limiting condition.<sup>97</sup> Since the firm's successful appeal, the state views each transplant case on its own merits.

#### B. Community Education

In addition to providing direct services, another important part of the firm's efforts to reduce health disparities in HIV throughout the state involves training and education of the community at large. During more than two decades, the AIDS Law Project of Pennsylvania has trained more than 32,000 Pennsylvanians, including people with HIV and their friends and families; health care professionals; social workers; and medical, law, and undergraduate students.

The firm offers three free monthly seminars: "Leaving Your Job," which explains how to make a smooth transition from the working world to disability benefits and how to avoid common debt pitfalls; "Back to Work," which details the work-incentive provisions of the Social Security Administration and private long-term disability insurers, helping people try to work without jeopardizing disability benefits and showing how additional income can improve a credit rating; and "Landlord-Tenant Law," which focuses on tenants' rights and responsibilities to prevent common landlord-tenant problems that threaten housing stability. The firm also offers seminars on HIV/AIDS-related legal issues such as discrimination and confidentiality of medical records, parental rights, and public benefits.

As part of its mission to educate about HIV/AIDS-related legal issues, the firm has partnered with Philadelphia's newest law school, the Drexel University Earle Mack School of Law, to establish a "field clinic" in which eight law students obtain real-world experience representing clients.<sup>98</sup> The students handle telephone and walk-in cases and meet twice a week to discuss cases and assign new ones. Each student specializes in a substantive area and has a specific caseload. The firm's law school partnership serves a two-fold benefit of providing our clients with additional resources to help access the services they need, and helping to educate the community about the barriers that people with HIV still face. As recent surveys have found that "notable shares [of individuals still report that] they would be uncomfortable with an HIV-positive co-worker (23 percent), child's teacher (35 percent of parents), or roommate (42 percent), and fully half (51 percent) of adults say they would be uncomfortable having their food prepared by someone who is HIV positive,"<sup>99</sup> education of the public in this respect is far from complete.

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97. *AIDS Law Project Helps Altoona Man Get New Liver After Medicaid Denies Coverage*, GOOD COUNSEL NEWSLETTER (AIDS Law Project of Pennsylvania, Philadelphia, PA) (Apr. 2004), available at <http://www.aidslawpa.org/spring2004.pdf>.

98. Earle Mack School of Law at Drexel University, Field Clinics, <http://www.earlemacklaw.drexel.edu/field-clinics.asp> (last visited Mar. 5, 2011).

99. THE HENRY J. KAISER FAMILY FOUNDATION, *supra* note 54, at 4.

C. *Public Policy*

Finally, the firm is extensively involved in advocating for and shaping policies that affect the lives of those living with HIV. The AIDS Law Project of Pennsylvania is the convener of the HIV Policy Collaborative of Pennsylvania, a statewide network of eighteen AIDS service organizations promoting equitable HIV/AIDS policy. Since its inception in 2007, the collaborative has worked on syringe access, development of an AIDS curriculum and policies for public schools and children-and-youth agencies, and monitoring implementation of the CDC's recommendations on HIV testing as it affects Pennsylvania's law on HIV testing and counseling.<sup>100</sup> The 2010 policy priorities include addressing potential cuts to HIV/AIDS services in Pennsylvania's budget.

The collaborative has successfully advocated to amend Pennsylvania's syringe regulations to allow over-the-counter pharmacy sales of hypodermic needles and syringes.<sup>101</sup> Previously a prescription was required to purchase these items, but the change reflects well-established evidence that increased access to clean needles and syringes is essential to reduce the spread of hepatitis C virus ("HCV") and HIV, and that such a change will not result in increased drug use.<sup>102</sup>

The firm has shaped public policy by representing an HIV-positive man who had been denied admission into cosmetology school. The school's denial was based on the state's occupational licensing rules requiring applicants for cosmetology licenses to certify that they were free of communicable disease.<sup>103</sup> After the firm challenged the regulations as violating the Americans with Disabilities Act, the Pennsylvania Board of Cosmetology disseminated a clarification to cosmetology schools that "denying admission to an HIV/AIDS applicant is in direct conflict with the federal ADA."<sup>104</sup> The firm made further strides on this issue in January, 2011, when it convinced Pennsylvania's Department of State to issue a policy statement specifically excluding HIV as an infectious, communicable, or contagious disease, since it is not transmitted

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100. A chart of the collaborative's accomplishments appears at Appendix 1.

101. The change in state pharmacy regulations comes as a result of more than a decade of advocacy efforts by a broad coalition of pharmacists and other health-care providers, HIV/AIDS service organizations, public-health professionals, legislators, lawyers, and individual HIV-prevention activists. In 2007, in response to these concerns, the state pharmacy board began the process, including opportunities for public comment and legislative input, to amend its syringe regulation. The Pennsylvania Independent Regulatory Review Commission approved the final regulation in July 2009, and it became effective Sept. 12, 2009. See 49 PA. CODE Ch. 27; 39 Pa. Bull. 5312 (Sept. 12, 2009) (amending 49 Pa. Code § 27.18 to include subsection (s)).

102. H. Hagan et al., *Reduced Risk of Hepatitis B and Hepatitis C Among Injection Drug Users in the Tacoma Syringe Exchange Program*, 85 AM. J. PUB. HEALTH 1531, 1536 (1995) (finding that needle exchange program led to significant reduction in hepatitis B and C as well as substantial reduction in HIV transmission).

103. Letter from Basil L. Merenda, Commissioner, Pennsylvania Bureau of Professional and Occupational Affairs (May 22, 2006), available at <http://www.portal.state.pa.us/portal/server.pt?open=18&objID=487676&mode=2>.

104. *Id.*

through casual contact or through the usual practice of the profession or occupation for which a license is required.<sup>105</sup>

The AIDS Law Project of Pennsylvania has had considerable impact on legislation.<sup>106</sup> The firm drafted Pennsylvania's standby-guardianship act, which was passed into law in 1998.<sup>107</sup> The law allows terminally ill parents to plan for their children's futures. Instead of being required to relinquish parental rights, a parent now may designate a guardian to be on "standby" in the event of illness or death.<sup>108</sup>

## VI. ANALYSIS OF SERVICES PROVIDED

The AIDS Law Project of Pennsylvania relies upon various sources of information to understand its clients' needs and develop appropriate responsive programs. The firm talks to clients and other AIDS service providers to track trends in how HIV/AIDS is affecting the people living with the disease. The firm also created a detailed database with client demographics and other relevant information.

Using this database, the firm can compare its client population with the epidemiological information collected by the Philadelphia Department of Public Health ("PDPH"). Comparing the firm's clients from 2007 with data from PDPH for the same year reveals that the firm's clients closely approximate the epidemic in Philadelphia in terms of gender and race/ethnicity.<sup>109</sup> The data regarding the age of HIV-infected adults demonstrates, not unsurprisingly, that an individual's legal needs increase as they age. This is important information for the firm in planning for the future. As younger people with HIV/AIDS age, the demand for legal services more closely connected with maturity (i.e., employment, personal finances, home ownership, etc.) will increase.

**Table 1. Demographic characteristics of AIDS Law Project of Pennsylvania clients and adults living with HIV/AIDS in Philadelphia County, 2007<sup>110</sup>**

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105. See Pennsylvania Department of State, Bureau of Professional and Occupational Affairs Policy Statement Interpreting the Term "Infectious, Communicable or Contagious Disease," available at <http://www.dos.state.pa.us/portal/server.pt/community/licensing/12483> (last visited Mar. 5, 2011).

106. The firm's deputy managing attorney, Cathryn Miller-Wilson Esq., the primary author of the bill, also actively educated and encouraged legislators to support it.

107. 23 PA. CONS. STAT. ANN. §§ 5601-5616 (2010).

108. *Id.* § 5611.

109. See *infra* table 1 for data showing that the gender and race/ethnicity of the firm's clients correlate with the gender and race/ethnicity of all Philadelphians with HIV/AIDS.

110. Sources for data (2007 is the latest year for which comparable data are available): AIDS Law Project of Pennsylvania client database; PHILA. DEP'T OF PUB. HEALTH, PHILADELPHIA HIV/AIDS EPIDEMIOLOGICAL UPDATE 6 tbl.4 (2007).

	AIDS Law Project of PA clients (Phila. residents only), 2007	Philadelphia residents living with HIV/AIDS, 2007
<b>Gender</b>		
Male	61.5 %	70.4 %
Female	37.6 %	29.6 %
Transgendered	0.9 %	n/a
	100.0 %	100.0 %
<b>Race/Ethnicity</b>		
Black / African American, not Hispanic	64.9 %	65.9 %
Hispanic	7.3 %	12.0 %
White, not Hispanic	25.0 %	21.0 %
Other	2.9 %	1.1 %
	100.0 %	100.0 %
<b>Age<sup>111</sup></b>		
13-19	0.4 %	3.8 %
20-29	6.2 %	25.5 %
30-39	18.8 %	36.1 %
40-49	44.1 %	23.5 %
50 +	24.9 %	9.8 %
Unknown	5.6 %	1.3 %
	100.0 %	100.0 %
<b>Annual Income</b>		
10 <sup>th</sup> percentile	\$ 2,460	
25 <sup>th</sup> percentile	\$ 6,720	<i>data</i>
Median	\$ 8,412	<i>not</i>
75 <sup>th</sup> percentile	\$ 15,600	<i>available</i>
90 <sup>th</sup> percentile	\$ 29,760	

111. AIDS Law Project of Pennsylvania clients: age at intake; Philadelphians Living with HIV/AIDS: age at time of diagnosis.

A review of the firm's database also reveals the connection between income and the type of legal service requested. The firm's poorest clients are seeking public benefits and other income replacements, while higher income clients are concerned with employment and private insurance matters. As the epidemic increasingly becomes a disease of poverty, legal services providers need to plan accordingly to offer those services that may be in greater demand.

**Table 2. Median annual income of AIDS Law Project of Pennsylvania clients, by type of service provided, 1992–2009<sup>112</sup>**

	Median income of clients provided this type of service	Number of cases
Public disability benefits (SSI and SSDI)	\$ 6,000	1,822
Prison-related	\$ 7,092	103
Family law	\$ 7,097	993
Welfare benefits and food stamps	\$ 7,100	222
Housing	\$ 7,800	2,614
Probate	\$ 7,980	116
Estate planning	\$ 8,202	864
Financial issues	\$ 9,384	1,261
Back to work	\$ 9,600	231
Public health insurance (Medicaid and Medicare)	\$ 9,768	490
Discrimination	\$ 10,440	631
HIV confidentiality	\$ 10,800	493
Immigration	\$ 12,000	245
HIV transmission	\$ 12,360	59
Employment-related benefits	\$ 13,200	83
Insurance	\$ 14,400	747
HIV testing	\$ 16,800	67

Finally, a review of the most prevalent types of services the firm has provided offers insight into how clients' attitudes toward the epidemic have changed.<sup>113</sup> In the early years of the epidemic, clients had very short life expectancies, and their

112. Source for data: AIDS Law Project of Pennsylvania client database. Some clients are categorized under multiple types of cases; only the most prevalent types of cases are listed.

113. See *infra* table 3 for data on the services provided by the firm.

primary legal needs were wills, living wills, and powers of attorney. Clients were also very concerned about their privacy. As time passed and clients lived longer, their needs shifted to concerns for income replacement and housing stability. Notably, confidentiality and discrimination have become relatively less of a priority, as the epidemic moves into its third decade. This decrease in demand, however, should not be misinterpreted as an end to HIV discrimination or the stigma associated with the disease, which studies have shown remains quite prevalent.<sup>114</sup>

**Table 3. Most prevalent types of services provided by the AIDS Law Project of Pennsylvania, 1992-2009**

*ranked by number of cases handled in each period*<sup>115</sup>

1992-1996	1997-2000	2001-2004	2005-2009
Estate planning (1,269)	SSI and SSDI (1,172)	Housing (1,158)	Housing (1,628)
HIV confidentiality (1,127)	Prison-related (740)	SSI and SSDI (916)	SSI and SSDI (1,045)
Insurance (943)	HIV confidentiality (680)	Family law (744)	Financial issues (659)
Discrimination (775)	Housing (675)	Financial issues (632)	Insurance (411)
SSI and SSDI (644)	Family law (614)	Estate planning (492)	Estate planning (372)
Family law (588)	Insurance (594)	HIV confidentiality (401)	HIV confidentiality (370)
HIV testing (532)	Estate planning (556)	Insurance (367)	Discrimination (352)
Housing (402)	Discrimination (542)	Discrimination (346)	Family law (340)
Financial issues (384)	Financial issues (419)	Medicaid, Medicare (251)	Medicaid, Medicare (333)
Prison-related (370)	Medicaid, Medicare (348)	Immigration (223)	Prison-related (302)

114. See *supra* notes 51-56 and accompanying text for a discussion of the prevalence of stigma.

115. Source for data: AIDS Law Project of Pennsylvania client database. Some clients are categorized under multiple types of cases; only the most prevalent types of cases are listed.



## VII. OTHER MODELS OF HIV/AIDS LEGAL SERVICES CENTER

The AIDS Law Project is certainly not the only legal service provider for people living with HIV and AIDS. The AIDS Law Project is an independent public interest law firm dedicated solely to representing individuals with HIV. Some other organizations follow this same model, such as the HIV & AIDS Legal Services Alliance (“HALSA”) in Los Angeles,<sup>116</sup> the HIV Law Project in New York,<sup>117</sup> the AIDS Legal Council of Chicago,<sup>118</sup> and AIDS Law of Louisiana.<sup>119</sup> Other legal organizations work within a dedicated health clinic, such as the Whitman-Walker Clinic in Washington, D.C.,<sup>120</sup> or the Gay Men’s Health Crisis in New York.<sup>121</sup> Still

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116. The HIV & AIDS Legal Services Alliance (“HALSA”) provides legal representation, technical assistance to attorneys, law firms, and public interest organizations, advocacy, and community education. HIV & AIDS Legal Services Alliance, <http://www.halsaservices.org> (last visited Mar. 5, 2011). It is a leading legal services provider for low-income individuals living with HIV/AIDS, and is an expert “in the fields of discrimination, privacy, immigration, employment, housing, public benefits, and tax issues.” HIV & AIDS Legal Services Alliance, Mission and Goals, [http://www.halsaservices.org/mission\\_and\\_goals.php](http://www.halsaservices.org/mission_and_goals.php) (last visited Mar. 5, 2011). HALSA originated as five separate legal services projects organized in Los Angeles throughout the 1980s. HIV & AIDS Legal Services Alliance, History, <http://www.halsaservices.org/history.php> (last visited Mar. 5, 2011). After determining that these five organizations could better meet the legal needs of local individuals living with HIV and AIDS, the five programs formed a collaborative consortium in 1997, later transitioning to a single, independent, nonprofit organization in 2001. *Id.* HALSA provides free counseling and legal assistance to individuals living with HIV and is the primary provider of such legal services in Southern California. HIV & AIDS Legal Services Alliance, *supra*.

117. The HIV Law Project was founded in 1989 in order to provide legal services and advocacy programs to underserved and low-income individuals living with HIV and AIDS in New York City. HIV Law Project, Who We Are, <http://hivlawproject.org/WhoWeAre/history.html> (last visited Mar. 5, 2011). Its work spans a wide range, including direct services, comprehensive family-centered services combining legal and social work, ancillary support services, community education, technical assistance, public policy advocacy, and impact litigation to effect systemic reform. HIV Law Project, What We Do, <http://hivlawproject.org/WhatWeDo/index.html> (last visited Mar. 5, 2011).

118. The AIDS Legal Council of Chicago was founded in 1987 in recognition of the legal problems faced by people with HIV, including discrimination and mistreatment in the areas of employment, insurance, housing, and education. AIDS Legal Council of Chicago, About Us, Mission and History, <http://aidslegal.com/mission-history.html> (last visited Mar. 5, 2011). Currently, the ALCC works on three fronts: it provides direct legal services to individuals in need, it educates the public on HIV-related issues, and it advocates for public policies that treat fairly those impacted by HIV/AIDS. *Id.* It includes such initiatives as the James Monroe Smith Outreach Office (an office on the campus of Cook County Hospital), a Latino Outreach Project, a Return-to-Work Project aimed at counseling individuals on their employment rights, an HIV-Positive Immigrants’ Rights Project, and a Youth Legal Rights Project that provides school workshops and health fairs. *Id.*

119. AIDS Law of Louisiana formed in 1989 and is the only organization in Louisiana that is dedicated to serving the needs of low-income individuals living with HIV and AIDS. AIDS Law of Louisiana, Inc., <http://www.aidslaw.org> (last visited Mar. 5, 2011). It provides legal assistance in areas including personal and estate planning, simple succession matters, family law, discrimination, notarial services, debtor/creditor issues, public benefits, privacy issues, and insurance. AIDS Law of Louisiana, Inc., Services Provided, <http://www.aidslaw.org/servicesprovided.php> (last visited Mar. 5, 2011). In addition to direct legal services, AIDS Law of Louisiana provides public education and training services and has submitted amicus curiae, or “friends of the court,” briefs on HIV/AIDS-related legal issues. *Id.*

120. The Whitman-Walker Clinic began in November 1973 as the Gay Men’s VD Clinic, part of the Washington Free Clinic. Whitman-Walker Clinic, Our History, [http://www.org/about\\_wwc/history.html](http://www.org/about_wwc/history.html) (last visited Mar. 5, 2011). It became officially known as the Whitman-Walker Clinic in 1978 and has as its mission “to be the highest quality, culturally competent community health center serving greater

other organizations work out of established law school clinics, such as the WilmerHale Legal Services Center at Harvard Law School in Boston,<sup>122</sup> and the East Bay Community Law Center in Berkeley, California.<sup>123</sup>

#### VIII. CONCLUSION

The AIDS Law Project of Pennsylvania and the organizations discussed above all developed to address the legal barriers that stand in the way of positive health outcomes for people living with HIV. As the needs of people living with HIV have changed over the years with the shifting demographics of the epidemic and the emergence of new treatments, so have these organizations correspondingly attempted to address these shifting needs.

In some ways, HIV/AIDS presents unique challenges to those whom it affects. At base, however, the AIDS activist movement that was born in the early 1980s and gave birth to organizations like the AIDS Law Project of Pennsylvania represented a fundamental shift in the way health was understood. AIDS activists

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Washington's diverse urban community." Whitman-Walker Clinic, Our Mission, [http://wwc.org/about\\_wwc/mission.html](http://wwc.org/about_wwc/mission.html) (last visited Mar. 5, 2011). It began providing HIV/AIDS-related legal services in 1986 and now provides pro bono HIV-related and LGBT health-related legal services in the areas of discrimination and reasonable accommodation, insurance, immigration, public benefits, return-to-work counseling, wills, advance directives and powers of attorney, and debtors' rights. Whitman-Walker Clinic, Our History, *supra*; Whitman-Walker Clinic, Legal Services, [http://wwc.org/about\\_wwc/fact7.htm](http://wwc.org/about_wwc/fact7.htm) (last visited Mar. 5, 2011).

121. The Gay Men's Health Crisis ("GMHC") began as the nation's first AIDS hotline in 1981 and now advocates at the city, state, and federal levels for HIV-related public policies that promote HIV prevention, treatment, and care. Gay Men's Health Crisis, About Us, <http://www.gmhc.org/about-us> (last visited Mar. 5, 2011). GMHC provides direct legal services in the areas of discrimination, confidentiality, employment, insurance, bankruptcy and debt management, estate planning, landlord/tenant disputes, and immigrant rights. Gay Men's Health Crisis, Legal Services, <http://www.gmhc.org/get-support/stay-healthy/legal-services> (last visited Mar. 5, 2011). It also provides technical assistance to legal and public interest organizations. *Id.*

122. The WilmerHale Legal Services Center ("LSC") is a general practice law firm and Harvard Law School's largest and oldest clinical teaching facility. WilmerHale Legal Services Center, About the Legal Services Center, <http://www.law.harvard.edu/academics/clinical/lsc/about/index.htm> (last visited Mar. 5, 2011). It was founded at Harvard Law School in 1979 to provide legal services to low-income clients and clinical education for law students and attorneys. WilmerHale Legal Services Center, History, [www.law.harvard.edu/academics/clinical/lsc/about/history.htm](http://www.law.harvard.edu/academics/clinical/lsc/about/history.htm) (last visited Mar. 5, 2011). "Beginning in 1987, the Center created the first law school-based AIDS law clinics in the nation." Robert Greenwald, *The Role of Community-Based Clinical Legal Education in Supporting Public Interest Lawyering*, 42 HARV. C.R.-C.L. L. REV. 569, 571 (2007). It now encompasses over a dozen clinics that provide direct legal services, including the Health Law and Policy Clinic, which participates in policy initiatives such as working legislation relating to HIV testing. WilmerHale Legal Services Center, Health Law & Policy Clinic, <http://www.law.harvard.edu/academics/clinical/lsc/clinics/health.htm> (last visited Mar. 5, 2011).

123. Located in Berkeley, California, the East Bay Community Law Center was founded in 1988 by law students at U.C. Berkeley's Boalt Hall School of Law. East Bay Community Law Center, History, <http://ebclc.org/history.php> (last visited Mar. 5, 2011). Initially a small clinic at the law school, the organization was formed as a means for law students at Boalt Hall to gain clinical experience while providing assistance to low-income clients. *Id.* It currently provides legal services in the areas of HIV and health, as well as housing, welfare, homelessness, and economic development, and has become the largest provider of free legal services in the East Bay area. East Bay Community Law Center, Our Mission, <http://ebclc.org/mission.php> (last visited Mar. 5, 2011).

pushed for a holistic understanding of health and stressed that positive health outcomes could best be achieved if interventions included a “community-based understanding of the social, cultural, and political forces that affect the lives of persons at heightened risk.”<sup>124</sup> For this communitarian approach to achieve success, communities must be empowered to fight for their own health, and health promotion must be based on voluntary involvement.

Although this framework grew out of the AIDS activist movement, its values have subsequently been recognized and applied to individuals with all sorts of health conditions, in an effort to mitigate health disparities that are exacerbated through legal challenges. The AIDS Law Project of Pennsylvania, along with many other organizations, works within this framework to eliminate health disparities and improve health outcomes by encouraging individuals to fight back against the challenges they face through legal intervention. It is our hope that the information provided in this Article can serve as a guide for practitioners seeking to develop such medical-legal partnerships or freestanding public interest law firms. In order to fully recognize that health is a human right to which all individuals should be entitled equal access, the models that have developed to address HIV should no longer be the exception, but must become the rule.

#### APPENDIX 1

##### HIV POLICY COLLABORATIVE 2007–2009 TASKS AND ACCOMPLISHMENTS<sup>125</sup>

ISSUE	AIDS LAW PROJECT, OBO THE HIV POLICY COLLABORATIVE, RESPONSE(S)	RESULTS / STATUS
Over-the-counter pharmacy sales of syringes	On behalf of the Collaborative, the AIDS Law Project participated in making public comments in support of this new pharmacy board regulation which would allow Pharmacies to sell up to thirty syringes without a prescription. <sup>126</sup>	The Final Form regulations, which no longer contain restrictions on age or quantity, were approved on July 23, 2009. After pro-forma review by the Attorney General and publication in the Pennsylvania Bulletin, the regulation will become effective on the

124. Michael T. Isbell, *AIDS and Public Health: The Enduring Relevance of a Communitarian Approach to Disease Prevention*, 8 AIDS & PUB. POL'Y J. 157, 159 (1993).

125. Appendix compiled by the AIDS Law Project of Philadelphia with data on file with the authors.

126. 49 PA. CODE § 27.18 (2009).

		date it is published.
Proposed amendment to drug and alcohol regulations— No. 10-186 Department of Health, Confidentiality of Patient Records and Information	On behalf of the HIV Policy Collaborative, the AIDS Law Project has prepared and sent letters to the co-chairs of the House and Senate Health & Safety Committees in opposition to the proposed regulations. The regulations propose to permit insurers greater access to patient information, in some cases without requiring the patient's consent. <sup>127</sup>	Thanks to our opposition, the Proposed Regulation has not been changed into its Final Form. If the Department of Health does not take further action on the proposed regulation before January 14, 2010, the Proposed Regulation will be deemed withdrawn.
Efforts to amend Act 148 <sup>128</sup> — House Bill 2465 <sup>129</sup> and Senate Bill 1261 <sup>130</sup>	The AIDS Law Project prepared an analysis of both bills and forwarded them along with information about how to comment on them to Collaborative members. Additionally, the AIDS Law Project presented testimony in opposition to Senate Bill 1261 on behalf of the Collaborative at a hearing convened by Senator Edwin Erickson in Harrisburg on May 14, 2008.	State Representative Josh Shapiro, sponsor of HB2465, convened a meeting on June 25, 2010 to discuss and clarify the purpose of the bill. At that meeting he announced his openness to reconsidering the intent of the bill, and he asked the state Department of Health to reconvene an Advisory Group with the purpose of developing "principles and recommendations" to guide him in drafting future legislation. The Collaborative participated in a meeting of the Advisory Group on August 1, 2008 that convinced Representative Shapiro to withdraw HB2465. SB1261 has been on hold without action.

127. Amendments to Confidentiality of Drug and Alcohol Treatment Patient Records and Information, Dep't of Health Reg. 10-186 (proposed Apr. 25, 2008) (to be codified at 4 PA. CODE § 255.5); see 37 PA. BULL. 6529 (Dec. 15, 2007) (discussing proposed amendments to 4 PA. CODE § 255.5).

128. Confidentiality of HIV-Related Information Act, P.L. 585, No. 148 (1990).

129. H.B. 2465, 2007–2008 Gen. Assem., Reg. Sess. (Pa. 2008).

130. S.B. 1261, 2007–2008 Gen. Assem., Reg. Sess. (Pa. 2008).

CDC Guidelines for Testing in Prison	The AIDS Law Project reviewed guidelines posted by the CDC and forwarded comments to HIV Policy Collaborative members. We also coordinated an effort to solicit additional comments and responses from members of the Collaborative. Those comments were then forwarded to the CDC.	Guidelines have been promulgated. <sup>131</sup>
HIV and Children and Youth Policy	The AIDS Law Project and the Juvenile Law Center are collaborating on providing county-by-county comments on Children and Youth policies regarding HIV disease and on creating a model policy for Children and Youth.	A first draft set of comments is complete but still in the editing stage. When the comments are ready to be sent to the Department of Public Welfare they will be shared with the Collaborative for preliminary review and comment. The AIDS Law Project continues to advocate in individual cases.
HIV and education	The AIDS Law Project attended a conference held by the Department of Education. Pennsylvania requires HIV education in the schools but does not have baseline standards for exactly what is taught. Additionally, the AIDS Law Project has participated in a coalition called Pennsylvania Advocates for Responsible Sexual Education (PARSE).	The AIDS Law Project is developing a strategy to introduce a bill in favor of scientifically-based comprehensive sex education.
Proposed amendments to the Family Medical Leave	The U.S. Department of Labor issued proposed amendments to the Family Medical Leave Act Regulations in February 2008. <sup>132</sup>	The submitted comments are available on the website <a href="http://www.regulations.gov">www.regulations.gov</a> . <sup>133</sup>

131. CTRS. FOR DISEASE CONTROL & PREVENTION, HIV TESTING IMPLEMENTATION GUIDANCE FOR CORRECTIONAL SETTINGS (2009), available at [http://www.cdc.gov/hiv/topics/testing/resources/guidelines/settings/pdf/Correctional\\_Settings\\_Guidelines.pdf](http://www.cdc.gov/hiv/topics/testing/resources/guidelines/settings/pdf/Correctional_Settings_Guidelines.pdf).

132. The Family and Medical Leave Act of 1993, Proposed Rule, 60 Fed. Reg. 2180 (proposed Feb. 11, 2008) (to be codified at 29 C.F.R. pt. 825).

Act Regulations	The AIDS Law Project prepared and submitted comments on behalf of the Collaborative regarding the proposed regulations on April 10, 2008.	The Department of Labor has issued Final Regulations. The AIDS Law Project is currently reviewing them in an effort to determine the impact of the regulations on persons living with HIV/AIDS.
Proposed bill to ensure greater information sharing between social service agencies serving dependent and/or delinquent children	The Juvenile Law Center approached the AIDS Law Project regarding Senate Bill 481. This bill proposed to permit social service agencies involved with a dependent or delinquent child to share information without the informed consent of either the parents or the child. <sup>134</sup> The bill in its original form violated both state and federal law. The AIDS Law Project, on behalf of the Collaborative, prepared and submitted comments on the proposed bill to Senator Patrick M. Browne. Additionally, the AIDS Law Project participated in a conference call involving several organizations in an effort to discuss strategy regarding this bill.	As a result of the Collaborative's comments submitted in November 2007, the bill was amended to comply with federal and state law. Additionally, as a result of comments that were prepared and submitted by the Collaborative, the bill was again amended to ensure that no mental health information sharing would take place without the express written consent of the children and/or parents.

133. See Letter from Ronda Goldfein, Executive Director, AIDS Law Project of Pennsylvania, et al., to Richard Brennan, Senior Regulatory Officer, Wage and Hour Division, Employment Standards Administration, U.S. Dep't of Labor (Apr. 11, 2008), available at <http://www.regulations.gov/search/Regs/home.html#documentDetail?R=09000064803abfe7> (voicing comments on behalf of AIDS Law Project of Philadelphia).

134. S.B. 481, 2007–2008 Gen. Assem., Reg. Sess. (Pa. 2007).