

**A WAITING ROOM OF THEIR OWN:  
THE FAMILY CARE NETWORK AS A MODEL FOR PROVIDING  
GENDER-SPECIFIC LEGAL SERVICES TO WOMEN WITH HIV**

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*What were the conditions in which women lived, I asked myself. . . .*<sup>1</sup>

*I've had this damn virus for almost ten years now. I've been taking care of everybody else and beating down doors trying to get help for me and other women with HIV. People have got to understand that we've got our own needs—it's our turn now.*<sup>2</sup>

I. INTRODUCTION

As the fastest growing segment of the HIV epidemic in the United States, women with HIV have substantial needs for services, including legal services, many of which go unmet.<sup>3</sup> HIV-infected women face numerous, varied, and

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1. VIRGINIA WOOLF, *A ROOM OF ONE'S OWN* 41 (Harvest/HJB Books 1989) (1929).
2. See Interview with Yvonne "Bunny" Knuckles, 59-year old, African-American, HIV-infected mother of two, grandmother of six, and Family Care Network peer advocate, in Oakland, Cal. (Dec. 10, 1997).
3. Cf. HEALTH RESOURCES & SERVS. ADMIN., U.S. DEP'T OF HEALTH & HUMAN SERVS., *RESPONDING TO THE NEEDS OF WOMEN WITH HIV: TITLE I AND TITLE II RYAN WHITE CARE ACT 1* (1997) (citation omitted) [hereinafter *RESPONDING TO THE NEEDS OF WOMEN WITH HIV*] ("In general, women affected by HIV have traditionally been underserved by the health care system . . . even when such factors as time since diagnosis, insurance status, exposure category, race, and disability status for Medicaid eligibility were controlled."); see also Susan L. Waysdorf, *Families in the AIDS Crisis: Access, Equality, Empowerment, and the Role of Kinship Caregivers*, 3 *TEX. J. WOMEN & L.* 145, 149 n.7 (1994) ("Women with HIV infection and AIDS generally have been excluded from clinical drug

complex gender-specific barriers that prevent them from accessing legal services at the rate and in the manner that they would in the absence of such barriers. The legal community can and should better serve women with HIV, and this Article describes a model for doing so.

Many actual or potential populations eligible for legal services are underserved, and providers of legal services have undertaken a variety of strategies to overcome the barriers such populations face. Legal services providers to people with HIV historically have tailored their delivery models in response to the “cultural” specificity of groups within the HIV-infected community.<sup>4</sup> Part II of this Article chronicles the legal community’s culture-specific responses to the changing needs of the HIV-infected community, from the early days of the “gay plague” and the first wave of the HIV epidemic to the second-wave needs of low-income people with HIV. Part III gives an overview of the “third wave,” which is marked by the burgeoning HIV epidemic among women, and explores the gender-specific barriers that make it difficult for HIV-infected women to access legal services. Part IV describes the Berkeley Community Law Center’s HIV/AIDS Law Project and its participation in the Family Care Network (“FCN”), a comprehensive, integrated model for serving low-income women with HIV. This Part explores four approaches to delivering gender-responsive legal services within the FCN model, and identifies some early challenges to their implementation. Finally, the Article concludes with a call to devote more ideas, attention, and resources to meeting the legal needs of HIV-infected women.

## II. A HISTORY OF LEGAL SERVICES TO PEOPLE LIVING WITH HIV

*Imaginatively she is of the highest importance; practically she is completely insignificant.*<sup>5</sup>

The history of legal services for people with HIV in the United States is in large part the history of the epidemic itself.<sup>6</sup> Until recently, there have been two

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trials, have been left undiagnosed, are generally poorer, have no health insurance, and have no point of entry into the health care system necessary to obtain effective treatment of AIDS.” (citation omitted).

4. Although the HIV-infected “community” includes all people living with HIV, its interests are not monolithic. People with HIV in the United States are of all ages, genders, ethnicities, races, nationalities, sexual orientations, economic backgrounds, spiritual communities, and abilities. Nevertheless, within subcommunities of the larger HIV-infected community—among, e.g., gay men, low-income people, or women—members share many distinct characteristics that have implications for service needs. The use of the term “culture” in this Article is meant to refer to these distinct characteristics.

5. WOOLF, *supra* note 1, at 43.

6. This Part does not purport to tell *the* history of legal services to people with HIV/AIDS. Like all histories, this one is constrained at a minimum by the purpose of the project, which in this instance is to describe the legal community’s response to the culture and gender-specific needs of individuals with HIV. It is not possible, therefore, to do justice here to the thousands of attorneys who have dedicated all or part of their legal careers to serving people with HIV, nor to the substantial amount of impact litigation and policy and legislative advocacy undertaken on behalf of people with HIV in general and women with HIV in particular by scores of local, state, and national organizations. For a survey of AIDS-related law, see generally AIDS AND THE LAW: A GUIDE FOR THE

demographic waves of the HIV epidemic that have affected overlapping but different subpopulations within society. As a result of significant cultural differences, the two communities have had distinct legal needs, not only in the substantive services they required, but also in terms of the manner in which these services were delivered. The legal community has responded to these differing needs with two distinct models of service provision.

#### A. The Epidemic's First Wave and the Referral Panel Response

The AIDS epidemic in the United States first manifested itself in the early 1980s among clusters of gay men in New York, San Francisco, and Los Angeles.<sup>7</sup> Otherwise healthy young men were dying from obscure illnesses, primarily Kaposi's Sarcoma, a rare form of cancer, and *Pneumocystis carinii* pneumonia, a rare pulmonary infection.<sup>8</sup> Although other people also were affected during this time, gay men were impacted in the greatest numbers. Of the 1366 AIDS cases reported to the Centers for Disease Control and Prevention (CDC) by May 1983, seventy-one percent were among gay men—nearly three-quarters of whom were between the ages of twenty and thirty-nine.<sup>9</sup> Compared to the individuals who would be infected in subsequent waves of the epidemic, many of those infected in the first wave were relatively affluent, educated, and employed.<sup>10</sup>

In addition to the obvious health and psychosocial implications of having AIDS, especially at a time when medical treatments largely were ineffective, the legal needs of these men were dramatically influenced by their illness. Due to the debilitating nature of HIV disease, most of these first-wave individuals were forced to cut back or stop work, to endure high medical costs not covered by in-

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PUBLIC (Harlon L. Dalton et al. eds., 1987), and AIDS AND THE LAW (David W. Webber ed., 3d ed. 1997).

7. See generally RANDY SHILTS, AND THE BAND PLAYED ON: POLITICS, PEOPLE, AND THE AIDS EPIDEMIC (1987) (providing a history of the early years of the HIV epidemic in the United States). The global AIDS pandemic, however, is predominantly a heterosexually-transmitted phenomenon. See UNAIDS/WORLD HEALTH ORG. WORKING GROUP ON GLOBAL HIV/AIDS AND STD SURVEILLANCE, REPORT ON THE GLOBAL HIV/AIDS EPIDEMIC (Nov. 29, 1997) <<http://www.unaids.org/highband/document/epidemio/report97.html>> (estimating that two-thirds of all people with HIV live in sub-Saharan Africa, where approximately 20.8 million individuals have been infected).

8. Before the term "AIDS" or Acquired Immune Deficiency Syndrome was adopted officially in July 1982, see SHILTS, *supra* note 7, at 169-71, the epidemic was often referred to as "GRID" or Gay-Related Immune Deficiency, see *id.* at 121. Kaposi's Sarcoma frequently was referred to as "gay cancer" and *pneumocystis* as "gay pneumonia." See *id.* at 110, 116.

9. See SHILTS, *supra* note 7, at 286-87. Men of all risk groups comprised about 93% of cumulative AIDS cases in 1985 and 90% of reported AIDS cases through the end of 1990. See RESPONDING TO THE NEEDS OF WOMEN WITH HIV, *supra* note 3, at 75. But see discussion *infra* note 57 for an explanation of the chronic undercounting of women prior to 1993.

10. Although no national data on the socioeconomic status of people with HIV have been collected, indirect indicia such as census tract information and the absence or presence of public or private health insurance, demonstrate a clear distinction between the *relative* affluence of those impacted in the early years of the epidemic and those impacted in later years. See Daniel Fife & Charles Mode, AIDS Incidence and Income, 5 J. ACQUIRED IMMUNE DEFICIENCY SYNDROMES 1105, 1108 (1992) (documenting differences in AIDS incidence, medical insurance status, and survival after diagnosis that were consistent with major differences in medical care by income and race); see also *infra* note 43 and accompanying text.

surance, and to plan for their early deaths.<sup>11</sup> Many needed assistance in understanding and accessing employee benefits as they left work and help with financial planning as their assets and savings were consumed by health care costs.<sup>12</sup> They very often required extensive estate planning assistance, such as wills, trusts, and durable powers of attorney, which often was made more complex by the law's indifference or even open hostility to their wishes with regard to their unmarried partners.<sup>13</sup> If their partners died first, people with AIDS often needed assistance in probating the estate and to counter challenges to wills,<sup>14</sup> again battling legal presumptions that either did not recognize—or actively discriminated against them because of—their “nontraditional” relationships. They further needed protection against the discrimination in employment, housing, and insurance that often accompanied a diagnosis of AIDS,<sup>15</sup> either on the basis of HIV status itself or on the basis of their sexual orientation, which was seen as synonymous with HIV infection.<sup>16</sup>

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11. From 1980-85, the median life expectancy for men from date of AIDS diagnosis was approximately 12 months. See Peter Bacchetti et al., *Concise Communications: Survival Patterns of the First 500 Patients with AIDS in San Francisco*, 157 J. INFECTIOUS DISEASES 1044, 1044 (1988) (noting that the “estimated overall median survival time was 11 mo [sic]”); Richard Rothenberg et al., *Survival with the Acquired Immunodeficiency Syndrome: Experience with 5833 Cases in New York City*, 317 NEW ENG. J. MED. 1297, 1299 (1987) (noting that the “median conditional probability of survival from the date of diagnosis was 347 days”).

12. See Rhonda R. Rivera, *Lawyers, Clients, and AIDS: Some Notes from the Trenches*, 49 OHIO ST. L.J. 883, 903-21 (1989) (discussing issues surrounding employer-provided health insurance and employment); see also AIDS LEGAL REFERRAL PANEL OF THE S.F. BAY AREA, *AIDSLAW: A MANUAL ON PROVIDING LEGAL SERVICES FOR PERSONS WITH HIV INFECTION* 1.6 (Clint Hockenberry ed., 2d ed. 1988) [hereinafter *AIDSLAW MANUAL*] (“Within a year a person with AIDS can go from a forty thousand dollar a year salary to an annual seven thousand dollars in social security payments. At the same time, the person with AIDS is liquidating assets rapidly to pay for medicines, shelter, and food.”); see generally Samuel A. Marcossou, *Who is “Us” and Who is “Them”—Common Threads and the Discriminatory Cut-Off of Health Care Benefits for AIDS Under ERISA and the Americans with Disabilities Act*, 44 AM. U. L. REV. 361, 369-432 (1994) (arguing that people with AIDS are treated differently by the law for purposes of employer-provided or employer-subsidized health insurance).

13. See AIDS PRACTICE MANUAL: A LEGAL AND EDUCATIONAL GUIDE 4-2 (Paul Albert et al. eds., 3d ed. 1992) [hereinafter *AIDS PRACTICE MANUAL*] (discussing procedures for personal and estate planning); Marcossou, *supra* note 12, at 403-04 (“[J]udges often appear unable to focus on the legal issues raised by litigation where sexual orientation issues lurk somewhere in the case, especially when recognition of the right asserted might produce what seems to be a pro-gay rights outcome . . . . [T]hey are failing to apply settled law to cases simply because they happen to touch on or implicate lesbian and gay rights.”); Rivera, *supra* note 12, at 893-903 (discussing estate planning issues for people with AIDS); see generally LESBIANS, GAY MEN, AND THE LAW (William Rubenstein ed., 1993) (discussing bias against gay men and lesbians in the law); 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.” (citations omitted)).

14. See AIDS PRACTICE MANUAL, *supra* note 13, at 4-14 (noting a disproportionate number of challenges to the wills of gay people with AIDS); Rivera, *supra* note 12, at 891-95, 900-03 (discussing the need for protection of gay men with AIDS and their partners from will contests and planning for funeral arrangements).

15. See Penn Lerblance, *Legal Redress for Disability Discrimination: Bob, Carol, Ted and Alice Encounter AIDS*, 24 GOLDEN GATE U. L. REV. 307, 311-12 (1994) (“AIDS-based discrimination has been, and continues to be, widespread in employment, housing, public accommodations, and other areas of life.”).

16. See CINDY PATTON, *INVENTING AIDS* 117 (1990) (“In addition to whatever individual prejudices non-gay people with AIDS had, they were also subject to a backhanded homophobia due to

Compounding the acuity and complexity of their medical and legal needs, people with AIDS in the early 1980s also faced barriers to accessing legal services. For instance, although many of these men were quite capable of identifying their own legal needs and were comfortable negotiating the terms of legal representation with an attorney, most became unable to afford such assistance due to their disease-induced downward economic mobility.<sup>17</sup> Understandably many also were reluctant to seek legal assistance for matters related to their disease. Homophobia was virulent prior to the AIDS epidemic; the early years of the "gay plague" added another level of hostility that often was visited upon anyone, whether gay or not, with an AIDS diagnosis.<sup>18</sup> Clients were afraid to seek help, for example, with an HIV-related insurance discrimination claim because they did not want to risk further discrimination from a homophobic or AIDS-phobic attorney. Most gay men with AIDS, therefore, needed legal services provided at low or no cost in a culturally safe setting.

The earliest response to the HIV epidemic by legal service providers came from gay and lesbian attorneys responding to this devastating crisis in their community.<sup>19</sup> In the early 1980s, at the epicenters of the epidemic in New York, Los Angeles, and San Francisco,<sup>20</sup> gay and lesbian organizations recognized that people with AIDS had legal needs as a result of being HIV-infected and established legal services programs to address them. In New York City in 1983, Gay Men's Health Crisis, an AIDS service organization formed the year before, and the Bar Association for Human Rights of Greater New York, a gay and lesbian bar association, jointly established a program to provide legal services to people with AIDS.<sup>21</sup> Similarly, the Los Angeles Gay and Lesbian Community Center added an AIDS component to its existing legal services program for gays and lesbians;<sup>22</sup> and in San Francisco in 1983, another gay and lesbian bar association,

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their association with a disease apparently inextricably marked as 'gay.');

Amber Hollibaugh et al., *The Second Epidemic*, in *AIDS: CULTURAL ANALYSIS, CULTURAL ACTIVISM* 128 (Douglas Crimp ed., 1988) ("[H]ealthy gay men and lesbians . . . were encountering both antigay and AIDS-related discrimination—being fired from their jobs, thrown out of their homes, called 'queers' and 'AIDS carriers' . . . because they were gay or . . . perceived to be gay.").

17. See AIDS LAW MANUAL, *supra* note 12, at 1.6.

18. See Lerblance, *supra* note 15, at 309-10 ("In a well known case, Ryan White, an HIV infected school child, was told he could not attend public school because he was HIV infected. . . . [H]e and his family were effectively run out of their home and forced to move to a different community because of hostile attitudes and adverse reactions to his presence."); see also *supra* note 16 and accompanying text.

19. See AIDS LAW MANUAL, *supra* note 12, at 1.10.

20. These three cities continue to be the hardest hit by the AIDS epidemic in the United States with 91,799, 34,643, and 24,272 cumulative AIDS cases reported through the end of 1996 in New York, Los Angeles, and San Francisco, respectively. See CENTERS FOR DISEASE CONTROL & PREVENTION, U.S. DEP'T OF HEALTH & HUMAN SERVS., NO. 2, HIV/AIDS SURVEILLANCE REPORT 8-9 tbl.2 (1996) [hereinafter HIV/AIDS SURVEILLANCE REPORT 1996].

21. See AIDS COORDINATION PROJECT, AMERICAN BAR ASS'N, DIRECTORY OF LEGAL RESOURCES FOR PEOPLE WITH AIDS & HIV 249 (Michele Zavos ed., 1991) [hereinafter DIRECTORY OF LEGAL RESOURCES 1991]; see also AIDS LAW MANUAL, *supra* note 12, at 1.12 (providing information and background on Gay Men's Health Crisis).

22. See DIRECTORY OF LEGAL RESOURCES 1991, *supra* note 21, at 57. In 1986, a second, and larger, AIDS-specific referral panel was established by the Los Angeles County Bar Association. See AIDS LAW MANUAL, *supra* note 12, at 1.13.

the Bay Area Lawyers for Individual Freedom, created the AIDS Legal Referral Panel to meet the growing legal needs of people with AIDS.<sup>23</sup> By 1988, Miami, Washington, D.C., and Chicago, the next three U.S. cities hardest hit by AIDS,<sup>24</sup> all had active referral panels, and by 1991, at least thirty-seven separate referral panels or AIDS service organizations with referral panel components existed.<sup>25</sup>

The basic service delivery model of the referral panel was to recruit attorneys who agreed to accept one or more cases on behalf of people with HIV on a *pro bono* or sliding-scale basis. Volunteer attorneys were trained, not only on issues of relevance to HIV and the area of law in which they would provide assistance, but frequently on HIV sensitivity and the disease itself. In fact, most panel attorneys in the early years were lesbians and gay men, many of whom were themselves HIV-infected, and the majority of whom were in private law practice.<sup>26</sup>

Clients accessed panel services by telephone, were screened to identify their legal needs by what was usually a small in-house staff, and then were referred to a volunteer attorney on the panel who practiced, or had been trained, in the relevant area of law. The client then contacted the attorney directly, described the legal issue, negotiated the terms of the representation and received legal assistance. As a means of triaging limited resources in the face of great need, some referral panels provided services only to potential clients who had progressed to a diagnosis of AIDS-related complex ("ARC") or AIDS, the later stages of HIV disease.<sup>27</sup>

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23. See DIRECTORY OF LEGAL RESOURCES 1991, *supra* note 21, at 65.

24. See HIV/AIDS SURVEILLANCE REPORT 1996, *supra* note 20, at 8-9.

25. See generally DIRECTORY OF LEGAL RESOURCES 1991, *supra* note 21 (counting self-described referral panels and those whose primary service model was volunteer attorneys). In Miami, the Volunteer Lawyers Program was established in 1988. See *id.* at 105-06. In Washington, D.C., the Whitman-Walker Clinic was established in 1986. See *id.* at 99. In Chicago, the AIDS and Civil Liberties Project was established in 1985 and the AIDS Legal Council of Chicago was established in 1988. See *id.* at 127-31. In addition to these local programs, several national organizations undertook AIDS law projects during this period—the National Lawyers Guild AIDS Network (1985), the AIDS Civil Rights Project of National Gay Rights Advocates ("NGRA") (1985), and the Lambda Legal Defense and Education Fund AIDS Project ("Lambda") (1987). The Guild AIDS Network produced an early manual for attorneys serving people with HIV, see AIDS PRACTICE MANUAL (1st ed. 1986), and co-produced the second edition with NGRA, see AIDS PRACTICE MANUAL: A LEGAL AND EDUCATIONAL GUIDE ix (Paul Farmer et al. eds., 2d ed. 1988). The third edition was produced by the Guild AIDS Network in conjunction with Gay Men's Health Crisis, see *supra* note 21 and accompanying text, AIDS Law Project of Pennsylvania, see *infra* note 46, and Whitman-Walker Clinic, see *infra* note 118. See AIDS PRACTICE MANUAL, *supra* note 13, at 15. Lambda has been instrumental in conducting AIDS-related litigation and also produced one of the first books on legal issues and AIDS. See Lambda Legal Defense & Educ. Fund, Inc., *AIDS Project Attorney Hired*, LAMBDA UPDATE, Winter 1987, at 4.

26. See AIDSLAW MANUAL, *supra* note 12, at 1.10.

27. See *id.* at 1.5 (describing one argument in the triage debate: "For every client with AIDS and ARC, there are ten more who are seropositive [infected with HIV]. Given the herculean response to the current caseload, it is impractical to extend services to those not in immediate need."). Some AIDS service providers continue to triage services based upon disease progression, though most referral panels no longer do so. Compare AIDS COORDINATION PROJECT, AMERICAN BAR ASS'N, DIRECTORY OF LEGAL RESOURCES FOR PEOPLE WITH AIDS & HIV 20-37 (Clifton J. Cortez, Jr. & Joel M. Long eds., 2d ed. 1997) (cataloging the legal resources for people with HIV/AIDS, including in California, for example, where only 1 of 16 AIDS projects in the state appeared to triage its clients by

Referral panels assisted gay men in part by offering them the substantive legal services that they most needed. More than half of all services provided by the referral panels were wills and powers of attorney.<sup>28</sup> Most panels also helped clients with a broad range of other legal matters, including discrimination claims, access to insurance and employee benefits, and filings for bankruptcy and probate.<sup>29</sup> Services to help clients secure public entitlements, such as Social Security Disability Insurance, typically were offered to assist the clients with appeals, the traditional entry point for an attorney in such cases.<sup>30</sup> Volunteer attorneys in larger programs provided services in virtually all areas of practice, from criminal defense to tax assistance.<sup>31</sup>

In addition to meeting their substantive legal needs, however, the referral panel model also addressed the culturally-constructed barriers HIV-infected gay men faced in obtaining access to services. The early referral panels not only were founded by gay and lesbian organizations, but often located their services within them.<sup>32</sup> The panels did not base services in the traditional, public legal services settings for low-income people, nor in the better-funded, but generally more conservative settings of local bar associations. Eschewing both of these traditional vehicles, referral panels offered gay men access to legal services in contexts that were neither homophobic in general, nor AIDS-phobic in particular. Most referral panel attorneys were also in private practice, so that actual service delivery usually took place in the discrete, confidential setting of a law office. Clients, therefore, did not have to worry about encountering a hostile or even an unsympathetic attorney, as the panel acted as a filter and an intermediary between clients and attorneys.

Over time, with the expansion of the HIV epidemic out of the gay male community, many AIDS service providers and legal referral panels began targeting broader populations. Indeed, most of the referral panels today are not operated exclusively within gay and lesbian organizations,<sup>33</sup> although the panels continue to serve large numbers of gay men who still constitute the majority of cumulative AIDS cases in the United States.<sup>34</sup> Each year the referral panels pro-

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disease progression in 1997) [hereinafter DIRECTORY OF LEGAL RESOURCES 1997], with DIRECTORY OF LEGAL RESOURCES 1991, *supra* note 21, at 45-74 (cataloging the legal resources for people with HIV/AIDS, including in California in 1991, where 3 of the 13 AIDS projects in the state triaged their clients by disease progression).

28. See AIDS LAW MANUAL, *supra* note 12, at 1.6-7.

29. See *id.* at 1.37.

30. See Irwin E. Keller, *Public Benefits for Persons with HIV*, in AIDS AND THE LAW, *supra* note 6, § 9.20, at 420; see also THOMAS P. MCCORMACK, THE AIDS BENEFITS HANDBOOK: EVERYTHING YOU NEED TO KNOW TO GET SOCIAL SECURITY, WELFARE, MEDICAID, MEDICARE, FOOD STAMPS, HOUSING, DRUGS, AND OTHER BENEFITS 19 (1990).

31. See AIDS LEGAL REFERRAL PANEL, 1991 ANNUAL REPORT 6 (1991); AIDS LAW MANUAL, *supra* note 12, at 1.37. The *AIDS Law Manual*, produced by the AIDS Legal Referral Panel of the San Francisco Bay Area, is one example of the many important contributions that referral panels have made to serving the legal needs of people with HIV.

32. See discussion *supra* notes 19-25 and accompanying text.

33. See generally DIRECTORY OF LEGAL RESOURCES 1997, *supra* note 27 (cataloging HIV/AIDS legal assistance programs in the country).

34. Gay men and injection drug-using gay men comprise 56% of cumulative reported AIDS cases through December 1996. See HIV/AIDS SURVEILLANCE REPORT 1996, *supra* note 20, at 10 tbl.3.

vide high-quality, free or low-cost legal services to thousands of individuals from all segments of the HIV-infected community.<sup>35</sup>

#### B. The Second Wave and the Direct Services Response

At the same time that legal referral panels were being established in New York, San Francisco, and Los Angeles, infection rates already were peaking among gay men,<sup>36</sup> although with the typical course of the HIV disease process, many would not become ill for years.<sup>37</sup> During that period, there were ominous signs that the virus respected no culturally-constructed boundaries such as gender, race, and class. Poor people—especially people of color, injection drug users, and women—were increasingly affected as the epidemic entered its “second wave.”<sup>38</sup>

By the mid-1980s, HIV infection, the harbinger of AIDS, was firmly entrenched in large urban populations throughout the United States,<sup>39</sup> and by the late 1980s and early 1990s, those infected in the second wave of the epidemic were beginning to get sick. From 1985 to 1993, for example, the proportion of gay men among new AIDS cases dropped from approximately sixty-seven percent to about forty-seven percent, while the proportion of injection drug users among new cases increased from about seventeen percent to nearly twenty-eight percent.<sup>40</sup> Among new cases in gay men in 1993, thirty-five percent were people of color; of the new cases among injection drug users that year, nearly eighty percent were people of color, including fifty percent African-Americans and almost thirty percent Latinos.<sup>41</sup> New cases among women, though still representing a relatively small percentage of cumulative cases, also were increasing at a much faster rate than were new cases among gay men.<sup>42</sup> And among men and women newly-diagnosed with AIDS in the late 1980s, from New York to California the common denominator was poverty.<sup>43</sup>

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35. See generally DIRECTORY OF LEGAL RESOURCES 1997, *supra* note 27.

36. See Philip S. Rosenberg et al., *Population-Based Monitoring of an Urban HIV/AIDS Epidemic: Magnitude and Trends in the District of Columbia*, 268 JAMA 495, 501 (1992) (“[M]odels of HIV-infection incidence suggest two broad epidemic waves of HIV infection. The first occurred in MSM [Men who have Sex With Men]. For this group, estimated infection peaked during the period from 1982 through 1983, with lower incidence from then on.”).

37. See TEXTBOOK OF AIDS MEDICINE 51 (Samuel Broder et al. eds., 1994) (noting that “the median time between initial infection [with HIV] and the development of an AIDS-defining illness is 10-12 years”).

38. See SHILTS, *supra* note 7, at 261 (“This proliferation of AIDS [in 1983] through the East Coast corridors of poverty heralded the start of the second AIDS epidemic in the United States, distinct from the epidemic in gay men.”); Rosenberg et al., *supra* note 36, at 501.

39. See Rosenberg et al., *supra* note 36, at 497-98.

40. See Centers for Disease Control & Prevention, U.S. Dep’t of Health & Human Servs., *Heterosexually Acquired AIDS—United States, 1993*, 43 MORBIDITY & MORTALITY WKLY. REP. 155 (1994).

41. See CENTERS FOR DISEASE CONTROL & PREVENTION, U.S. DEP’T OF HEALTH & HUMAN SERVS., NO. 4, HIV/AIDS SURVEILLANCE REPORT 9 (1993).

42. See *id.* at 8.

43. Although national statistics on AIDS and income are not kept, see discussion *supra* note 10, Medicaid utilization studies in New York and California, and census tract studies in several urban cities support the trend described here. See Daniel Fife & Charles Mode, *AIDS Prevalence by Income Group in Philadelphia*, 5 J. ACQUIRED IMMUNE DEFICIENCY SYNDROMES 1111, 1114 (1992) (citing Tho-

As the epidemic increasingly impacted low-income communities of color, the legal needs of people with HIV also began to shift. Although the referral panels continued to provide services to a growing and more diverse group of clients, the needs of low-income people with HIV were distinct in important ways from those of first-wave clients. Due to long histories of chemical dependency, low incomes, poor housing, and limited access to health care and other support services, most of the new faces of the epidemic had substantial unmet legal needs prior to contracting HIV. Many of these needs were ones that traditionally had been addressed in poverty law practices: basic public entitlements advocacy for welfare, SSI and Medicaid benefits; landlord/tenant law, especially eviction defense from private and public housing; family law, such as divorces and child custody matters; and consumer law, especially for relief from debts. They also had new needs as a result of facing a terminal illness, including simple estate planning in general, and planning for the care of minor children in particular.<sup>44</sup>

Like the HIV-infected gay men of the epidemic's first wave, the low-income individuals in the epidemic's second wave faced culture-specific barriers to accessing legal services. First, most low-income clients with HIV could not afford to pay for legal services, even on a sliding scale. Second, many low-income HIV-infected clients had limited transportation resources and needed legal services physically accessible to their communities, either located within the low-income community itself, or within easy reach of it by public transportation. Third, for injection drug users to access services at all, they often required the safety of a setting that was non-judgmental of their substance use. Fourth, some low-income people with HIV needed services either to be accessible to low-literacy English-speakers or to accommodate clients with first languages other than English, especially the growing number of Spanish-speaking clients. And finally, because many of their legal problems often were interwoven with poverty, racism, sexism, or chemical dependency, which, although exacerbated by their HIV disease also typically pre-dated it, low-income people with HIV needed services available at all stages of illness, not just at the end stages of AIDS.

As the legal services and delivery needs of the HIV-infected population changed, a new response emerged from the legal community: the in-house, direct services approach based in existing legal aid offices and law school clinics throughout the country. In 1987, law school clinical programs in Boston and Baltimore<sup>45</sup> and a legal aid office in Atlanta<sup>46</sup> founded projects specifically to

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mas R. Fanning et al., *The Epidemiology of AIDS in the New York and California Medicaid Programs*, 4 J. ACQUIRED IMMUNE DEFICIENCY SYNDROMES 1025, 1034 (1991)); Leigh E. Krueger et al., *Poverty and HIV Seropositivity: The Poor are More Likely to Be Infected*, 4 AIDS 811, 811 (1990).

44. See Rivera, *supra* note 12, at 891-911, 921-25. Many attorneys assume that low-income people do not need "estate" planning. However, durable powers of attorney for health care and finances are important tools for people who have wishes regarding these issues, regardless of economic status. Further, wills are important both for planning, often including planning for the care of minor children, and also culturally for some clients who feel that executing a will is what a responsible person preparing for her death does.

45. The clinics were located at the Legal Services Center of Jamaica Plain, a clinical program sponsored by Harvard Law School and at the AIDS Legal Clinic of the University of Maryland Law School. See DIRECTORY OF LEGAL RESOURCES 1991, *supra* note 21, at 175, 159. Over the next few years, other law school clinical programs began providing HIV-specific services, including St. Louis

provide legal services to low-income people with HIV. Throughout the 1990s, direct legal services programs for people with HIV proliferated such that by 1997, they were comparable in number to the referral panels.<sup>47</sup>

Unlike many of the referral panels, these programs were founded predominantly by public interest and legal aid attorneys, not members of the private bar; like their predecessors at the referral panels, however, many direct services program founders were also members of the gay and lesbian community. These attorneys began seeing increasing numbers of HIV-infected clients in their day-to-day poverty law practices and felt compelled to respond.<sup>48</sup>

The basic delivery model of the direct services program is for attorneys, paralegals, and law students to provide site-based legal assistance to HIV-infected clients out of poverty law and law school clinic offices. Potential clients come to the law office or clinic by referral from other service providers in the community, by word of mouth in the client community, or through outreach. Once reaching the office, either by telephone or in person, clients generally are scheduled for an intake appointment during which they are interviewed. In law school clinics, this work typically is done by law students under the supervision of attorneys. Once legal needs are identified, as many services as possible are provided directly to HIV-infected clients and referrals are made for services not available on-site.

Most direct services programs for people with HIV already were designed to serve low-income clients generally, and thus were well-suited to meet the legal needs of low-income people with HIV. In addition to assistance with legal

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University Law School (Health Law Clinic) (1988); University of Wisconsin (AIDS Legal Services Project, Center for Public Representation, Inc.) (1989); Arizona State University (HIV Legal Support Clinic) (1989); University of Iowa College of Law (AIDS Representation Project) (1990). *See id.* at 199, 359, 41, 143; *see also* Aiken, *supra* note 13, at 31-46 (providing a general description of the Arizona State University clinic). The HIV/AIDS Law Project at the Berkeley Community Law Center, which is affiliated with the University of California, Boalt Hall, was established in 1990. *See infra* Part IV.A.

46. The legal aid office in Atlanta was the Atlanta Legal Aid Society. *See* DIRECTORY OF LEGAL RESOURCES 1991, *supra* note 21, at 115. Other early legal aid programs for people with HIV were in Alabama (Legal Services Corporation of Alabama, 1987), Indiana (Legal Services Organization of Indiana, 1991), and New York (Brooklyn Legal Services Corporation, 1989 and Nassau/Suffolk Law Services, 1990). *See id.* at 33, 135, 233, 225. An independent non-profit was established with both a direct services and a referral panel component in Philadelphia (The AIDS Law Project of Pennsylvania, 1988). *See id.* at 307.

47. This comparison is derived from cross-referencing three different, but overlapping, sources. *Compare* DIRECTORY OF LEGAL RESOURCES 1997, *supra* note 27, *and* NATIONAL LEGAL AID & DEFENDER ASS'N, THE 1995/96 DIRECTORY OF LEGAL AID & DEFENDER OFFICES IN THE UNITED STATES & TERRITORIES 221-22 (1995), *and* ASSOCIATION OF AM. LAW SCHOOLS SECTION ON CLINICAL EDUC., 1996 DIRECTORY 101-02 (1996), *with* DIRECTORY OF LEGAL RESOURCES 1991, *supra* note 21 (listing specific legal services programs and referral programs).

48. Attorney Theresa McGovern, who founded the HIV Project at MFY Legal Services in New York, described her experience as follows:

In 1988, I was working in a poverty-law office in Manhattan's Hell's Kitchen neighborhood. The office, which was in a city-owned, run-down vermin-infested building, had only one great resource—clients. I hadn't thought about AIDS as an issue facing our clients until I noticed that some of our clients, particularly women—were dying.

Theresa McGovern, *Book Notes: Women, AIDS & Communities: A Guide to Action*, PAACNOTES, May-June 1992, at 156.

problems falling into the broad range of services already offered in these programs, many direct services providers added basic estate planning and established or expanded existing family law practices to meet the growing demand of young HIV-infected clients with children.

In addition to the substantive services being offered, direct services programs also met many of the other needs of low-income people with HIV. All programs provided free services,<sup>49</sup> and almost all were located in the communities they were serving, making them physically accessible to many low-income HIV-infected clients. Most programs did not refuse to serve or otherwise restrict services to active injection drug users, and, based on years of experience in doing so, many provided services that were adapted to the needs of clients with low literacy or limited English. Finally, in spite of scarce resources, almost none of the legal services offices and law school clinics triaged assistance based on disease progression.<sup>50</sup>

Today, at least forty-nine organizations around the country, including at least ten law school clinics and twenty-one legal aid offices, have targeted direct legal services programs for people with HIV.<sup>51</sup> These programs make an enormous contribution to meeting the legal needs of thousands of low-income people with HIV across the country each year.

While referral panels and direct services programs continue to address the legal needs of many first and second wave HIV-infected clients, a "third wave" of the HIV epidemic is underway. Women, particularly low-income women of color, have emerged as the fastest-growing segment of the epidemic.<sup>52</sup> This demographic shift has important implications both for service needs and for the manner in which these services are delivered. The next Part explores in more detail the feminization of the epidemic and the gender-specific barriers to legal services for the rapidly expanding number of HIV-infected women.

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49. See DIRECTORY OF LEGAL RESOURCES 1991, *supra* note 21. At least one program, the AIDS Law Clinic at the Legal Services Center in Jamaica Plain, Massachusetts, however, had sliding-scale services in anticipation of serving some HIV-infected clients who were not low-income. See *id.* at 175.

50. See *supra* note 27.

51. See DIRECTORY OF LEGAL RESOURCES 1997, *supra* note 27. Although most legal services providers assisting people with HIV fall into the two categories of volunteer referral panels and direct services providers, increasingly some do not. For instance, some referral panel providers have added direct services components, while some direct services providers also maintain panels of volunteer attorneys. See *generally id.* Moreover, many referral panels responded to the changing demographics of HIV-infection by adding new components such as outreach programs, in-house direct services, and by linking with other providers to reach underserved groups. See AIDS LEGAL REFERRAL PANEL, 1990 ANNUAL REPORT 11 (1990) (providing an example of outreach programs to people of color and other underserved groups).

52. See discussion *infra* notes 54-69 and accompanying text.

## III. THE "THIRD WAVE" AND THE NEEDS OF HIV-INFECTED WOMEN

*She lives in you and in me, and in many other women who are not here tonight, for they are washing up the dishes and putting the children to bed.*<sup>53</sup>

AIDS in the United States is increasingly a disease of low-income women of color, disproportionately affecting some of the most politically, socially, and economically disempowered and marginalized members of society. Although they share many legal and other needs with low-income HIV-infected people generally, women living with HIV also face many distinct, gender-specific barriers to having their needs met.

## A. The Feminization and Marginalization of the HIV Epidemic

By December 31, 1996, 89,208 women had been diagnosed with AIDS in the United States, representing approximately fifteen percent of the cumulative reported AIDS cases.<sup>54</sup> In 1985, however, women represented just over seven percent of AIDS cases,<sup>55</sup> while in 1996 alone, 13,820 women were diagnosed with AIDS,<sup>56</sup> representing twenty percent of the total number of new cases that year, the highest proportion of women ever diagnosed.<sup>57</sup>

Women of color are dramatically overrepresented in the AIDS epidemic. More than three-quarters of all women with AIDS in the United States are women of color, including fifty-five percent who are African-American and another twenty percent who are Latina.<sup>58</sup> These figures for African-American and Latina women are seventeen and six times higher, respectively, than they are for white women.<sup>59</sup> While AIDS is already the third leading cause of death among all women in the United States between the ages of twenty-five and forty-four, it is *the* leading cause of death for African-American women of those ages.<sup>60</sup> As these statistics suggest, AIDS continues to impact primarily young women. To date, eighty-four percent of all women with AIDS were diagnosed before the age

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53. WOOLF, *supra* note 1, at 113.

54. See HIV/AIDS SURVEILLANCE REPORT 1996, *supra* note 20, at 16 tbl.9. A total of 581,429 AIDS cases were reported to the CDC from local health jurisdictions in the United States from 1981-96. See *id.* at 7 tbl.1.

55. See RESPONDING TO THE NEEDS OF WOMEN WITH HIV, *supra* note 3, at 17.

56. See CENTERS FOR DISEASE CONTROL & PREVENTION, UPDATE: HIV/AIDS AND WOMEN IN THE UNITED STATES 1 (1997) [hereinafter UPDATE].

57. See HIV/AIDS SURVEILLANCE REPORT 1996, *supra* note 20, at 5. In 1996, a total of 68,473 adults were diagnosed with AIDS. See *id.* Although the percentage of women has grown steadily since 1985, women with AIDS were undercounted in official statistics prior to 1993. See RESPONDING TO THE NEEDS OF WOMEN WITH HIV, *supra* note 3, at 2-3. Through the advocacy of women and their allies, in 1993 the CDC changed the definition of AIDS to better account for manifestations of HIV disease that are specific to women. See *id.* The changed CDC definition resulted in an immediate increase in the number of women officially diagnosed with AIDS in the United States, although the overall trend described here is accurate even taking into consideration prior undercounting. See *id.*

58. See HIV/AIDS SURVEILLANCE REPORT 1996, *supra* note 20, at 12 tbl.5.

59. See *id.* at 17. Rates are approximately 61.7, 22.7, and 3.5 per 100,000 for African-American, Latina, and white women, respectively. See *id.*

60. See UPDATE, *supra* note 56, at 1.

of forty-five,<sup>61</sup> the vast majority of whom contracted the virus in their teens and twenties, given the typical disease progression of HIV.<sup>62</sup> Although national statistics regarding these data are not maintained, data from representative studies of HIV-infected women show that most have low incomes and many have two or more dependent children for whom they are the primary provider.<sup>63</sup>

Women with HIV also are disproportionately either injection drug users or have sexual partners who are injection drug users. Since 1981, forty-five percent of the women diagnosed with AIDS contracted HIV through intravenous drug use and thirty-eight percent contracted the virus through heterosexual contact.<sup>64</sup> Given the number of infected women who contracted the virus either through sexual partners who are known injection drug users or through sexual partners whose risk factor is unknown, between sixty and eighty percent of all women with AIDS contracted HIV either through injection drug use or through sex with an injection drug user.<sup>65</sup>

Given current trends, there are more than 100,000 women in the United States who have now been diagnosed with AIDS.<sup>66</sup> Since AIDS diagnoses represent only the end stage of what often is a ten to fifteen year disease process,<sup>67</sup> it is estimated that as many as 250,000 women in the United States have been in-

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61. See HIV/AIDS SURVEILLANCE REPORT 1996, *supra* note 20, at 16 tbl.10.

62. See UPDATE, *supra* note 56, at 1; see *supra* note 37 and accompanying text.

63. See Charles C. J. Carpenter et al., *Human Immunodeficiency Virus Infection in North American Women: Experience with 200 Cases and a Review of the Literature*, 70 *MEDICINE* 307, 322 (1991) (according to the largest longitudinal cohort study of women with HIV in the United States, "most HIV-seropositive North American women are mothers with dependent children . . . [and in this study] . . . the majority of [them] were single parents and often provided the only source of income for their minor children").

64. See HIV/AIDS SURVEILLANCE REPORT 1996, *supra* note 20, at 12 tbl.5. In 1996, 40% of HIV transmissions to women with AIDS were through heterosexual contact and 34% were through injection drug use, see *id.*, suggesting an increase in heterosexual transmission relative to injection drug use. Both of these figures, however, understate the full extent of transmission via these routes: in 1996, 24% of reported AIDS cases among women lacked information on transmission category, and cumulatively through 1996, 12% of all women's AIDS cases lacked such information. See *id.* Note also that among HIV-infected women, women who have sex with women, and especially lesbians of color, have historically been undercounted. See RESPONDING TO THE NEEDS OF WOMEN WITH HIV, *supra* note 3, at 46.

65. See HIV/AIDS SURVEILLANCE REPORT 1996, *supra* note 20, at 12 tbl.5. Of the 38% of all women with AIDS who contracted HIV through heterosexual transmissions, 46% (17% of total AIDS cases in women) were exposed to the virus through sex with an injection drug user and another 43% (16% of total AIDS cases in women) were exposed through sex with an HIV-positive person whose risk factor was not identified. See *id.*

66. As of June 1997, 92,242 women have been diagnosed with AIDS. See PUBLIC POL'Y DEP'T, SAN FRANCISCO AIDS FOUND., *RENEWING THE COMMITMENT: AN HIV/AIDS POLICY AGENDA FOR THE NATION* 4 (1988) [hereinafter *RENEWING THE COMMITMENT*]. Given both the intervening months and the inherent reporting lags and inadequacies, it is reasonable to assume that there are at least another 8000 women with AIDS in the United States. See HIV/AIDS SURVEILLANCE REPORT 1996, *supra* note 20, at 36.

67. See *id.* at 5 ("[T]he cumulative number of persons living with AIDS underrepresents the number of living persons who have been diagnosed with HIV disease because most HIV-infected persons have not yet progressed to AIDS and many persons infected with HIV have not been tested.").

ected with HIV and/or have AIDS.<sup>68</sup> Even with no new HIV infections, the number of women with AIDS will continue to grow both in real numbers and as a percentage of all AIDS cases well into the next century.<sup>69</sup>

#### B. Obstacles to Meeting the Legal Needs of Low-Income Women with HIV

According to the most comprehensive and detailed report on the needs of HIV-infected women in the United States:

Women [with HIV/AIDS] often have multiple service needs. For example, a woman with HIV/AIDS may need drug treatment, primary health care including gynecological care, and mental health services, as well as child care and transportation. Particularly important are "bridge services," which enable women to take advantage of other services. For example, a woman may need temporary guardianship or emergency child care during hospitalization. Other roles and demands may prevent women with HIV/AIDS from seeking treatment. Women "often place seeking care for themselves below subsistence needs such as food, housing, employment, and the welfare of their children."<sup>70</sup>

Women with HIV face considerable, gender-specific barriers to having these multiple and complex needs met. Barriers both external to service provision and inherent in current delivery models make the task of providing legal services to HIV-infected women daunting.

The first and perhaps greatest single obstacle to serving HIV-infected women is reaching them.<sup>71</sup> Evidence and experience alike show that because they are typically the primary care providers, women will put the needs of their children above almost all else, even to their own detriment.<sup>72</sup> Even if childcare itself is not an obstacle to care, many low-income women with HIV lack the financial and logistical resources to transport themselves and their children to one or more service providers; being ill, trying to get to an appointment via public transportation, and having to bring along two or three small children, one or more of whom may themselves be sick, is an overwhelming task for many HIV-infected women.

HIV-infected women also often face internal barriers erected by legal providers themselves. Some HIV programs continue to triage scarce resources by

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68. See RENEWING THE COMMITMENT, *supra* note 66, at 4-5 (reporting that in the United States through June 1997, in addition to the 92,242 cases of AIDS in women, there are another 110,000 to 155,000 women who are infected with HIV).

69. See *id.* at 2 (noting that although in September 1997, the CDC reported a first-ever decrease in overall AIDS cases (down 6%), AIDS cases in women continued to increase (up 2%)). This trend also is true internationally; see also Lynellyn D. Long, *Introduction: Counting Women's Experiences to WOMEN'S EXPERIENCES WITH HIV/AIDS: AN INTERNATIONAL PERSPECTIVE* 1, 1 (Lynellyn D. Long & E. Maxine Ankrah eds., 1996) (noting that by the beginning of the next century, the number of women living with HIV and AIDS throughout the world likely will outnumber men).

70. RESPONDING TO THE NEEDS OF WOMEN WITH HIV, *supra* note 3, at 70-71 (citations omitted).

71. See *id.* at 69 (noting that "Women at highest risk for acquiring HIV—drug users, members of poor, underserved ethnic minority communities—may be the most difficult to reach, enroll, and retain in traditional treatment, prevention, and research studies" (quoting U.S. DEP'T OF HEALTH & HUMAN SERVS., HIV/AIDS WORK GROUP ON HEALTH CARE ACCESS FOR WOMEN, DHHS PUBLICATION NO. HRSA-RD-SP-93-7 (1993))).

72. See *id.* at 71.

providing services only to people with more advanced disease. While in some respects this may be a reasonable way to ration services,<sup>73</sup> it simultaneously denies assistance to those for whom legal need is independent of disease progression and to those in the later waves of the epidemic. As with other low-income clients, the legal needs of HIV-infected women often either predate their infection or are otherwise not related directly to their stage of illness. And since women are in the third and most recent wave of the epidemic, and therefore less likely as a group to be as ill as those infected in the earlier waves, such triaging also disproportionately limits the services available to them.<sup>74</sup>

In addition, given the demographics of the early epidemic, many HIV service providers were neither founded by women, nor designed with their needs in mind.<sup>75</sup> While women with HIV may not demand that services to them be provided only by women, they do define "good" HIV care to "include respect, understanding, good listening skills, clear communication, patience, non-judgmental attitude, and willingness to help the women make the best decisions for themselves."<sup>76</sup> The gender and cultural differences that often exist between women with HIV and legal providers further add to the challenge of effectively reaching and appropriately serving HIV-infected women.

The second major obstacle to providing legal services to HIV-infected women is that they often do not identify their needs as legal. Many clients are not aware of, for example, the full range of public benefit programs for which they or their children are eligible. Public assistance programs such as Temporary Assistance to Needy Families (TANF),<sup>77</sup> which impact more women than men, have undergone significant changes in eligibility requirements in recent years;<sup>78</sup> likewise, several states recently have enacted new guardianship laws of particular relevance for many women with HIV.<sup>79</sup> In fact, most low-income women with HIV have multiple legal needs, many of which can be met in tradi-

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73. See discussion *supra* note 27 and accompanying text.

74. While 15% of cumulative AIDS cases in the United States are among women, see HIV/AIDS SURVEILLANCE REPORT 1996, *supra* note 20, at 16 tbl.9, an estimated 29% of the adults newly infected with HIV are women, see *id.* at 30-31.

75. See RESPONDING TO THE NEEDS OF WOMEN WITH HIV, *supra* note 3, at 28-29.

76. See *id.* at 29-30 (citing Sharon Lerner, *Patients' Perspectives: Interviews with HIV-Positive Women*, 50 J. AM. MED. WOMEN'S ASS'N 127, 127 (1995)).

77. See 42 U.S.C.A. § 601-606 (West Supp. 1997). TANF is the "non-entitlement" replacement for Aid to Families with Dependant Children (AFDC), see 42 U.S.C. § 601-606 (1994), the former federally guaranteed welfare program that was eliminated by the Personal Responsibility and Work Opportunity Reconciliation Act of 1996, see Pub. L. No. 104-193, 110 Stat. 2105.

78. See Laurence Lavin, *AIDS, Medicaid, and Women*, 5 DUKE J. GENDER L. & POL'Y 193, 198-207 (1998) (discussing how female Medicaid beneficiaries are impacted by the AIDS epidemic and the recent changes in federal welfare laws); cf. Katherine Marconi et al., *The Paradigm Shift in Medicaid: Women with HIV Under Managed Care*, 5 DUKE J. GENDER L. & POL'Y 211, 212-21 (1998) (discussing issues HIV-positive women face as Medicaid shifts from a fee-for-service system to managed care).

79. See Alice Herb, *Standby Guardianship: A Viable Legal Option for the Future Care of Children*, 50 J. AM. MED. WOMEN'S ASS'N 95, 98 (1995); see also Sunny Rosenfeld, *Developments in Custody Options for HIV-Positive Parents*, 11 BERKELEY WOMEN'S L.J. 194, 197-99 (1996) (describing the standby and joint guardianship schemes enacted in 8 states); cf. Lauren Shapiro, *An HIV Advocate's View of Family Court: Lessons from a Broken System*, 5 DUKE J. GENDER L. & POL'Y 133, 145-61 (1998) (providing an overview of difficulties HIV-positive litigants, and particularly poor women of color, face in guardianship and other court proceedings).

tional poverty law practices.<sup>80</sup> They also have other needs, such as advocacy around access to clinical trials and new therapies, domestic violence prevention, and assistance in making provision for the care of minor children,<sup>81</sup> which, though not of exclusive concern to women with HIV, are nonetheless disproportionately particular to them. However, women can avail themselves of these options and services only if they are aware of them and understand that the issues they are confronting—e.g., insufficient income, substandard housing, inadequate access to health care, and uncertain financial and family planning—are at least partly “legal” in nature.

A third obstacle to providing legal care for many HIV-infected women is a corollary to the second obstacle described above. Women with HIV often need services before a problem they are experiencing has progressed to the point where an attorney will recognize it as a “legal” one. For instance, most public and private law offices will only take public benefits cases once they are scheduled to be heard by an administrative law judge.<sup>82</sup> Since many low-income women with HIV either do not seek public benefits to which they are entitled or are unable to follow through with the cumbersome and complicated application and appeal processes, this effectively precludes them not only from obtaining any legal assistance, but more importantly from securing much-needed benefits. Many low-income women with HIV also need relief from creditors for debts ranging from local charge cards to ambulance bills. Since these same women often are “judgment-proof,”<sup>83</sup> they need not, and in fact, cannot, discharge their debts in bankruptcy, which is the “legal” proceeding for doing so. They could greatly benefit, however, from the relatively simple assistance of an attorney sending a letter to the creditor and invoking the federal law that requires the creditor to cease correspondence with the debtor and deal only with the attorney regarding collection activity.<sup>84</sup> This seemingly minor, “non-legal” assistance can make an important difference in the day-to-day life of an HIV-infected client who needs relief from an aggressive bill collector.<sup>85</sup>

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80. See *supra* note 44 and accompanying text.

81. See Marina T. Sarmiento, *Comments by Marina T. Sarmiento: The Legal Needs of Women with HIV*, 9 BERKELEY WOMEN'S L.J. 155, 161 (1994) (noting that women with HIV should receive increased information about wills, durable powers of attorney for healthcare, and guardianship); Waysdorf, *supra* note 3, at 180-88 (discussing the issues mothers with AIDS face as they try to use traditional family law mechanisms to plan for the future care of their children).

82. See *supra* note 30 and accompanying text.

83. A person is “judgment-proof” if a creditor who has obtained a judgment cannot collect or enforce it because the person has neither income that legally may be garnished nor assets that legally may be attached. See AIDS LEGAL REFERRAL PANEL OF THE S.F. BAY AREA, AIDS LAW: A MANUAL ON PROVIDING LEGAL SERVICES TO PERSONS WITH HIV INFECTION, Ch. 8, 4 (Betsy Johnsen ed., 3d ed. 1995).

84. See 15 U.S.C. § 1692c(a)(2) (1994).

85. Support in traditional medical literature for the proposition that relief from stress reduces health problems, particularly where immune disorders are involved, is mixed. Compare Sheldon Cohen et al., *Psychological Stress and Susceptibility to the Common Cold*, 325 NEW ENG. J. MED. 606, 610-11 (1991) (finding that psychological stress is associated with an increased risk of acute infectious respiratory illness), with Judith G. Rabkin et al., *Depression, Distress, Lymphocyte Subsets, and Human Immunodeficiency Virus Symptoms on Two Occasions in HIV-Positive Homosexual Men*, 48 ARCHIVES GEN. PSYCHOL. 111, 117-18 (1991) (demonstrating that the patients studied who were de-

Finally, an important barrier to fully serving women with HIV is that their legal needs are almost always inextricably linked with non-legal needs.<sup>86</sup> Women with HIV have multiple roles within family and society that result in a complex set of challenges and responsibilities, including, for many, trying to make ends meet on very low incomes, caring for children on their own, living in overcrowded and/or substandard housing, struggling with chemical dependency, dealing with the criminal justice system,<sup>87</sup> and worrying about their health and the health of their children who may themselves be HIV-infected. Legal services that are not integrated with other vital services to HIV-infected women—such as primary medical care, mental health, substance use treatment, case management, emergency financial assistance, and respite care—will at best only partially address clients' needs.<sup>88</sup>

Any model for delivering legal services to HIV-infected women, therefore, must address these barriers and the next Part describes one such model.

#### IV. A MODEL FOR COMPREHENSIVE INTEGRATED LEGAL CARE FOR HIV-INFECTED WOMEN

*Drawing her life from the lives of the unknown who were her forerunners . . . she will be born. As for her coming without that preparation, without that effort on our part, without that determination that when she is born again she shall find it possible to live . . . that we cannot expect, for that would be impossible.*<sup>89</sup>

The evolving demographics of the AIDS epidemic have necessitated culture-specific responses to meet the legal needs of people with HIV. As a second wave provider, the Berkeley Community Law Center (BCLC) has offered direct legal services to low-income people with HIV for more than seven years. Recently, BCLC joined a project created explicitly to meet the needs of HIV-infected women. Described below is the history of BCLC's direct services program, a new gender-specific model designed to serve the legal needs of women with HIV, and some early challenges that have been identified in implementing the model.

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pressed, distressed, or who reported more life stressors did not evince greater immunosuppression or more advanced illness).

86. See discussion *supra* note 70 and accompanying text. This phenomenon is true not only for women with HIV, but also for many low-income people struggling, for example, to obtain income, to maintain housing, and to access health care for themselves and their dependents. See generally Leigh Goodmark, *Can Poverty Lawyers Play Well with Others? Including Legal Services in Integrated, School-Based Service Delivery Programs*, 4 GEO. J. FIGHTING POVERTY 243, 244-45 (1997) (noting that professionals in many disciplines recognize that low-income families have a broad range of varied and interconnected problems).

87. A study of 46 correctional facilities found that people entering such facilities had a median infection rate of 1.7%; in some facilities, however, rates for women were as high as 20.6%. See CENTER FOR AIDS PREVENTION STUDIES (CAPS), UNIVERSITY OF CAL., S.F., WHAT ARE INMATES' HIV PREVENTION NEEDS? 2 (1995); see also Waysdorf, *supra* note 3, at 170-71 n.91-93 (cataloging the special problems that incarcerated women with HIV face).

88. See discussion *supra* note 70 and accompanying text.

89. WOOLF, *supra* note 1, at 114.

### A. The Berkeley Community Law Center's HIV/AIDS Law Project

The Berkeley Community Law Center is a non-profit law office founded in 1988 to provide free legal services to low-income residents of Alameda County, California, and to serve as a clinical placement for law students from the University of California's Boalt Hall School of Law. In September 1990, BCLC conducted a needs assessment and identified substantial unmet need for legal services among low-income HIV-infected people in the county.<sup>90</sup> Following the assessment, BCLC established the HIV/AIDS Law Project ("Project") to provide such services. As with many other direct services programs,<sup>91</sup> the Project targets legal services to low-income HIV-infected clients, especially women, children, people of color, the homeless, and injection drug users. The Project assists clients at all stages of illness, from asymptomatic HIV to end-stage AIDS. Since October 1990, the Project has provided direct legal representation to over 1000 HIV-infected clients with more than 2500 legal issues,<sup>92</sup> including benefits advocacy, simple estate planning, debt relief, family law, and other basic civil legal services. The clients have been predominantly men, most of whom have been people of color, primarily African-American (61%), with smaller numbers of Latino (10%), Asian-American (2%), and Native American (1%) clients.<sup>93</sup>

Day-to-day client services are provided by staff attorneys and trained law students working under the supervision of staff attorneys. Clients are referred to the HIV/AIDS Law Project from other service providers, are contacted by the staff at outreach sites<sup>94</sup> and community education efforts,<sup>95</sup> or come to the Project through word of mouth. Attorneys and students screen callers and drop-in clients to establish that the client is a low-income Alameda County resident with HIV, and schedule intake appointments or see drop-in clients immediately in order to assess the client's legal needs. In addition to discussing the legal problem originally identified by the client, advocates conduct a thorough screening of the client's short and long-term legal services needs. The Project provides as

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90. In 1990, Alameda County was not completely without legal services for people with HIV. The San Francisco-based AIDS Legal Referral Panel conducted legal clinics in the county and made referrals to attorneys from the county on their panel. See AIDS LEGAL REFERRAL PANEL, *supra* note 51, at 11.

91. See discussion *supra* Part II.B.

92. See JEFF SELBIN, BERKELEY COMMUNITY LAW CENTER PROGRAM UPDATE FORM: HIV/AIDS LAW PROJECT CLIENT STATISTICS (1997) (on file with the *Duke Journal of Gender Law & Policy*). In addition, the Project has provided legal advice, brief service, and/or referral to another 400 people with HIV and has reached more than 500 other people with HIV at clinics, workshops, and through outreach. See *id.*

93. See HIV/AIDS LAW PROJECT WORKPLAN: SEPTEMBER 1, 1997-AUGUST 31, 2000 (1997) (on file with the *Duke Journal of Gender Law & Policy*).

94. The Project trains first-year law students to conduct outreach in North Oakland at a day center for people with HIV, in Central Oakland at the county hospital's AIDS clinic, in East Oakland at a multi-service shelter serving people with HIV, and in West Oakland at a needle exchange site (where clean syringes are exchanged one-for-one with used syringes). The Project also provides, through a subcontract with the San Francisco-based AIDS Legal Referral Panel, regular legal clinics in Central, South, and East Alameda County.

95. The Project regularly conducts community education forums. Most recently the Project sponsored a series of HIV "WORK"shops for people with HIV considering a return or first attempt to work.

many basic legal services as possible on-site to reduce the inevitable attrition involved in making off-site referrals.<sup>96</sup>

By focusing representation on a narrow class of clients (low-income people with HIV are a relatively small percentage of all low-income people), the Project has tried to increase its impact on the people and institutions whose decisions affect clients' lives and the lives of similarly-situated clients.<sup>97</sup> This "direct service as impact" approach has had some successes and also has encountered some challenges.<sup>98</sup> Importantly, through a relatively high-volume practice, the Project has identified and addressed some substantial issues affecting its clients. For example, based on needs expressed by many HIV-infected women, the Project initiated efforts to make California's guardianship options more user-friendly for all terminally ill parents, and helped draft California's joint guardianship legislation and later amendments.<sup>99</sup>

The Project has tailored its services and delivery system in response to the external input of on-going needs assessments conducted by HIV-specific planning bodies in the county, which routinely include interviews and focus groups with HIV-infected clients. In addition, the Project conducts internal evaluation and review of its programs via user audits, client surveys, and focus groups to minimize the danger of routinizing insensitive, improper, or substandard practices. And finally, the Project helped develop, and now operates under, a written "standard of care" that sets forth minimum expectations for all providers of client advocacy, including legal services, to people with HIV in Alameda County.<sup>100</sup>

In spite of the Project's having had modest success in serving women with HIV over the last seven years,<sup>101</sup> many women nonetheless continue to face substantial and extensive barriers to accessing legal services.<sup>102</sup>

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96. The Project has implemented a "directed" referral process that includes a written "feedback loop" in collaboration with the AIDS Legal Referral Panel to increase the likelihood of successful referrals.

97. Cf. Gary Bellow, *Turning Solutions into Problems: The Legal Aid Experience*, 34 NAT'L LEGAL AID & DEFENDER ASS'N BRIEFCASE 106, 121-22 (1977) (advocating such focused representation).

98. The Project has been very successful in impacting the individuals and agencies involved in adjudicating SSI and Social Security Disability claims on behalf of people with HIV, although it has been difficult for the Project to have a broader impact outside of the disability benefits area. For example, collection activity is usually done by very large, impersonal, and bureaucratic entities that cannot be influenced significantly by a community law practice that represents individual clients.

99. See CAL. PROB. CODE § 2105(f) (West Supp. 1997); Rosenfeld, *supra* note 79, at 198.

100. See PROPOSED QUALITY STANDARDS FOR HIV/AIDS: CLIENT ADVOCACY—DRAFT (revised Oct. 1, 1997) (on file with the *Duke Journal of Gender Law & Policy*).

101. In 1991, the first statistically significant year of the Project's services, 19% of its clients were women. See MARK DEL MONTE, HIV/AIDS LAW PROJECT, BERKELEY COMMUNITY LAW CENTER, END OF YEAR STATISTICS: 1997 (1997) (on file with the *Duke Journal of Gender Law & Policy*). Since then, the Project has served as many as 29% women (1993) and as few as 18% women (1995) in a calendar year. See *id.* Through December 1997, of the 1022 HIV-infected clients to whom the Project has provided full representation, 254, or approximately 25%, were women. See *id.*

102. See generally ERIKA JENSSEN, WOMEN'S EARLY INTERVENTION CTR., FOCUS GROUP OVERVIEW: DRAFT (May 1995) (on file with the *Duke Journal of Gender Law & Policy*).

## B. The Family Care Network and Gender-Equitable Legal Services for Women with HIV

In August 1997, the HIV/AIDS Law Project was invited to join the Family Care Network, which was founded in 1994 as a consortium of two public entities—a county hospital serving adults with HIV and a home-based nurse case management provider to people with HIV, and two private entities—a hospital serving children with HIV and a methadone clinic serving HIV-infected injection drug users. In addition to adding the Project as a legal services component, the network also was expanded to include substance abuse and mental health counseling, peer advocacy, and a third primary health care site.

The devastating impact of the AIDS epidemic in Alameda County, which is generally representative of the epidemic nationally, provided the impetus for the FCN.<sup>103</sup> Of the 4835 people who have been diagnosed with AIDS in Alameda County through 1996,<sup>104</sup> three-quarters reside in the urban, northern part of the county,<sup>105</sup> and most of the rest live in cities to the south.<sup>106</sup> Although men still constitute the majority of cumulative reported AIDS cases (90%),<sup>107</sup> and whites a plurality of cumulative cases (48%),<sup>108</sup> AIDS is growing fastest in the county among women and African-Americans, who made up twenty<sup>109</sup> and fifty-five percent,<sup>110</sup> respectively, of all new AIDS cases in 1996.

Consistent with national trends, seventy-six percent of all women diagnosed with AIDS in Alameda County are women of color: including African-Americans (62%), Latinas (9%), Asian/Pacific Islanders (3%), and Native Americans (1%). Of the women with AIDS in the county, eighty-four percent are between the ages of twenty and forty-nine,<sup>111</sup> forty-four percent contracted HIV through injection drug use, and another forty percent were infected through heterosexual contact.<sup>112</sup> Heterosexual contact is the fastest-growing transmission category, representing eleven percent of new AIDS cases in Alameda County in

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103. For a history of the HIV epidemic in Alameda County and local needs and services, see OAKLAND, CALIFORNIA ELIGIBLE METROPOLITAN AREA (ALAMEDA COUNTY, CONTRA COSTA COUNTY, CITY OF BERKELEY), CHALLENGE AND OPPORTUNITY: THE COMPREHENSIVE HIV/AIDS HEALTH SERVICES PLAN, 1998-2000 5-68 (1997) (on file with the *Duke Journal of Gender Law & Policy*).

104. See ALAMEDA COUNTY HEALTH CARE SERVS. AGENCY, PUB. HEALTH DEP'T, AIDS CASES: 1996 ALAMEDA COUNTY DATA TABLES 5 (1996) (on file with the *Duke Journal of Gender Law & Policy*).

105. See *id.* Those residing in the northern part of the county include 58% living in Oakland, and 17% living in Berkeley, Albany, Alameda, and Emeryville. See *id.*

106. See *id.* Those residing in the southern part of the county include 18% living in the cities of Hayward (8%), San Leandro (6%), and Fremont (4%). See *id.*

107. See *id.*

108. See *id.*

109. See *id.* at 8. This 20% rate of new AIDS cases among women represents an increase from 7% in 1991 and 1% prior to 1985. See *id.*

110. See *id.* at 6-7. This 55% rate of new AIDS cases among African-Americans represents an increase from 40% in 1991 and 16% prior to 1985. See *id.* at 11.

111. See *id.* at 16.

112. See *id.* Heterosexual contact statistics are not available by transmission category of the partner. It is therefore unknown how many of the women in Alameda County who contracted the virus heterosexually did so as a result of having sex with an injection drug using partner.

1996.<sup>113</sup> It is estimated that another 7100 Alameda County residents are infected with HIV, but not yet diagnosed with AIDS<sup>114</sup>—at least twenty percent of whom are women.<sup>115</sup> And as with HIV-infected women nationally, most HIV-infected women in the county are also low-income, and three-quarters have children.<sup>116</sup>

The goal of the Family Care Network is to provide comprehensive, integrated care to HIV-infected women, children, and adolescents by bringing a broad range of needed services under one roof, and by linking the providers in a care team. Through integrating services and moving from a crisis-response to a crisis-prevention approach to care, providers from several disciplines work together with HIV-infected women to address some of their most complex needs. The HIV/AIDS Law Project's role within the FCN model of care is designed explicitly to respond to the gender-specific needs of HIV-infected women by emphasizing four approaches to delivering legal services: 1) "one-stop shopping;" 2) proactive needs assessment; 3) early intervention; and 4) multidisciplinary integration and coordination of services.

### 1. "One-Stop Shopping"

Recognizing that HIV-infected women often seek medical care for their children before tending to their own health care and face substantial barriers to all services because of childcare and transportation needs, the FCN has centralized its services at Children's Hospital Oakland ("Children's"), a primary health care provider serving virtually every child either infected with HIV or born to an HIV-infected mother in the East Bay.<sup>117</sup> During a doctor's appointment with her child at Children's, an HIV-infected mother can have her own health care and other needs addressed by accessing on-site services that include adult primary care and continuity nursing services provided by the Alameda County Medical Center HIV Services Division ("Highland"), peer advocacy provided by Women Organized to Respond to Life-threatening Disease ("WORLD"), substance use and mental health counseling provided by the East Bay Community Recovery

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113. See *id.* at 26. Heterosexual transmission has increased from 3% in 1991 and 0% in 1985. See *id.*

114. This estimate is derived by multiplying the number of people diagnosed with AIDS in Alameda County by 147% (the percentage of people with HIV relative to those with AIDS in the 26 states that report HIV infection). See HIV/AIDS SURVEILLANCE REPORT 1996, *supra* note 20, at 5-6. The 147% figure still underestimates the number of people with HIV because it does not include individuals who have not been tested or who were tested anonymously. See *id.* at 5.

115. See ALAMEDA COUNTY HEALTH SERVS. AGENCY, *supra* note 104, at 4.

116. See REBECCA DENISON, WOMEN ORGANIZED TO RESPOND TO LIFE-THREATENING DISEASES (WORLD), RESULTS OF RYAN WHITE TITLE IV CONSUMER SURVEY 2 (Apr. 10, 1997) (on file with the *Duke Journal of Gender Law & Policy*).

117. Not all children born to HIV-infected women are HIV-infected themselves. See CENTERS FOR DISEASE CONTROL & PREVENTION, UPDATE: PERINATAL HIV PREVENTION UPDATE: EVIDENCE OF PROGRESS AND CHALLENGES FOR THE FUTURE 1 (Feb. 1997). In fact, recent advances in care, particularly with the use of zidovudine (AZT or ZDV) during pregnancy, labor, delivery, and after birth, can dramatically reduce perinatal transmission. See *id.* Children born to HIV-infected mothers are followed at Children's for at least 18-24 months, allowing for the monitoring of the child's HIV status and for care to be provided simultaneously to the mother. If the children are HIV-infected, they are followed into adulthood. See Telephone Interview with Kim Ross, Social Worker, Children's Hospital (Feb. 3, 1998).

Project, hospital-based case management and clinical social work provided by Children's, and legal services provided by BCLC's HIV/AIDS Law Project.<sup>118</sup>

The three FCN primary health care providers, Children's, Highland, and Alta Bates Medical Center's East Bay AIDS Center ("EBAC"), also can enroll an HIV-infected mother and/or her children in clinical trials,<sup>119</sup> and all of the on-site providers can refer her directly to FCN-dedicated slots for additional services including home-based nursing case management provided by the Alameda County Ambulatory Care HIV Services and methadone maintenance at the Fourteenth Street Clinic. Finally, the FCN administers a "Consumer Access Fund" at Children's, which is a financial resource dedicated expressly to "remov[ing] barriers to families' access to care, such as child care, transportation, physician-recommended over-the-counter drugs, toiletries, emergency utility bills and food vouchers."<sup>120</sup> Any FCN provider can obtain these funds quickly and directly on behalf of clients who face such barriers. Although many women may choose to avail themselves of only one or two of these services on any given visit,<sup>121</sup> this "one-stop shopping" is a major improvement over the decentralized service delivery system that existed prior to the FCN.<sup>122</sup>

## 2. Proactive Legal Needs Assessment

Once a relationship with an FCN client has been established at one of the primary care sites, the Project provides a proactive assessment to assist her in identifying her legal needs. This "legal checkup"<sup>123</sup> takes the form of a thorough interview with the client where staff attorneys ask explicit questions about the client's potential legal needs. The Project has developed a legal screening form for this purpose that staff attorneys attempt to complete during the course of

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118. Though different from the model proposed in this Article, the Montefiore Medical Center (Bronx, NY) and the Whitman-Walker Clinic (Washington, DC) established on-site legal services components for their HIV-infected patients in 1985 and 1986, respectively. See *DIRECTORY OF LEGAL RESOURCES* 1991, *supra* note 21, at 229, 99; see also Gary Bellow & Jeanne Charn, *Paths Not Yet Taken: Some Comments on Feldman's Critique of Legal Services Practice*, 83 *GEO. L.J.* 1633, 1659-63 (1995) (describing another hospital-based legal services project serving low-income clients).

119. Cf. Anna C. Mastroianni, *HIV, Women, and Access to Clinical Trials: Tort Liability and Lessons from DES*, 5 *DUKE J. GENDER L. & POL'Y* 167, 172-92 (1998) (discussing tort liability issues surrounding clinical trials and offering recommendations for how to mitigate tort liability exposure for clinical trial sponsors who include women of childbearing age and pregnant women in their trials).

120. See *BUDGET JUSTIFICATION AND NARRATIVE: CHILDREN'S HOSPITAL OAKLAND, GRANTEE* (on file with the *Duke Journal of Gender Law & Policy*).

121. All FCN providers are aware of the sensory overload risk in concentrating so many services in one setting, and work closely and carefully with clients so as not to overwhelm them with too much information at any one time.

122. Since some FCN clients receive their primary care at Highland or EBAC, an attorney from the Project sees them at those sites during their medical visits. If legal services cannot be located on-site with other services to HIV-infected women, there are other means of seeking them out. For example, targeted outreach can greatly increase access to services for HIV-infected women. Possible outreach sites include: HIV/AIDS service providers, especially those already serving women; support groups for HIV-infected women; substance use and drug rehabilitation programs, including methadone clinics (both maintenance and detoxification) and needle exchange sites; alternative testing sites; women's prisons and the criminal justice system generally (especially as it relates to sex workers); and churches, soup kitchens, homeless shelters, and battered women's shelters, particularly those with programs already serving women with HIV.

123. See Bellow, *supra* note 97, at 120; Bellow & Charn, *supra* note 118, at 1659.

representation, although the client is not pressured into going through the entire screening on the first encounter. For example, a woman with children may be uncomfortable discussing plans or even options for the care of her children upon her incapacity or death during her first meeting with an attorney. Although the Project's goal is to identify issues early and address them before they become crises, during the initial meeting it is sometimes necessary for Project attorneys to respond to such a crisis, in which case the staff "stabilizes" the client's legal situation before proceeding with a fuller assessment at a later date.

Proactive assessments also can help to uncover issues that may seem unrelated to the identified legal need but that in fact may be connected intimately. For example, the Project assists clients who are being evicted for non-payment of rent when the underlying cause of the eviction, e.g., the inability to pay rent, is due to a lack of cash benefits to which the client is entitled, but which she is not receiving. Only by screening the client for a range of issues when she presents for assistance can such connections be made and adequately addressed. The Project also proactively screens HIV-infected women to counsel them about the legal issues they may face in the future and the options they have for resolving them. This on-going process is an important form of education, both for the client about her options and also for the attorney in assessing the client's evolving needs.

### 3. Early Legal Intervention

Once a client's needs have been identified in the process described above, the Project provides a broad range of civil legal assistance to HIV-infected women.<sup>124</sup> In order to achieve a better legal outcome for clients and to reduce the stress of waiting until matters reach emergency proportions, the Project has adopted what is called an "early intervention" model of service provision.<sup>125</sup> Assuming the Project has identified client needs in these areas, examples of early intervention include, but are not limited to, assistance with: all public and private benefits and health insurance needs, regardless of the "stage" at which they are identified; all disputes with landlords, public or private and all family and immigration matters, irrespective of whether a formal legal proceeding is underway; and all matters involving creditors or collection agencies, whether or not a bankruptcy is necessary or desirable. The Project also encourages all FCN clients to complete "estate" documents such as wills and powers of attorney for health care and finances well in advance of any illness that may necessitate the use of such documents. Early intervention can prevent many incipient legal

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124. As a recipient of Ryan White CARE Act Title I and II funds, *see infra* notes 150-54 and accompanying text, the Project is prohibited from providing representation in criminal matters. *See* HEALTH RESOURCES & SERVS. ADMIN., U.S. DEP'T HEALTH & HUMAN SERVS., GUIDANCE FOR IMPLEMENTING TITLE I & TITLE II OF THE RYAN WHITE COMPREHENSIVE AIDS RESOURCES EMERGENCY (CARE) ACT, PROGRAM POLICY NOTICE NO. 97-02, § 97-02.9, at IV-16 (1997) [hereinafter HRSA PROGRAM POLICY NOTICE]. Many women with HIV, however, need assistance with criminal matters, and the Project refers them to the Women's Positive Legal Action Network ("Women's PLAN"), a law office in Oakland, California. *See* Nancy Waring, *Advocating for Women Prisoners with AIDS*, 49 HARV. L. BULL. 5 (1997) (describing Women's PLAN).

125. *See* Interview with Dr. Kathleen Clanon, Director, Division of HIV Services, Alameda County Medical Center, in Oakland, Cal. (Nov. 14, 1997) (discussing the analogous use of this term in the health care setting).

problems from becoming more difficult, time-consuming, and stressful for the client and the Project to resolve.

#### 4. Multidisciplinary Integration and Coordination of Services

Finally, legal help may be an important “enabling” or “bridge” service,<sup>126</sup> but only if it is provided in coordination with other services. As in the medical care setting, where HIV-infected women prefer to be treated holistically,<sup>127</sup> so too in the legal services setting do women need integrated services that recognize, respect, and respond to the complexity of their lives.<sup>128</sup> The FCN coordinates all care, including legal assistance, at several levels.

The FCN is administered by an Executive Committee that is comprised of one representative from each agency and a representative from the Alameda County Department of Public Health’s Maternal, Adolescent, and Child Health.<sup>129</sup> At least one member of the Executive Committee also must be a person infected with HIV.<sup>130</sup> The Executive Committee meets monthly to plan services, allocate funds, and ensure the implementation of coordinated services.

In addition, the frontline providers of services from each agency meet monthly as the Client Services Workgroup (“Workgroup”). The goal of the Workgroup is to serve as the multidisciplinary setting in which clients’ cases are discussed in order to maximize the effectiveness of service provision. The meetings are similar to the multidisciplinary case conferences often utilized in health care settings.<sup>131</sup> Workgroup and Executive Committee members also each serve on at least one of several Subcommittees, established to address issues of importance to the functioning of the FCN and the delivery of its services.<sup>132</sup> The Executive Committee, Workgroup, and Subcommittees are staffed by the FCN Program Director, a full-time administrator whose primary responsibility is coordinating Network activities.

If the Executive Committee is the head of the FCN and the Workgroup its hands, the “peer advocates” from WORLD are the eyes, ears, and heart of the Network. These ten HIV-infected women provide part-time, peer-based psy-

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126. Cf. RESPONDING TO THE NEEDS OF WOMEN WITH HIV, *supra* note 3, at iv, 70.

127. See *id.* at 29.

128. Various forms of “integrated service delivery” have been attempted by other legal services providers. See Bellow & Charn, *supra* note 118, at 1659-63 (describing integrated legal services in the health care setting); Goodmark, *supra* note 86, at 258 (describing integrated legal services in a school-based setting); see also Louise G. Trubek, *Embedded Practices: Lawyers, Clients and Social Change*, 31 HARV. C.R.-C.L. L. REV. 415, 420-24 (1996) (describing integrated legal services for battered women and seniors).

129. See TITLE IV FAMILY CARE NETWORK, EXECUTIVE COMMITTEE BYLAWS, art. III, § 2 (Nov. 1997) (on file with the *Duke Journal of Gender Law & Policy*).

130. See *id.* art. III, § 3.

131. See Interview with Dr. Kathleen Clanon, *supra* note 125; cf. Diane Jones & J.B. Molaghan, *HIV Nursing Care*, in THE MEDICAL MANAGEMENT OF AIDS 491, 491 (Merle A. Sande & Paul A. Volberding eds., 5th ed. 1997) (“A multidisciplinary model is required to successfully integrate the efforts of AIDS care delivery to patients throughout the entire spectrum of the disease process.”).

132. Currently the FCN has the following Subcommittees: Adolescent, Perinatal, Clinical Trials, Consumer Input, Confidentiality/Database, and Evaluation. See ARLENE JOE, RYAN WHITE TITLE IV FAMILY CARE NETWORK, PROPOSED PROGRAM STRUCTURE (1997) (on file with the *Duke Journal of Gender Law & Policy*).

chosocial case management to FCN women and families, including emotional support, information and referral, escorts for women on medical visits, and general assistance in reducing barriers to care. The peer advocates have primary assignments to the other providers in the FCN, where they act as “point persons” to help providers overcome any internal barriers to services. The peer advocates not only come from the community they serve, but as HIV-infected women of color, mothers, and in recovery,<sup>133</sup> they are the community they serve; and as such, they are a critical component in fully integrating services to FCN clients.

The advantages of integrating legal services with other services to HIV-infected women clients are substantial. For example, a claim for Medicaid or Supplemental Security Income disability benefits on behalf of an HIV-infected woman will be more likely to succeed if it is undertaken both with the close collaboration of the treating primary and mental health care providers whose opinions are so central to such claims, and with the emotional and practical support of a peer advocate who may have already gone through the process herself. Successful permanency planning, such as petitioning for joint or standby guardianship, likewise benefits from the multidisciplinary team approach of health care providers, social workers, peer support, and attorneys who together with the client can best address her medical, psychosocial, logistical, and legal needs in considering the future care of her children. Finally, the synergy of professionals and peer advocates from different backgrounds educating each other and bringing to the Network different perspectives on how to meet needs can increase considerably the information and options available to HIV-infected women as they make important health care, legal, and other decisions for themselves.<sup>134</sup>

### C. Some Early Challenges to Comprehensive, Integrated Legal Care

The FCN model has shown great promise for increasing and improving services to women with HIV. During the six months in which the Project has participated in the Network, more HIV-infected women have been served than in any other comparable period in the Project's seven-year history. In addition to the general challenge of reaching and serving HIV-infected women, however, there are other challenges to integrating attorneys into the delivery model described above. The components of this new legal services delivery system—off-site provision, proactive legal assessments, early intervention, and integrated, comprehensive legal care—raise questions about the role of the Project's attorneys, their relationships to their clients, and the feasibility of reproducing the model elsewhere. Upon evaluating the Project's brief participation in the FCN, the following initial observations are offered.

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133. Of the ten WORLD peer advocates, five are African-American; two are Latina (and completely bilingual); eight have children; and at least three are former injection drug users. See Rebecca Denison, *Peer Advocates!*, WORLD (Women Organized to Respond to Life-threatening Diseases, Oakland, Cal.), Nov. 1997, at 3.

134. See Alan W. Houseman, *Political Lessons: Legal Services for the Poor—A Commentary*, 83 GEO. L.J. 1669, 1707 (1995) (“Solving problems of individual and group clients will involve more than attorneys, law students, and paralegals. It will require utilizing skills of people from a variety of different disciplines and developing interdisciplinary and holistic approaches to advocacy.”).

### 1. Decentering Legal Services and Professional Culture

Having been involved in providing legal services to women with HIV for many years and having tried to respond to their needs, the Project agreed to join the FCN and integrate its services with others in the Network. This decision has meant that the Project's work has been decentered in at least a couple of important ways. First, the Project has placed a staff attorney off-site in order to fully participate in the Network. On the one hand, this clearly locates services in a setting more accessible to FCN clients and provides for the multidisciplinary "synergy" discussed above. On the other hand, it may be professionally isolating for the attorney, who loses the support of office culture, the consequences of which are not yet known.<sup>135</sup> Second, in this new model, legal needs often are secondary to the overall care of an FCN client. Attorneys are accustomed both to seeing their role as central and to having others view them that way. In a truly integrated model, the attorneys are only one of many important voices. For the aspirations of the new model to be fully realized, attorneys will have to learn to challenge some of their own professional, and perhaps personal, norms.<sup>136</sup>

### 2. Proactive Assessments and Client Autonomy

Although the Project has been conducting proactive legal assessments for many years, participating in the FCN has refocused the Project's attention on what it means to assist clients in identifying their own legal needs. The Project utilizes a screening form developed specifically for the FCN that is completed with each client during the course of the Project's assistance. The form was designed to include most of the legal needs and issues facing low-income women with HIV. Nonetheless, the Project is cautious about imposing this conceptual framework on clients' complex and varied experiences, especially since they often are so different from those of the attorneys assisting them.<sup>137</sup> The Project also faces an additional challenge given the inordinate influence the attorneys' views typically have on clients' understanding of their choices and the decisions they make in relation to those choices.<sup>138</sup> The presence of other care providers, such as

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135. Note, however, that in important ways it may be liberating for the attorney who is removed from the law office bureaucracy and its focus on compartmentalized legal problems. Cf. MICHAEL LIPSKY, *STREET-LEVEL BUREAUCRACY: DILEMMAS OF THE INDIVIDUAL IN PUBLIC SERVICES* 76-77 (1980) (exploring issues of alienation in the public service sector, including in poverty law offices, which are exacerbated by bureaucratization and compartmentalization).

136. See generally Randy Retkin et al., *Attorneys and Social Workers Collaborating in HIV Care: Breaking New Ground*, 24 *FORDHAM URB. L.J.* 533 (1997) (exploring the professional role of attorneys who aid in serving people with HIV).

137. See Anthony V. Alfieri, Essay, *Reconstructive Poverty Law Practice: Learning Lessons of Client Narrative*, 100 *YALE L.J.* 2107, 2123-24 (1991) (identifying the risk of "pre-understanding," noting that "[t]he poverty lawyer's interpretive practices are predicated on his *pre-understanding* of the client's world. Pre-understanding is a method of social construction that operates by applying a standard narrative reading to a client's story. The reading imposes the lawyer's narrative meaning onto the story . . . result[ing] . . . in the silencing of client narrative and in the naming of [the] client story [as dependent] . . . . The result is the divesting of client story from empowering narratives." (citations omitted)).

138. See Richard D. Marisco, *Working for Social Change and Preserving Client Autonomy: Is There a Role for "Facilitative" Lawyering?*, 1 *CLINICAL L. REV.* 639, 648 (1995) ("[T]here is a threat to client autonomy inherent in any attorney-client relationship . . . . Clients may surrender their power to

social workers, case managers, and especially the peer advocates, may mitigate these risks, but attorneys at the Project will continue to struggle with achieving the appropriate balance between proactively assessing clients' legal needs and simultaneously respecting their autonomy.<sup>139</sup>

### 3. Early Intervention and "Role Uncertainty"

In order for the Project's services to meet more fully the needs of HIV-infected women, attorneys must be generalists, both by providing a wide range of legal services and by expanding their notion of what it means to act in their professional role through practicing early intervention: assisting in eviction cases before they become formal legal matters; advocating for clients in disability cases before they get to the hearing stage; and intervening on behalf of clients with creditors and collection agencies even when a bankruptcy is not needed. This raises questions such as: What is an attorney's "role"? How do attorneys, or should attorneys, distinguish themselves from other professional services providers?<sup>140</sup> And even if attorneys in such a model focus just on traditional legal representation, can they competently practice as generalists, when the legal profession, and the law itself, continues to move in what seem like inexorably more complex and specialized directions? These are large and unresolved questions that can be answered at best in partial, contingent steps as the Project evolves.

### 4. Service Integration and Client Confidentiality

The FCN model also poses many challenges to traditional conceptions of client confidentiality. Integrated service delivery requires a great deal of information-sharing about some of the most personal and intimate concerns of a client.<sup>141</sup> For example, a client's HIV status, the HIV status of her children, her relationship to the father of her children, the nature and extent of any disabling symptoms she experiences, and other information may need to be shared among

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attorneys due to attorneys' technical expertise, their privileged access to the legal system, or their familiarity and detachment in contrast to their clients' unfamiliarity and emotionalism. Human communication is imperfect, and clients' ability to communicate their concerns, goals, and objectives to attorneys may be further inhibited by their lack of trust in their attorneys, embarrassment at revealing unsavory or unflattering facts, or inability to recognize legally relevant facts—and by the attorneys' failure to listen.”).

139. Cf. GERALD P. LÓPEZ, *REBELLIOUS LAWYERING: ONE CHICANO'S VISION OF PROGRESSIVE LAW PRACTICE* 44-56 (1992) (arguing that legal services providers discount their clients' abilities to solve their own problems); Lucie E. White, *To Learn and Teach: Lessons from Driefontein on Lawyering and Power*, 1988 WIS. L. REV. 699, 760-66 (urging attorneys and clients, through shared deliberations, to reevaluate their respective roles in the attorney-client relationship).

140. See Marc Feldman, *Political Lessons: Legal Services for the Poor*, 83 GEO. L.J. 1529, 1539 (1995) (“Legal Services lawyers experience considerable uncertainty and ambivalence about whether they are or should be litigators, facilitators, social workers, or community educators and organizers.”). *But see* Goodmark, *supra* note 86, at 258 (advocating for an expansion of the understanding of which problems are “legal”); *but see generally* Stacy Brustin, *Expanding Our Vision of Legal Services Representation—The Hermanas Unidas Project*, 1 AM. U. J. GENDER & L. 39 (1993) (advocating for legal services providers to adopt a more expansive view of their role).

141. Cf. Heather A. Wydra, Note, *Keeping Secrets Within the Team: Maintaining Client Confidentiality While Offering Interdisciplinary Services to the Elderly Client*, 62 FORDHAM L. REV. 1517, 1523 (1994) (discussing these issues in the elder care context).

FCN providers. When such information is obtained in the law office setting at BCLC, attorneys emphasize to the client that it is held in strict confidence. In addition to meeting professional responsibilities, making such an assurance increases the level of trust a client has in her attorney and thereby presumably increases the amount and veracity of the information she will share.

In an integrated delivery system, by contrast, the client is asked to divulge information with the explicit understanding that it may be shared with other services providers, including her health care provider, case manager, substance use counselor, and peer advocate, who will also share what information they obtain from the client with the Project's attorneys.<sup>142</sup> In fact, when a client's consent to share information is sought, the client is informed that she can be better served if she agrees to allow the Project to share her information with the other providers in the FCN. Given both the great need such a client typically has for all FCN services and the substantial power imbalance inherent in the attorney's relationship to the client, it is questionable whether such consent can be freely and meaningfully obtained. Negotiating such an important and difficult issue is critical to the ultimate success of an integrated delivery system.

#### 5. The FCN Model and Resource Scarcity

Finally, resource scarcity clearly is implicated in the FCN model. Proactive, comprehensive, integrated legal care is more resource-intensive than is traditional provision of legal services. For example, while a typical legal aid attorney might assist several hundred clients per year, the large majority of whom are provided only advice or brief service,<sup>143</sup> the Project anticipates an attorney serving approximately sixty FCN clients per year. Such a limited, focused approach might be controversial even in an era of plentiful resources, but it is being proposed at a time of great financial uncertainty for most legal services providers.

Traditional public resources for legal assistance to low-income clients are dwindling. The 1996 budget of the federally funded Legal Services Corporation (LSC), which supported many of the early direct services programs for people with HIV, was cut by one-third.<sup>144</sup> Most legal aid programs across the country

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142. See Retkin et al., *supra* note 136, at 542-47 (exploring these issues in terms of the differing roles and responsibilities of social workers and attorneys serving people with HIV).

143. See STATE BAR OF CALIFORNIA, AND JUSTICE FOR ALL: FULFILLING THE PROMISE OF ACCESS TO CIVIL JUSTICE IN CALIFORNIA 21 (1996) (noting that, for example, in California in 1993, 85% of legal aid's closed cases involved only advice, brief service, referral, or the determination that there was insufficient merit to proceed).

144. See Mary Wisniewski Holden, *Clipped Wings and Budget Cuts Tax Legal Aid*, CHI. LAW., Aug. 1997, at 1, 58. The reduction was from \$415 million in 1995 to \$278 million in 1996. See *id.* The \$415 million appropriated in 1995 still represented less than one-half, in inflation-adjusted terms, of the \$321 million spent in 1981, which was the highest single-year real-dollar federal expenditure for legal services. See STATE BAR OF CALIFORNIA, *supra* note 143, at 8. Fiscal year 1997 LSC funding was \$283 million. See Holden, *supra*, at 58. Fiscal year 1998 funding remains at \$283 million. See Departments of Commerce, Justice, and State, The Judiciary, and Related Agencies Appropriations Act of 1998, Pub. L. No. 105-119, 111 Stat. 2510 (1997). In addition to significant budget cuts for federally-funded legal services, important new restrictions have been placed on legal services programs receiving LSC funds. See *generally* CENTER FOR LAW & SOC. POL'Y, SUMMARY OF THE FY 96 RESTRICTIONS ON RECIPIENTS OF LSC FUNDS (1996) (cataloging the most significant recent restrictions on LSC-funded programs).

either are scaling back their programs, including centralizing offices,<sup>145</sup> thereby decreasing clients' access to services, or are closing altogether. In addition, Interest on Lawyers Trust Accounts (IOLTA) funding, which has supported many direct services and referral panels for people with HIV,<sup>146</sup> has fallen by at least one-half due to sharp decreases in interest rates since the early 1990s and teeters on the brink of elimination.<sup>147</sup> The future of foundation and corporate support, which has been important to serving people with HIV, is uncertain at best, with some funders shifting their focus from an epidemic erroneously declared "over" to communities impacted by welfare reform.<sup>148</sup> Law school clinic expansion also is unpredictable and has been relatively static in terms of the number of HIV-dedicated clinics since their proliferation in the early 1990s.<sup>149</sup>

The lone, but substantial, good news continues to be the federally-funded Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, which was passed in 1990<sup>150</sup> and was reauthorized in 1996 for a second five-year period.<sup>151</sup> Titles I and II of the CARE Act support many referral panel and direct services programs for people with HIV,<sup>152</sup> including BCLC's HIV/AIDS Law Project. Title IV of the CARE Act specifically supports comprehensive services to women, children, and adolescents with HIV,<sup>153</sup> and is the source of all FCN funding. Even if these sources of funding continue to be available beyond their current authorization, however, the dearth of resources in the face of an overwhelming need for services among low-income people likely will persist. For the foreseeable future, low-income communities and those who provide services

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145. Cf. Edgar S. Cahn, *Reinventing Poverty Law*, 103 YALE L.J. 2133, 2146 n.46 (1994) (identifying the trend toward centralization of neighborhood legal services offices prior to the 1996 LSC cuts).

146. See generally DIRECTORY OF LEGAL RESOURCES 1997, *supra* note 27 (noting which HIV/AIDS legal services organizations receive IOLTA funding).

147. IOLTA is a program that distributes interest generated from attorneys' client trust accounts to legal services programs for the poor. The United States Court of Appeals for the Fifth Circuit recently held that Texas' IOLTA program was unconstitutional as an unlawful taking, jeopardizing the program in all 50 states. See *Washington Legal Found. v. Texas Equal Access to Justice Found.*, 94 F.3d 996, 1000 (5th Cir. 1996), *cert. granted*, 117 S. Ct. 2537 (1997).

148. See Interview with Jonathon Marley, Development Director, Berkeley Community Law Center, in Berkeley, Cal. (Dec. 5, 1997)

149. See discussion *supra* note 47 and accompanying text.

150. See 42 U.S.C. § 300ff (1994), as amended by Ryan White CARE Act Amendments of 1996, 42 U.S.C.A. § 300ff (West Supp. 1997); see also RESPONDING TO THE NEEDS OF WOMEN WITH HIV, *supra* note 3, at 7-11 (giving an historical overview of the Ryan White CARE Act).

151. See 42 U.S.C.A. §§ 300ff-13, -101 (West Supp. 1997). The 1996 reauthorization, however, linked direct state funding (Title II) to the implementation of mandatory newborn testing measures prior to the year 2000. See 42 U.S.C.A. §§ 300ff-21, -34 (West Supp. 1997); see also Suzanne M. Malloy, *Mandatory HIV Screening of Newborns: A Proposal Whose Time Has Not Yet Come*, 45 AM. U. L. REV. 1185, 1212-13 (1996) (discussing mandatory HIV screening of newborns and recommending instead mandatory HIV counseling of pregnant women). In addition, in February 1997, the Health Resources Services Administration ("HRSA"), which administers the Ryan White CARE Act funds, issued guidelines prohibiting the use of Title I and II funds for "any criminal defense, or for class action suits unrelated to access to services eligible for funding under the CARE Act." HRSA PROGRAM POLICY NOTICE, *supra* note 124, § 97-02.9, at IV-16.

152. See 42 U.S.C. §§ 300ff-21 to -30 (1994); see generally DIRECTORY OF LEGAL RESOURCES 1997, *supra* note 27 (cataloging most of the legal aid programs that receive CARE Act funding).

153. See 42 U.S.C. §§ 300ff-22, -71 (1994); see also RESPONDING TO THE NEEDS OF WOMEN WITH HIV, *supra* note 3, at 7-8.

to them will be left to make painful choices about where and how to direct the existing limited resources.<sup>154</sup>

## V. CONCLUSION

*But I maintain that she would come if we worked for her, and that so to work, even in poverty and obscurity, is worth while.*<sup>155</sup>

Individuals and organizations that have been providing legal services to people with HIV during the last fifteen years have attempted to meet the changing needs of the HIV-infected community by offering culture-responsive models of care. The referral panel and direct services models have been exemplary in overcoming many of the barriers to accessing legal services faced by people with HIV in the first and second waves of the epidemic.

Women with HIV, however, face obstacles that are distinct from first and second wave clients and necessitate a service model that addresses their specific needs. The approaches embodied in BCLC's participation in the Family Care Network—one-stop shopping, proactive needs assessment, early intervention, and multidisciplinary integration and coordination of services—represent one effort to overcome the gender-specific barriers to legal services for women with HIV. This model cannot and will not be replicated everywhere, but it is offered in the hope of generating more ideas, targeting more resources, and identifying more opportunities to serve the increasing number of HIV-infected women in the United States who have such extraordinary unmet legal needs.

The challenges to meeting these needs are formidable, but the stakes are high. For an HIV-infected woman, access to legal services can mean the difference—for her and her children—between eating and going hungry, between being housed and being homeless, and between having improved access to quality health care and no health care at all. For the legal community, providing gender-equitable legal services to women with HIV fulfills the profession's highest aspirations—giving content to the commitment of equal justice for all.

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154. Compare Gary Bellow & Jeanne Kettleon, *From Ethics to Politics: Confronting Scarcity and Fairness in Public Interest Practice*, 58 B.U. L. REV. 337, 354-62 (1978) (arguing for a zealous approach to advocacy on behalf of a limited number of poor people, which may be in tension with providing minimum services to the greatest number of clients), with Paul R. Tremblay, *Toward a Community-Based Ethic for Legal Services Practice*, 37 UCLA L. REV. 1101, 1137 (1990) (arguing for triaging and sometimes less-than-minimally-adequate legal services to poor people grounded in community-based standards and "the *realpolitik* of legal services practice").

155. WOOLF, *supra* note 1, at 114.