RYAN WHITE CARE ACT POLICY STUDY

Ensuring Access to Health Care for People with HIV/AIDS:

The Role of Legal Services

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Ensuring Access to Health Care for People with HIV/AIDS: The Role of Legal Services

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Introduction

In this report, we will demonstrate that services which address the legal needs of persons with HIV/AIDS help to improve their access to health care services and their health. Based on a review of the relevant literature and our own interviews with nearly half the organizations nationwide offering such legal services, we will look at the range of areas in which legal services assist individuals in overcoming the obstacles, such as discrimination, that can prevent them from receiving necessary health care. We will further examine the role these legal services play in addressing individuals’ conflicting subsistence needs (such as food, clothing, housing, and transportation) that also stand in the way of their receiving appropriate care.

In developing this report we set out to learn how legal services help people living with HIV/AIDS access health care services. We wanted to know whether there is a correlation between having legal needs met and being able to receive health care services that keep an individual with HIV/AIDS functioning and independent. We aimed to answer the questions that readily present themselves: What is unique about HIV/AIDS that requires legal services specifically tailored to the needs of persons living with it? What are the legal barriers to accessing health care services faced by an individual with HIV/AIDS? What legal services are available to persons with HIV/AIDS, and who is providing them? Does accessing these services correlate with better health care? Finally, should and how can CARE act funding support these service providers?

As of June 1999, 711,344 Americans had been diagnosed with or died from AIDS. By the end of 1998, there were 297,137 persons in this country living with AIDS. A
significantly decreased death rate between 1996 and 1998 has been attributed to the effect of new treatments for HIV infection. A similar drop in the total number of AIDS diagnoses for the 12-month period from July 1998 through June 1999X47,083, down from 54,140 in the previous 12-month periodXlikewise attests to the salutary effects of recently developed combination therapies.

The proportions of those with AIDS continue to reflect the same skewed numbers that have characterized the AIDS epidemic in the U.S. from its 1981 beginning: Men who have sex with men still account for the single largest percentage of the total new cases (45 percent) and cumulative cases (57 percent), followed by female injection drug users (28 percent of new cases; 42 percent of the cumulative total), females who contracted HIV heterosexually (40 percent of both new and cumulative cases), and male injection drug users (21 percent of new cases and 22 percent of the cumulative total). Notably, more blacks (70,720) were diagnosed between 1996 and 1998 than whites (50,855). Among women, who account for 23 percent of reported adult AIDS cases, blacks and Hispanics account for 80 percent of cases; among men, blacks and Hispanics account for 61 percent of cases.¹

As the demographics of AIDS in the U.S. have shifted into poorer and marginalized communities, the HIV/AIDS-related legal services these new clients need has also changed. Many of these individuals have had histories of chemical dependency, low incomes, poor housing, and limited access to health care and other supportive services. Their legal needs are typically those traditionally addressed in poverty law practicesXincluding advocacy for public entitlement programs such as welfare, SSI, and Medicaid; landlord/tenant law; family law; and consumer law, particularly for debt relief. They also frequently need estate planning documents and assistance in planning for the care of minor children.²
Because of the correlation of HIV/AIDS and poverty, and the higher rate of poverty among women, women with HIV/AIDS are likely to be poor and either under- or uninsured. Frequently women in need of legal assistance are unable to make an appointment for legal counseling because they are caring for children or can’t find childcare. Women often do not access legal assistance for the same reason they frequently do not access early health care services: because they learn later in the course of their HIV infection than men that they are infected. The legal needs of women with HIV/AIDS often include wills, durable powers of attorney for health care, and guardianship for their children.\textsuperscript{3,4} With an estimated 80,000 AIDS orphans in the U.S., children whose mothers have died from HIV/AIDS, it is essential to address the legal, social, and cultural issues surrounding care and custody of children.\textsuperscript{5}

A recent national study of HIV costs and services utilization found that while the rate of inadequate HIV care had declined between early 1996 and early 1997, there were several populations still receiving inadequate care. Blacks, Latinos, women, the uninsured, and the Medicaid-insured all had less desirable patterns of care.\textsuperscript{6} Using data from the same study population of 2,864 Americans being treated regularly for HIV/AIDS, a recent RAND study noted that for impoverished or socially marginalized persons, addressing subsistence needs\textsuperscript{X}including the need for food, clothing, and housing\textsuperscript{X}may not only be difficult, but in fact can result in poor health outcomes. More than one-third of those studied went without or postponed medical care because of needing the money for food, clothing, or housing; not having transportation; not being able to get out of work; or being too sick. Most likely to be affected were non-whites, younger persons, women, injection drug users, those with lower income or education, and the uninsured.
Besides impeding access to health care services in general, the RAND study found that competing subsistence needs and barriers frequently meant not receiving antiretroviral therapy. Nationwide, only 32 percent of the study participants had private health insurance; 48 percent had public insurance; and 20 percent had no insurance at all. The study concluded that to benefit from improved medical therapy, persons with HIV require interventions aimed at alleviating their subsistence needs in addition to medical services.\(^7\)

As more people with HIV live longer, healthier lives, more of them are choosing to return to work. This positive development also presents a number of potential legal issues revolving around the Americans with Disabilities Act (ADA), and the requirement that employers make Areasonable accommodations\(\approx\) for persons with disabilities including HIV infection and AIDS.\(^8\)

Between 1991 and 1994, four demonstration projects funded by the Special Projects of National Significance (SPNS) established models for providing statewide HIV-related legal services. Each program helped clients who encountered discriminatory practices requiring the assistance of legal service providers. But discriminatory barriers went beyond those that directly restricted access to health and human services. Access to care is clearly compromised when a medical provider refuses to provide treatment. But care is also affected when discrimination results in the loss of employment or housing.

Although most reports of discrimination involve services provided or regulated by states, the ADA, the Rehabilitation Act of 1973, and the Fair Housing Amendments Act of 1998, are cited most frequently in resolving these cases. In the SPNS demonstration projects, federally funded legal services\(\times\)including general Protection
and Advocacy services as well as HIV-specific projects were found to enable people with HIV to access available statutory protections and navigate the requirements of public entitlement programs including Social Security, Medicaid, and Medicare. Federal funds also gave the projects a measure of independence from state and local political pressures, an important consideration with such a politicized disease.

The report on the SPNS legal services programs noted that the demonstration project nature of SPNS provided only one-time funding for these groups. It concluded that since CARE act funding provides for medical and support services for persons with HIV, planning bodies should strongly consider how legal protection and advocacy services can support the mission of the CARE act to provide a comprehensive continuum of care.  

In view of the widely reported discrimination and other legal needs of persons with HIV/AIDS, we hypothesized that legal advocacy and protection services ought to be central components of HIV/AIDS services. Whether involving the assertion of a legal right, providing assistance in obtaining benefits, or helping with legal planning, the need for legal advocacy has been evident throughout the AIDS epidemic. Such services improve access to health care, housing, and support services through education, empowerment, and enforcement of legal rights.

In this report, we first describe the methods used to gather information about the legal needs of people with HIV/AIDS and the legal services available to them. In the findings section, we share what we found out about how legal services help HIV/AIDS clients access and maintain health care. We look in detail at how legal services help people with HIV/AIDS overcome barriers that directly impede their access to health care. And we explore the ways that HIV/AIDS-related legal services help clients to
meet subsistence needs, thereby keeping them fed, clothed, and housed prerequisites of good health. We include case examples and anecdotes that illustrate our findings.

Finally, we offer recommendations to the federal government for the role of CARE act funding in supporting the kinds of legal services that are correlated with health care access. The report’s appendixes include a list of the organizations we contacted, highlighting those that responded, and a detailed look at the structures, finances, and services provided by these legal services programs and organizations.
Methods

We used a two-pronged information gathering process to look at the relationship between legal services for people living with HIV/AIDS and their ability to access health care services. First, we reviewed the relevant literature, as well as earlier needs assessments conducted by AIDS service providers. Second, we contacted organizations throughout the U.S. providing legal services to people with HIV/AIDS, collecting firsthand information from them on the clients they serve, the types of services they provide, the gaps in services, and how those gaps might be filled.

To shape and guide this report, we formed a panel of expert advisors recognized for their own or their organizations’ work on issues related to HIV/AIDS-related legal services. Advisors provided literature references, information about their own organization’s experiences with HIV/AIDS legal services, and guidance in presenting the report’s findings. We determined there were five key areas that would provide a workable overview of the legal needs of people with HIV/AIDS, the services available to meet them, and the service providers’ own needs in continuing their work. Specifically, we wanted to know:
What are the legal services-related needs of people living with HIV/AIDS, and to what extent are different needs being met for the diverse populations affected by the epidemic?

How do legal services help HIV/AIDS clients to access and maintain health care?

What types of organizations are providing HIV/AIDS-related legal services, including their staff size and composition, and budgets?

What legal services are these organizations providing to HIV/AIDS clients?

What kinds of support and resources do these organizations need to provide these services and how can the CARE act support them?

Of the 51 HIV/AIDS legal services providers (see the list at Appendix A) we contacted, 44 were selected from the Directory of Resources for People with AIDS & HIV published by the AIDS Coordination Project of the American Bar Association in 1997 (ABA directory). These represented every legal service provider in the ABA Directory indicating it had at least one full-time staff attorney dedicated to providing HIV legal services, and confirmable address, phone number, and contact person. We also contacted seven Protection & Advocacy organizations recommended to us by the National Association of Protection & Advocacy Systems, Inc., in Washington, D.C. These AP & A=systems were selected because of their known focus on HIV/AIDS issues and/or because they are located in states with a high prevalence of HIV infection.

One of the obstacles we encountered was the fact that legal service providers have different organizational structures, definitions of clients (i.e., is a client only

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someone in an ongoing client relationship or is it also someone who is provided one-time information by telephone?) and cases (i.e., what constitutes a Alegal service=?), and methods for collecting data. To get more uniform data, we defined certain terms and asked service providers to apply these terms to their own experiences. Specifically, we defined AHIV cases as any legal service provided to a client with or affected by HIV/AIDS, including referrals to other agencies and brief advice and counseling. An AHIV legal services program was defined as any freestanding legal services program or a legal program within an organization serving clients living with or affected by HIV/AIDS.

Although we were unable to obtain information from all the nation=s HIV/AIDS legal service providers, we postulated that because organizations were selected based on their locations and experience with providing HIV/AIDS legal services, their responses would indeed provide a broadly representative illustration of the issues we wanted to measure.
Findings

Through our literature survey and assessment of the information we gathered directly from legal service providers, we found that there are two primary ways that legal services help people living with HIV/AIDS to access health care services: (1) by helping them overcome the barriers that directly prevent access to health care, and (2) by helping them to meet subsistence needs that compete with and may even prevent them from receiving the medical care they need.

People living with HIV/AIDS typically face one or more barriers to health care, including discrimination and breaches of confidentiality by health care providers, problems in accessing and using public benefits and private insurance that provides for medical care, and the provision of inadequate medical care. For those who are able to work, balancing their job responsibilities and their medical care is a major challenge—even with the protections of the Americans with Disabilities Act (ADA). Many face problems participating in their health care decision-making when HIV-related illnesses make them mentally incompetent. In addition, certain sub-groups within the HIV/AIDS-affected population—including families with children, non-citizens, and the incarcerated—face special legal challenges that affect their access to health care.
Legal services also help people with HIV/AIDS to meet the subsistence needs—food, clothing, and shelter—that can compete with and prevent them from accessing the health care services they need. By addressing housing issues, for example, legal services help clients to obtain and maintain low-income housing which provides the stability they need to receive medical care and to use more of their limited financial resources for their health care needs. Legal services can help clients maintain or increase their limited income and financial resources by addressing employment-related issues, problems with obtaining or maintaining public benefits, life and disability insurance, debtor/creditor and bankruptcy issues, and tax problems.

Below in further detail is what we learned about the specific ways in which legal services help people with HIV/AIDS access the health care and ancillary services they need to achieve healthy, stable lives. The first section focuses on the role of legal services in addressing direct barriers to health care; the second looks at how legal services help to meet clients’ subsistence needs in ways that contribute to their overall well-being and allow them to better access health care services. We offer examples from the legal services providers we contacted for this report to illustrate the legal needs of people with HIV/AIDS and how those needs are being addressed by legal services programs.
Direct Barriers to Health Care Addressed by Legal Services

Addressing the range of direct barriers to health care a person with HIV/AIDS frequently encounters accounted for the largest single area of legal services by all of the legal services providers we contacted for this report. Health care issues represented nearly 30 percent of the programs’ total case loads in their most recent year. Programs offer a broad range of legal services related to health care law, particularly brief advice and counseling, limited direct representation (short of litigation), and referrals to other legal and non-legal service providers and programs. Below are the major areas in which legal services programs have assisted their HIV/AIDS clients.

2. Health-related discrimination by health care providers

Since the beginning of the AIDS epidemic, people with HIV/AIDS have faced discrimination in a variety of areas, including health care. When the National Association of People with AIDS in 1992 conducted the largest survey of people living with HIV and AIDS done to that point, more than 36 percent of the 1,800 respondents reported incidents of health care discrimination. One individual said, “Health care workers seem afraid because I have HIV.”

Among the populations now being hit hardest by HIV, discrimination related to having the virus is added to the burdens of poverty, hunger, homelessness, inadequate
health care, and racial discrimination. For HIV-positive women of childbearing age in particular, health care discrimination, personal isolation, and psychological sequelae are common. Although it appears to be decreasing discrimination persists among health care providers. For example, a national study of dentists published in 1995 reported that 84 percent maintained it was their right to decide whether or not to accept an HIV-positive patient for treatment.

A landmark 1998 ruling in the case of Bragdon v. Abbott by the United States Supreme Court confirmed that asymptomatic HIV infection is considered a covered disability under the Americans with Disabilities Act (ADA). Because of this definition, people with HIV and AIDS have the right to be free from discrimination by health care professionals. Besides the ADA, the Rehabilitation Act of 1973, state laws, and local ordinances also prohibit discrimination against individuals with a disability. Unfortunately, persons living with HIV/AIDS are still denied services and care by medical providers.

Discrimination includes not only health care facilities and practitioners' explicit policies of refusing to treat HIV-positive patients, but the segregation of HIV-positive patients, the refusal to provide the full range of services offered to other patients, unjustified referrals to other providers or to non-profit or publicly funded HIV-health clinics, and the taking of unnecessary and sometimes humiliating safety precautions. HIV-positive clients have reported discrimination by general practitioners, surgeons, ob/gyns, dentists, and emergency rooms.

In light of the widespread prevalence of discrimination against people with HIV/AIDS, it was not surprising to find that the overwhelming majority of HIV/AIDS legal services

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programs offer assistance and representation to clients in countering health care-related discrimination of one type or another.

**Examples:**

X In Boston, MA, Gay and Lesbian Advocates and Defenders (GLAD) sued a doctor who refused to treat an HIV-positive pregnant woman. The doctor stated that he did not know how to administer the AZT protocol that reduces the risk of HIV transmission from mother to child. GLAD has brought suit under the ADA which allows health care providers to refer out patients with a disability only when the services required are outside the physician=s area of expertise.

X The HIV/AIDS Advocacy Program of Michigan=s Protection and Advocacy and the HIV/AIDS Legal Services Alliance (HALSA) of Los Angeles reported currently having a total of three lawsuits in federal court against dentists who refused to provide routine dental service to clients living with AIDS. HALSA also reported that it has settled three HIV/AIDS dental discrimination suits during the past year.

X The AIDS Legal Council of Chicago intervened when a surgeon refused to perform surgery on an HIV-positive patient. The client had lost half his leg in battle and had begun to develop recurring sores on his amputated leg. The client=s doctor determined that the client needed surgery on his thigh bone to stop the sores from returning, and referred the client to an orthopedic surgeon. As the client lay on the gurney prepped for surgery, the surgeon introduced himself and flipped through the client=s chart. ≈Wait a minute,≈ the surgeon said. ≈You should have told me you were HIV-positive. I can=t perform this surgery.≈ The surgeon walked away, the IV=s were removed from the client=s
arm, and he was sent home. The AIDS Legal Council immediately contacted the hospital, and the client was scheduled for surgery with a new surgeon the next day.

2. Breaches of confidentiality and testing rights by health care providers

Most HIV/AIDS legal service providers offer counseling to clients on their right to privacy regarding their HIV status and medical records in connection with health care providers and health insurance companies. They also represent clients whose confidentiality has been violated, those who have been tested without their consent by medical providers, and the rights of minors to consent to HIV testing.

Ensuring that the confidentiality of clients’ HIV status is protected is essential to ensuring that they will access health care. Without the assurance of confidentiality, people at risk for HIV infection will go untested and those in need of health care services will forgo them. For example, a North Carolina survey found that 54 percent of people who tested HIV-positive would not participate in a study that required partner notification. Other studies have found that among gay men who engage in high-risk sexual activity, the majority would not be willing to test if names reporting were required.

Examples:

X The AIDS Legal Assistance Program of Legal Aid of Western Missouri assisted a client who would not apply for group insurance benefits through his employer

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because he feared his employer would learn of his HIV status. The program educated the client about how to protect his confidentiality at work and how to submit his insurance application directly to the carrier. Consequently, the client received health insurance.

Michigan Protection and Advocacy’s HIV/AIDS Advocacy Program advocated on behalf of a client whose HIV status was disclosed by her physician at a major medical facility in Michigan, which has a specialty clinic serving persons living with HIV and AIDS. HAAP staff informed the physician that he had breached the client’s confidentiality when he openly discussed her status in a crowded hallway of the hospital. As a result of HAAP staff intervention, the physician apologized for his error and asked HAAP staff to provide training to his entire staff. The client was pleased with the outcome because she wanted to make sure this situation did not happen to someone else.

The HIV/AIDS Legal Services Alliance of Los Angeles, CA, assisted a client whose HIV-status was disclosed to California’s Department of Motor Vehicles by a nurse at an HIV/AIDS medical clinic. The client lived in a remote part of Los Angeles County, and the clinic was the only HIV/AIDS specialty clinic near where she lived. After the disclosure, the client stopped getting health care services at the clinic and decided to drive 60 miles to another clinic for her health care. HALSA intervened on behalf of the client, and the clinic agreed to discipline the nurse who had disclosed the client’s HIV-status, adopt a more stringent HIV confidentiality policy for its staff, and conduct a training for its staff on HIV/AIDS confidentiality and discrimination issues. As a result, the client felt comfortable returning to the clinic for her health care needs.
X The AIDS Legal Clinic of the University of Maryland Law School is often consulted by doctors and parents about whether a child’s HIV-status must be disclosed to the school system and about what rights to confidentiality the child can expect from the school system if his HIV status is disclosed. This is becoming a more pressing issue as more HIV-positive children are living long enough to attend elementary and secondary schools. The AIDS Legal Clinic is working with the Maryland State Board of Education on a revision of its recommendations in this area, to insure that confidentiality is protected so disclosure is possible where necessary. Such protections allow children living with HIV/AIDS to attend school without fear of harassment and discrimination, while still taking care of their health care needs during the school dayBsuch as taking breaks for rest or to take their medications.

3. Problems with accessing/using public medical benefits

People with HIV/AIDS frequently rely upon public benefits programs to assist them in paying for essential services and the expensive drugs now available to treat HIV. Medicaid is the largest single source of federal assistance for health care for people with HIV/AIDS. In 1998, Medicaid was estimated to cover 50 percent of the adults and 90 percent of the children living with HIV/AIDS in the U.S. In fiscal 1999, the federal government spent $5.8 billion for HIV/AIDS-related treatment, and $1.4 billion for income and support programs.

Virtually all HIV/AIDS legal service programs assist clients in accessing and using public benefits to which they are entitled. The 16 programs we contacted that provided the
number of clients served reported a combined total of 3,031 cases. The programs most commonly offer brief advice and counseling, limited direct representation, client education, and referrals to other providers and programs.

Services in this area include helping clients apply for state and federal public benefits, such as Medicaid and Medicare, which provide assistance through supplementary income and access to health care. The programs help ensure that clients’ treatments are properly covered and medical bills properly paid for by Medicare and Medicaid. These services help clients to maintain coverage as they re-enter the workforce and navigate Medicare and Medicaid managed care programs. The programs also assist with accessing state AIDS Drugs Assistance Programs and ensuring that low-income clients can use and receive quality care from free and low-cost public clinics. Programs help clients appeal denials of their benefits claims, handle improper delays in receiving public benefits, and assist clients with issues such as dealing with charges of overpayment, improper terminations of benefits, and problems with representative payees.

Legal services in the area of public benefits also assist clients in accessing health care by providing them income to pay for health care costs and because for many clients, obtaining Social Security or welfare benefits is the only way to access public health care services. For example, to be eligible for Medicare clients must first receive SSDI benefits for two years. Clients who receive SSI benefits are eligible for Medicaid. For many women with children, securing AFDC is a prerequisite to receiving Medicaid benefits.

Examples:
The HIV Law Project (HLP) of New York, NY, helped a client successfully appeal a denial of Social Security benefits. The client could not work because he suffered from regular herpes outbreaks, major depression, and constant diarrhea (a side effect of his HIV medication). Nevertheless, he was unable to obtain benefits from the Social Security Administration (SSA). SSA decides on a claim based upon medical evidence. After examining the client's papers, HLP quickly realized that SSA did not have sufficient medical records to document his condition. HLP gathered medical evidence and helped the client articulate the cumulative effects of his various symptoms.

Gay and Lesbian Advocates and Defenders, in Boston, MA, recently negotiated a settlement with Metropolitan Life Insurance Company, one of the country's largest disability insurers, which had abruptly terminated a client's disability income benefits because despite clear medical evidence, it insisted the client's condition had been "stabilized by new medications." Met Life agreed to reinstate all of the client's benefits.

When a client was at risk of losing disability benefits, the Legal Aid of Western Missouri=AIDS Legal Assistance Program negotiated an agreement with the carrier. The client was being charged with an overpayment of benefits by the insurance company. Failure to repay the overpayment would have resulted in termination of employment and loss of medical insurance. The AIDS Legal Assistance program negotiated an agreement that allowed the client to maintain employment status and continue disability and health care benefits.

The AIDS Legal Project of the Atlanta Legal Aid Society successfully appealed Medicaid's denial of a client's transportation to and from his pharmacy and health
care provider. Medicaid denied transportation because the client’s roommate has a car. This car was not available to the client to travel back and forth to his health care appointments, and the client could not access health care without the covered transportation.

X The AIDS Law Project of Pennsylvania has initiated a project to expedite approval of Medicaid for eligible applicants living with HIV. Three community-based clinics have been paired with three local welfare offices to meet regularly and develop relationships to improve Medicaid approval for patients living with HIV/AIDS. The project has developed expedited procedures to approve Medicaid for HIV-infected individuals to within five days. Approval and billing are effective on the applicant’s first medical appointment, and in-person visits to the welfare office are waived for federally eligible applicants. The program hopes to replicate this project citywide, perhaps even statewide. The project also is working to improve retroactive Medicaid billing by providers the law permits three months of retroactive billing to serve CARE act health services funding for those who are not Medicaid-eligible.

4. Problems with accessing and using private health insurance

HIV-related life and health insurance claims dropped 39 percent between 1994 and 1998. The drop was attributed to the use of protease inhibitors keeping people with HIV healthier for a longer time, innovative ways that managed care programs had found to drive down costs, and the fact that the increasingly poor populations affected by HIV generally do not have private insurance.

Earlier studies indicate that approximately one in three people with HIV/AIDS have private insurance, while 40 percent are covered by

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some form of public program (Medicaid, Medicare, CHAMPUS, or VA), and 27 percent have no coverage.\textsuperscript{19,20} As HIV infection progresses to AIDS, individuals have tended to lose their jobs and, consequently, their private health insurance.\textsuperscript{21}

People living with HIV also face discrimination by health insurance companies that deny them coverage, limit the services for which they are eligible, and impose $\Delta$HIV caps, which cap the total amount of health insurance coverage that can be received by a person living with HIV disease at a lower amount that the coverage of other persons.

Two important pieces of legislation help people with HIV/AIDS who are employed to keep their private health insurance, though it is contingent upon their being able to afford the monthly premiums. The first was the 1985 Consolidated Omnibus Budget Reconciliation Act (COBRA), which allows employees to continue their insurance coverage for up to 18 months after leaving a job\textsuperscript{29} months if they are disabled, which is often the reason many people with HIV/AIDS leave their jobs. Coverage remains the same, but the former employee must pay the total cost of the group health coverage including both the portion paid by employees and any portion previously paid by the employer, as well as an administrative fee.\textsuperscript{22}

The other, more recent, law was the 1996 Health Insurance Portability and Accountability Act (HIPAA), which eliminated the possibility that individuals can be denied insurance coverage due to a preexisting medical condition if they maintained employer coverage. It also prevents insurers from denying coverage to any individual or company based on any type of health risk factors.\textsuperscript{23}

Many HIV/AIDS clients are able to stay connected to the health care services they need only so long as they can work and thereby maintain their employer-funded health

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insurance. Beyond health insurance, life and disability insurance are important to maintain and may even provide income. Seventy-two percent of the legal services programs we contacted provide assistance in obtaining private health insurance and representing clients who are unlawfully denied coverage for treatments or services or have their health insurance coverage unlawfully terminated.

Many clients delay or fail to apply for health insurance offered by their employers because they inaccurately believe that they will be denied insurance because they have a pre-existing condition, or because they fear that their employers or others will learn of their HIV status from insurance companies. Legal service providers assist clients with the many issues that arise from employment-related health insurance coverage, such as being unlawfully denied or terminated from coverage by employers, applying for and maintaining COBRA coverage, and being able to change jobs and maintain health insurance coverage.

Advocates report they must be vigilant in arguing insurance issues in a variety of forums, including federal and state courts, state insurance commissions, and other state and federal agencies, and be prepared to refer clients to alternate sources of medical care, such as state high-risk pools and Ryan White-funded clinics, when the discrimination is insurmountable.

Examples:

X A suburban Chicago widow with four children found herself with more than $55,000 in unpaid medical bills when her health insurer refused to pay on the grounds that she had failed to disclose a *negative* HIV antibody test when she first applied for the
policy. After threatened litigation by an AIDS Legal Council of Chicago volunteer attorney, the past-due bills were paid and her full health insurance benefits restored.

X A volunteer attorney working with the AIDS Legal Resource Project of the Legal Aid of Western Oklahoma helped a client obtain approval from his insurance company to pay for surgery for a rare life-threatening condition known as trigeminal neuralgia. This condition causes a painful sensation on the face that is so severe it frequently pushes its victims to suicide. The client’s insurance company had deemed the surgery to be an experimental treatment not covered by his insurance contract. When correspondence and phone calls to the insurer did not help, the attorney filed a complaint in federal court. Three days after the complaint was filed, the insurer agreed to provide coverage for the client’s surgery.

X The AIDS Legal Project of the Atlanta Legal Aid Society secured an additional 11 months of COBRA insurance coverage for a client. The client’s former employer initially denied the continuation of insurance coverage under OBRA, which provides for continuation of COBRA coverage for disabled employees until they are eligible for Medicare. Without the continuation the client would have been uninsured for 11 months until his Medicare began. The Legal Project also secured COBRA benefits for another client in a similar situation for 29 months (18 months under and COBRA and 11 months under OBRA) until his Medicare coverage began.

X Equip for Equality successfully appealed CIGNA’s policy that people with HIV/AIDS were not proper candidates for organ transplants, based as it was on out-of-date information in that it failed to take into account the recent advances in HIV therapy that have allowed people with HIV to live longer, and become better candidates for

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invasive operations such as organ transplants. Although medical professionals agreed that the client was an excellent candidate for a transplant, CIGNA refused to provide it. Equip for Equality wrote a demand letter to CIGNA and as a result the insurance company=s decision was reversed on appeal. CIGNA has since changed its policy about organ transplants for people living with HIV.

X The AIDS Legal Council of Chicago intervened when an insurance company refused to pay for a client=s viral load test. The client had good insurance coverage with a major Illinois insurance company. The client did not need much in the way of health care; just her prescriptions and viral load tests every four months in order to evaluate the efficacy of her medications. For two years her insurer had paid for her viral load tests. Then, one month she received a notice denying payment for a viral load test. The stated reason was that viral load tests were not approved by the FDA (in fact, viral load tests have been FDA approved since 1996). The client could not afford to pay for the viral load tests herself since she was on disability, and without the tests her doctor could not properly monitor her health. So she called the AIDS Legal Council. A Council staff member called several people at the client=s insurance company, none of whom could explain the denial of payment. Finally, the Council staff member called the insurance company=s general counsel and asked how an FDA-approved test was determined to be non-FDA-approved. The insurance company=s general counsel replied ΑWe don=t have to explain our policies to you!= The general counsel then said that the insurance company would pay for the client=s viral load test if she would sign a waiver releasing the insurance company of all liability. The Council staff member replied, ΑShe doesn=t need to sign a waiver. You have all the information you need to pay this claim.= Despite the insurance
company=s refusal to cooperate, the viral load test was paid for by the insurance company shortly thereafter.

5. Barriers to employment-based health coverage

Because the U.S. health care system ties private health insurance to employment, it is not surprising that as people with HIV infection have developed AIDS-related complications and experienced declining health, they have tended to become unemployed and lose their private health insurance, eventually becoming dependent upon public programs. Since 1999, persons with HIV/AIDS who have been out of work and collecting Medicare as a result of long-term disability and then return to work are able to keep their Medicare coverage. Although they generally are required to pay a modest monthly premium, Medicare can help reduce the deductibles and copayments they will face even with private health insurance through their employer.

The return to work for those doing well on combination therapies has created new variations on long-familiar themes: discrimination based primarily on the fear of contagion, and attempts by employers to screen job applicants. Although the Americans with Disabilities Act prohibits employers from asking about the existence, nature, or severity of a disability, they can under certain conditions ask whether the applicant has AIDS or a disability or illness the employer should know about, and about how many days the potential employee was sick in the previous year. Under the ADA, employers must also make reasonable accommodations for employees with a disability including those with asymptomatic HIV infection.
Many people with HIV/AIDS need such accommodations as time off for periods of illness and to attend health care appointments; extra breaks during the day for rest, taking medications, eating, or going to the bathroom; changes in work hours to accommodate periods of fatigue or nausea in the morning or other times of the day; or switching jobs, shifts, or hours due to stress or low energy. Some employees living with HIV have requested a refrigerator at work to store their AIDS-related medications that require refrigeration.

Virtually every legal services program (22 of the 25 we contacted) provides legal services in the area of employment. In addition to employment-related discrimination, employment-specific issues include employees’ and job applicants’ confidentiality rights and the right to be free from unnecessary requests for medical information, HIV-testing, and medical exams. Unless employees’ rights to confidentiality are maintained, they may face HIV discrimination and lose their jobs, income, and access to health insurance.

Programs also counsel and assist clients with obtaining medical leave without losing their jobs under the Family Medical Leave Act (FMLA) and/or as a reasonable accommodation under the ADA. Medical leave allows clients to take time off for their own health care needs as well as to care for family members who may be ill due to HIV disease. Legal services have helped HIV/AIDS clients return to work after periods of leave and to be reinstated when they are wrongfully terminated for requesting or for taking medical leaves.
Examples:

X The University of Maryland’s AIDS Legal Clinic successfully settled a case under the Family Medical Leave Act (FMLA) for a mother who lost her job when she took time to care for her eight-year-old son who has AIDS. The company, a national retail store, agreed to pay the client $8,500 in back wages and agreed to educate its managers and change its policy manual to clarify the availability of intermittent leave under these circumstances. As a result of this case, the national retail chain’s employees frequently described as the working poor, earning minimum wage or slightly more will be educated about their rights to take intermittent leave if necessary to meet their own or a family member’s health needs.

X The AIDS Legal Assistance Program of the Legal Aid of Western Missouri assisted a client in obtaining reasonable accommodation in a job. When an employer threatened to fire a client because of absences caused by medical appointments, the AIDS Legal Assistance Program intervened. The program coached the client on disclosing his status and setting up reasonable accommodation. The client was able to maintain his job and protect his health insurance coverage.

6. Barriers created by AIDS-related incapacitation

Advance directives, legal documents that allow an individual to determine treatment options and a representative to make health care decisions in case of incapacity, are among the most important yet underused legal tools available for people with HIV/AIDS. Although the overwhelming majority of health care providers say they
understand advance directives well enough to explain them to patients, small numbers of patients say their providers have actually done so. What is more, patients say they are open to using advance directives, but few actually use them.

Advance directives include healthcare proxies and living wills that allow the individual to appoint a trusted individual to make all medical decisions if s/he becomes incapacitated. Health care professionals, including home care providers, must honor the healthcare proxy and abide by the health care decisions made. A medical directive, also known as a living will, gives written instructions about what kind of medical care an individual wishes to receive in the future if s/he cannot make decisions for her/himself. A Do Not Resuscitate order, called a ADNR, is a written or oral statement indicating the individual does not want stopped breathing or heartbeat restarted. Finally, a power of attorney designates an agent to act on behalf of an incapacitated individual in managing assets and other affairs.

All of the organizations we contacted with separate HIV/AIDS direct legal services programs provide assistance with advance directives. Services in this area include drafting health care powers of attorney, financial powers of attorneys, living wills or physician=s directives, and hospital visitation forms for clients. All of them also assist clients with testamentary documents, particularly their wills, by providing brief advice, referrals to pro bono attorneys, client education, and provider education.

Examples:

X The AIDS Legal Assistance Program of Legal Aid of Western Missouri completes health care directives ensuring that numerous clients receive medical care consistent with their wishes.
At the Georgia Legal Services Program, a legal assistant asks each new client whether s/he has a will, living will, or health care power of attorney. If the client does not, the legal assistant explains their functions and asks whether the client would like to have one drafted.

7. Other health care issues

More than a third of legal services programs we contacted provide services related to other health care law issues, including such areas as medical malpractice, informed consent for medical treatment, ensuring that incarcerated persons receive medical care, and helping non-citizens obtain access to health care and health care benefits.

Examples:

X The AIDS Law Project of Pennsylvania has co-produced a directory of experienced physicians who treat people with HIV who lack private insurance or public benefits. The AIDS Law Project has also distributed a list of pharmaceutical companies= compassionate use and expanded access programs to all HIV-related physicians and case managers in the Philadelphia metropolitan area.

X The AIDS Legal Clinic of the University of Maryland assisted an HIV-positive pregnant mother who was being pressured by her physician to take AZT during her pregnancy to avoid transmission of HIV to her child. The hospital threatened court action if she failed to comply. She was concerned about the side effects of AZT, and the level of HIV in her body was undetectable without the use of drugs.
By assisting her in identifying another HIV expert who could counsel her about her options, and talking with her medical provider, the AIDS Legal Clinic facilitated a resolution where the client agreed to take AZT for only a short time just prior to and during delivery rather than for her entire pregnancy. The compromise reached in the case is the new standard for care for pregnant women who are HIV-positive.

The AIDS Legal Clinic of the University of Maryland assisted a mother living with HIV who had been accused of medical neglect for allegedly failing to give her seven-year-old daughter the HIV medication she needed to remain healthy. The Clinic successfully facilitated communication between the client and the child's physician, enabling them to reach an agreement about which medical regimen would work best for the child. The case was complicated because the client was depressed and the child resisted taking the prescribed medication. The attorneys, in collaboration with social workers were able to provide a behavioral therapist to help the mother cope with the daughter's resistance. The Clinic has successfully intervened in three other similar cases to ensure that the child receives the medical treatment they need and help to avoid placement of the child in foster care. The Clinic is developing a mediation project to help avoid such cases from occurring in the future.

8. Barriers to health care faced by HIV-affected families

With an estimated 80,000 AIDS orphans in the U.S., children who have lost their parents to AIDS, permanency planning is a critical issue for families affected by HIV/AIDS. Permanency planning provides families with options for planning how
minor children will be taken care of in the event that a parent dies from AIDS. These options include designating a standby guardian, someone whose guardianship goes into effect in the event the parent becomes unable to care for the child(ren) as the result of mental incapacity, physical debilitation, or death; guardianship and custody; temporary care and custody, which gives another person permission informally to make medical and educational decisions for a child when the parent cannot do so; and adoption.\(^3\)

Among women with or at risk for HIV, arrangements for care of their children are among the legal needs with which a majority report they would need legal assistance.\(^34\) For Washington, D.C.=’s Family Ties Project, an innovative, decentralized, multidisciplinary program for HIV-affected families, legal services are the most frequently used services by the 70 families served by the program. Two-thirds of the families= legal needs relate to permanency planning\(\times\)custody, wills, affidavit regarding custody, as well as advance directives.\(^35\)

Planning to ensure ongoing care for minor children gives parents with HIV/AIDS peace of mind about what will happen to their children in case they become ill or die. It also provides for a continuity of care for children living with HIV/AIDS if their parents become ill or die. Legal custody and guardianships permit custodians to continue benefits for children and, in some instances, to have access to benefits themselves. Options include adoptions, appointing guardians, and naming guardians in wills. Eighteen of the 25 organizations we contacted provide legal services in the general area of permanency planning, most commonly brief advice and counseling, referrals to pro bono attorneys, provider and client education.

**Examples:**

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The HIV Law Project, Inc. of New York, NY, worked with a client for many months to solidify permanency plans for her 13-year old son, her youngest child. The client has serious wasting syndrome and requires regular home visits by nurses who administer her medication. The client’s mother has taken over most responsibilities for raising the youngest son and the client wanted to appoint her as his standby guardian. However, an HLP social worker identified that her older son might interfere with this plan because of an internal power struggle in the household. The older son, an "interested party" in the guardianship, might appear in court and contest it. The client was reluctant to discuss the guardianship issue with her older son because she feared an angry confrontation. HLP’s attorney made a home visit, and spoke with the older son, with his mother present, explaining the advantages of having a court-appointed standby guardian for his brother. The attorney helped him understand that he would not be forced out his brother’s life by the permanency plan. As a result, he willingly signed a waiver and consented to the standby guardianship petition. The client was relieved to have the cooperation of her older son, and could finally go forward with the petition.

Advocates from the AIDS Legal Clinic of the University of Maryland School of Law in Baltimore, MD, were called to the University of Maryland Hospital to assist a gravely ill single mother of an HIV-positive six-year-old boy to appoint a standby guardian to care for her in her absence. The mother had been unwilling to appoint a standby guardian earlier, due to fear that her son would be removed from her care prematurely. The mother was transferred to a nursing home after her hospitalization, but with the AIDS Legal Clinic’s assistance, a foster care placement was avoided. The client’s father, the child’s grandfather, was able to
assume responsibility for the boy=s care and successfully enrolled him in the school in his neighborhood. This legal intervention provided peace of mind for the mother, and allowed the child to continue living with a relative who was aware of and could provide for his health care needs.

X The HIV/AIDS Legal Clinic of the University of the District of Columbia School of Law helped 13 clients draft Medical Consent Authorizations during its most recent fiscal year. MCAs allows parents or guardians to designate another individual to consent for medical care for a child. This authorization is important when a parent living with HIV/AIDS no longer has the capacity to consent to medical care for their child living with HIV/AIDS.

9. Barriers to health care for the foreign-born living in the U.S.

As a nation of immigrants and their descendents, the U.S. HIV/AIDS epidemic has also affected a great many foreign-born individuals and legal aliens. In New York City, where one in four residents is born outside the U.S., one in 10 people with AIDS diagnosed through June 1998 was foreign-born. Although they were from some 150 different countries, 73 percent were from the Caribbean or Latin America, and 17 percent were from former Soviet Union countries.36

Public health and medical benefits for non-citizens living in the U.S. are available to some, but not all. The 1996 welfare reform bill denied SSI and Medicaid to most legal aliens, except aged and disabled legal aliens in those programs as of August 22, 1996, and those legally in the U.S. before that date. Most legal aliens admitted after that date are ineligible for SSI and Medicaid until and unless they become citizens or

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meet certain narrow criteria. Illegal aliens remain ineligible for SSI, welfare, food stamps, or Medicaid.37

For legal service providers, immigration-related issues include helping non-citizens to apply for temporary visas, permanent resident status, and naturalization. Helping non-citizens to obtain legal permanent resident status or citizenship enables them to work legally in the U.S. and obtain job and private health insurance as well as to be eligible for public benefits. Non-citizens often need counseling about the public benefits for which they are eligible, as well as in applying for such benefits. Legal service providers also have helped persons living with HIV/AIDS who would be denied health care or persecuted in their countries of origin to seek asylum in the United States.

Nearly half of the programs we contacted provide legal services in the area of immigration. Nine of the programs alone reported a total of 3,557 immigration-related cases for their most recent year—the second-highest number of cases reported in terms of general legal area. The vast majority of these cases were handled by two programs, the legal services and advocacy department of Gay Men=s Health Crisis in New York, NY (2,883), and the HIV/AIDS Legal Services Alliance in Los Angeles CA (435). The most common types of immigration services are referrals to pro bono attorneys, referrals to other providers and programs, and brief advice and counseling.

Example:

X In addition to giving free legal services to individuals with HIV who are not US citizens, the AIDS Law Project of Pennsylvania also links non-citizens to experienced health care providers who accept patients without insurance. The
AIDS Law Project has also co-created task forces with a variety of consumer and HIV groups to address the unique health care access issues of non-citizens with HIV/AIDS.
More than four million persons are imprisoned annually in the U.S. With a rate of drug use and prostitution before incarceration that well exceeds the norm for non-incarcerated individuals, this group includes many at high risk for HIV infection. One study of 46 correctional facilities in 19 metropolitan areas found an HIV seroprevalence of 4.2 percent. Because a disproportionate number of the incarcerated population is African-American, the African-American community has a correspondingly high number of those who have been incarcerated at one time or another. Incarceration can provide opportunities to diagnose HIV, connect inmates to health care while they are incarcerated, and continue linkages to community-based HIV/AIDS care and services upon release. For incarcerated minors, many of whom engage in behaviors that put them at risk for HIV infection, the correctional facility setting provides a convenient moment to be tested.

The main goal of HIV/AIDS legal services for the incarcerated is to ensure access to health care. Programs have advocated in jails and prisons to ensure that HIV-positive inmates have proper diets, living conditions, and access to health care. Nine of the organizations we contacted provide legal incarceration-related services. These services, however, represented the third-lowest number of cases overall among the six programs that actually reported their total number of incarceration cases for their most recent year (348). Despite the relatively low number of cases, it is important to note that a case in this area may actually represent an effort to change an entire penal system’s delivery of care to incarcerated persons with HIV/AIDS. The most common types of incarceration-related legal services offered are referrals to pro bono attorneys, brief advice and counsel, limited direct legal representation, and referrals to other providers and programs.
Legal services also assist HIV/AIDS clients in criminal justice matters, such as helping to clear up outstanding warrants that prevent them from obtaining public benefits. Warrants or past convictions may also prevent non-citizens from becoming citizens or legal permanent residents. In addition, people living with HIV can be prosecuted for intentional transmission of HIV, and people charged or convicted of certain crimes can be ordered by courts to be tested for the virus. Legal services programs help to ensure that HIV criminalization and testing laws are enforced appropriately and fairly, and are not used to persecute people living with HIV/AIDS. One in five of the legal services programs we contacted provide criminal justice-related services. The most common types of criminal justice legal services offered are referrals to other providers and programs, and brief advice and counseling.

Examples:

X As a result of advocacy by the HIV/AIDS Legal Services Alliance (HALSA), the Los Angeles sheriff’s department agreed to implement an unprecedented, interactive program that allows HIV medical and educational professionals to access the jail system and educate the medical staff of the Sheriff’s Department. HALSA had received reports from incarcerated clients about substandard medical care, and contacted the sheriff’s department with serious concerns. Inmates had complained that the jail medical staff would not provide them with their combination HIV medication Acocktails on time or give them enough pills, and would substitute one protease inhibitor for another due to a low supply of HIV medications kept by the jail. This haphazard dispensing of HIV-medications was potentially life-threatening, since missing even one dose can lead to resistance that makes the drugs ineffective.
The new program established by HALSA’s efforts allows HIV/AIDS medical specialists to train deputies and nurses to help ensure the proper care of HIV-positive inmates. The sheriff’s department also has agreed to maintain a full and constant supply of medication for HIV-positive inmates and to fully implement a self-medication program which allows inmates to keep a supply of medications in their cells. To ensure that these changes occur, the sheriff’s department has allowed HALSA to monitor the implementation of this plan. HALSA has also formed a working group with representatives from other public interest law organizations, law firms, and medical providers that will continue to work with the sheriff’s department to assess the health care problems of people with HIV in the LA County Jail and to propose and implement solutions.

- **Michigan Protection and Advocacy’s HIV/AIDS Advocacy Program (HAAP)** negotiated a settlement with the Michigan Department of Corrections on behalf of prisoners to secure appropriate mental health services. With HAAP staff intervention, one particular prisoner was transferred to a different facility, a transfer he had previously requested, where he was able to receive appropriate mental health services.

- **The AIDS Legal Assistance Program of the Legal Aid of Western Missouri** helped a client whose Social Security and Medicaid benefits were stopped because he had outstanding felony warrants. The program had the warrants dismissed so the client could receive public benefits.
Competing Subsistence Needs Addressed by Legal Services

In the RAND study noted in the introduction, more than one-third of the sample representing over 83,000 persons with HIV/AIDS nationally went without or postponed care at least once in a six-month period because of competing subsistence needs. These included needing the money they would have spent on the care for food, clothing, or housing; not having transportation; being too sick; and not being able to get time off from work. Non-whites, drug users, and those in lower socioeconomic groups were most likely to report these problems.\textsuperscript{42}

Earlier studies of other populations have likewise found a correlation between competing needs and the ability to access health care, particularly among younger persons, women, nonwhites, drug users, those with lower education or income, and the uninsured.\textsuperscript{43,44} The RAND study represented the first assessment of the impact of competing needs on the ability of people with HIV/AIDS to access necessary health care services. The authors point out that although subsistence needs may appear to be beyond the scope of health care, they are closely connected as demonstrated in the study. What is more, they note that for persons with HIV to benefit from recent improvements in medical therapy, interventions to alleviate subsistence needs may be required along with provision of medical services themselves.

Legal services programs help to address their HIV/AIDS clients’ subsistence needs in a variety of areas. The programs help to eliminate barriers to clients’ ability to access health care services by assisting in the legal aspects of housing, private and
public insurance programs, and public income assistance programs, and by helping to keep them free from harassment due to financial and credit-related issues. Below are the main areas in which legal services provide such assistance.

1. Housing & Landlord/Tenant

Virtually all HIV/AIDS legal services address housing and landlord/tenant issues because clients need stable homes to access and maintain health care services. Recognizing the connection between proper housing and well-being, the federal government in fiscal 1999 funded $200.5 million for its AIDS housing assistance program, HOPWA, which provides housing assistance and supportive services for low-income persons with HIV/AIDS and their families.45

By ensuring that clients have quality housing, HIV legal service programs provide clients with a stable living environment that is essential for clients to take care of their health. The stress of being homeless, evicted, or moving can have a negative impact on the health of a person living with HIV/AIDS. If clients are living in housing that lacks adequate heating, plumbing, and appliances such as a working stove and refrigerator, it is also more difficult for them to take care of their health. Without stable housing, client face difficulties in staying on complicated drug regimes. Without an address and a phone number, it is difficult to maintain relationships with health care professionals and facilities and to apply and receive public benefits. Finally, by helping clients obtain access to residential health care facilities, programs are directly ensuring that client have access to both housing and health care.

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Housing-related legal issues include helping clients apply for and obtain housing-related public benefits such as Section 8 and HOPWA; representing clients in eviction (unlawful detainer) proceedings; assisting clients with getting repairs made to their apartments; ensuring that clients’ apartments are habitable; and helping clients get security deposits back from landlords when they move. They can also include ensuring that clients have access to apartments, temporary housing, shelters, residential drug treatment programs, and residential health care facilities on a non-discriminatory basis.

Examples:

X The HIV Law Project (HLP) prevented the eviction of a client who first came to the program because she was behind on her rent. HLP successfully represented her at a Fair Hearing for an increased Social Security budget because she was the caretaker of two minor family members. The Division of AIDS Services and Income Support (DASIS), however, refused to help her pay the back rent. Without the back rent, her situation soon deteriorated. She was sued for non-payment of rent in Bronx Housing Court, the eviction date was set, and, although she had been looking for a new apartment, her DASIS caseworker threatened to place her in a shelter if she did not move into a scattered site housing unit. To make matters even worse, the client was admitted to the hospital with an opportunistic infection and was extremely frightened that she would be evicted while hospitalized.

Although she finally found a new private apartment, DASIS refused to approve the moving benefits so she could leave her old apartment before the scheduled eviction. Although HLP requested and won an Emergency Fair Hearing on the
issue of the denial of the moving benefits, DASIS again refused to comply with the judge=s decision. Aggressive advocacy by an HLP paralegal convinced DASIS to reverse its decision and finally approve the apartment so the client and her children could move before the eviction date. HLP also helped her attend financial management classes at Citizens= Advice Bureau, a non-profit organization in the Bronx, which will help her pay her rent on time and budget her money.

A client asked the AIDS Legal Project of the Atlanta Legal Aid Society for help with an appeal when his application for Social Security benefits was denied. Because the client had no income, he had not been able to pay his mortgage in several months; consequently, his home was scheduled to be sold at a foreclosure auction. The AIDS Legal Project informed the mortgage company that the client was almost certain to be provided with Social Security benefits, and it agreed to delay the auction. The client was approved for Social Security benefits and received a large benefits check which he used to reinstate his mortgage.

The Los Angeles City Attorney=s AIDS/HIV Discrimination Unit helped a woman obtain placement at an intermediate health care facility. A 27-year-old woman with a degenerative neurological condition could no longer live on her own despite regular visits from a social worker and a home health aid. The intermediate care facility that had accepted her for placement refused to admit her when it learned that she was HIV-positive. She filed a complaint with the City Attorney=s Office, which investigated the matter and contacted the facility=s attorney. The city attorney educated the client about her legal rights. He contacted the facility and insisted that measures be taken to implement HIV-related procedures. In the end, he obtained placement for the woman in a matter of days.
2. Public and income-related benefits

Besides the links described in the health care benefits and housing sections, legal services in the area of public benefits also assist clients in accessing health care by providing them with income to pay for health care costs. For many clients, obtaining Social Security or welfare benefits is the only way to access public health care benefits. For example, to be eligible for Medicare clients must first receive SSDI benefits for two years. Clients who receive SSI benefits are also eligible for Medicaid. For many women with children, securing AFDC is a prerequisite to receiving Medicaid benefits.

Many clients require assistance with public benefits, and 22 of the 25 legal services programs we contacted provide such assistance. The 16 programs that provided their number of public benefits cases for their most recent year reported a combined total of 3,031 cases—the third-highest number of cases reported for any general legal services area. The most common types of public benefits legal services offered in this area are brief advice and counseling, limited direct representation, client education, and referrals to other providers and programs.

Services in this area include helping clients apply for state and federal public benefits that provide assistance through supplementary income, access to health care, and housing. Programs also help clients appeal denials of their benefits claims and handle improper delays in receiving public benefits. In addition, programs assist clients with issues such as dealing with charges of overpayment, improper
terminations of benefits, and problems with representative payees. Programs also counsel clients on how to maintain public benefits while they attempt to return to work.

**Examples:**

X The HIV Law Project (HLP) of New York, NY, helped a client successfully appeal a denial of Social Security benefits. The client could not work because he suffered from regular herpes outbreaks, major depression, and constant diarrhea, a side effect of his HIV medication. Nevertheless, he was unable to obtain benefits from the Social Security Administration (SSA). SSA decides on a claim based upon medical evidence. After examining the client's papers, HLP quickly realized that SSA did not have sufficient medical records to document his condition. HLP gathered medical evidence and helped the client articulate the cumulative effects of his various symptoms.

X The University of the District of Columbia HIV/AIDS Legal Clinic has helped many clients secure Social Security benefits. One mother, who is the sole support of her family, was in danger of losing her home if she was forced to pay an overpayment charge being levied by the Agency. A law student drafted an appeals brief, which convinced the administrative law judge to make the favorable decision on the record, rather than hold a hearing. Another law student assisted a client whose daughter was granted Social Security benefits, but had the payment reduced considerably because SSA claimed the family was receiving in-kind rent benefits which had to be subtracted from the whole. The student successfully argued before an Administrative Law Judge that everyone living in the rental unit was on public assistance, and the full payment was restored to the client.
X The University of Maryland=s AIDS Legal Clinic periodically conducts workshops for social workers and medical providers. For example, the clinic conducted a workshop addressing issues raised for people living with HIV by the new work requirements of welfare reform. The presentation also addressed how the Family Medical Leave Act might enable people to work longer and eligibility for social security disability requirements for those whose illnesses prevent them from working. The FMLA and Social Security require very specific documentation of a patient=s condition that often goes beyond what a medical provider would maintain for treatment purposes alone. It is helpful for medical providers and social workers to have an understanding of these systems to enable them to provide necessary support to their patients. The clinic=s goal is to prevent legal problems from arising when possible, and to enable social workers and medical providers to act as advocates for their patients where possible. In addition, these educational workshops help them identify situations or problems that should be referred for legal assistance.

3. Life and disability insurance

Maintaining life and disability insurance can provide HIV/AIDS clients with needed income to cover daily and health care costs. Four out of five of the legal services programs we contacted provide services in the area of private insurance of various types. Most commonly they provide brief advice and counseling, client education, and referrals to other providers and programs.
In addition to the health care insurance issues discussed above, private insurance issues can also involve life and disability insurance. Programs counsel clients on how to obtain life insurance and how to sell their life insurance while they are still alive to viatical settlement companies. Programs also assist clients in obtaining disability insurance and enforcing their rights when they are unlawfully denied benefits under their disability insurance policies. For some employees, staying on employment disability insurance allows them to maintain their employment status and their employment-related health care insurance.

Examples:

Χ Gay and Lesbian Advocates and Defenders (GLAD) of Boston, MA, has discovered that some private disability insurers are being overly zealous in terminating disability income benefits, even for people who remain significantly debilitated by advanced HIV disease. GLAD recently negotiated a settlement with Metropolitan Life Insurance Company, one of the country's largest disability insurers, who abruptly terminated a client's disability income benefits because despite clear medical evidence, it insisted that the client's condition had been "stabilized by new medications." Met Life agreed to reinstate all of the client's benefits.

Χ When a client was at risk of losing disability benefits, the Legal Aid of Western Missouri's AIDS Legal Assistance Program negotiated an agreement with the carrier. The client was being charged with an overpayment of benefits by the insurance company. Failure to repay the overpayment would have resulted in termination of employment and loss of medical insurance. The AIDS Legal
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Assistance program negotiated an agreement that allowed the client to maintain employment status and continue disability and health care benefits.

The staff of the HIV/AIDS Advocacy Program of Michigan Protection and Advocacy is working with case managers of AIDS service organizations to locate and develop a list of infectious disease specialists who would be willing to do individual medical evaluations for people living with HIV/AIDS who are dealing with disability insurance issues.

4. Debtor/creditor, bankruptcy, tax assistance

Unpaid medical bills, and other bills, can prevent poor clients from accessing future health care services and create stress from worrying about the debt as well as from the harassment of creditors and collection agencies. HIV legal services programs assist clients with unpaid bills by providing credit counseling, assisting clients who are being harassed by creditors, writing Ajudgement-proof= letters for clients who are no longer able to pay their bills and who are disabled or have limited incomes, and helping clients to file bankruptcy. Services in this area help relieve clients of the stress of having debts and help them use their income to take care of their daily needs and health care instead of paying for debts accrued before they became disabled with AIDS.

Legal services have been helpful in relieving the stress of debts and enabling clients to use their income to take care of their daily needs and health care instead of paying for debts accrued before they became disabled with AIDS. These kinds of cases accounted for the fifth-highest number of cases among the 17 organizations that provided figures. The most common types of debtor/creditor and bankruptcy legal
services offered are brief advice, referrals to other service providers and programs, and referrals to pro bono attorneys.

Legal services also assist clients with tax-related matters, particularly by offering referrals to pro bono attorneys, brief advice and counsel, and referrals to other providers and programs. Tax-related legal services include helping clients to file tax returns for current and past years and assisting clients with negotiating offers in compromise for outstanding tax debt.

**Example:**

A volunteer at East Bay Community Law Center (EBCLC) in Berkeley, CA, realizes the importance of helping clients reduce stress through assistance with credit-related matters. She recalled, "I got a call once from a woman whose brother was living with full-blown AIDS and was horribly anxious about the creditors. I explained to her he had to reduce his stress and that we could help him. And we did. Several weeks later he came in with his sister. He started crying and I started crying and we hugged. A week later we got a letter from his sister saying that he had passed and that the last six weeks were the happiest, that he could go home in peace, thanks to EBCLC's help. Once we took the case he didn't have to worry anymore."
Recommendations

Our findings demonstrate that legal services for people with HIV/AIDS play a central role in their ability to access and maintain health care services. Based upon our review of the literature and the stated needs and experiences of the legal services programs we contacted for this report, we offer the following recommendations.

Legal services should be considered core, not ancillary, in the network of services available to persons living with HIV/AIDS.

As demonstrated by the full range of legal areas affecting people with HIV/AIDS, and the legal services being provided, issues such as housing, employment, and access to public benefits are all critical to the health and well-being of the individual living with HIV/AIDS. Through effective protection and advocacy-related legal services, the subsistence needs of HIV/AIDS clients can be met and better access to health care ensured.
Options to accomplish this goal:

1. Change guidance which severely limits the types of legal services that can be provided with Ryan White CARE Act funds.

2. Develop strategies to infuse Titles I and II projects with legal services funding.

3. Commission a white paper on the laws protecting people with HIV/AIDS, making the point that legal advocacy is a mainstream essential service.

Expand federal and other sectors’ funding of HIV/AIDS legal services.

Legal service providers strongly support increased funding for legal services and free access to general legal research resources. They indicated that free access to general legal research resources such as legal publications, Westlaw, and Lexis would be of tremendous assistance.

Options to accomplish this goal:


2. Develop group discounts that would enable a nationwide network of HIV/AIDS legal services providers to obtain services such as
Westlaw and malpractice insurance at a substantial savings to individual organizations.

γ Support needs assessments to ascertain HIV/AIDS clients' specific legal needs.

Few communities or legal service providers have conducted formal needs assessments of their HIV/AIDS clients' needs or of legal services to ensure that the services they provide are suited to the clients' perceived needs. Since most of the legal programs use computer software tracking programs, it is conceivable to do a large and perhaps national legal needs assessment.

Options to accomplish this goal:

1. Contract out for legal services-specific needs assessment(s) using SPNS funds.

2. Add HIV/AIDS legal services needs assessment(s) to other HRSA surveys.

γ Support the development of attorney training and client education materials.

There is not a strong need for any one type of client education or attorney training materials. In the areas of tax and immigration law, new client education and attorney training materials would be useful. No organization reported authoring tax materials.
while four organizations reported needing such materials. In the area of immigration law, for both attorney training and client education materials, more programs reported needing such materials than organizations reported having authored such materials.

For every organization that expressed a need for particular materials, another organization had already created it. Networking and sharing such materials would become cost-effective by preventing unnecessary duplication. In most relevant legal areas, it would be most useful to establish a successful mechanism for organizations to share attorney training and client education materials than to support the publication of new materials.

**Options to accomplish this goal:**

1. Use SPNS funding for a clearinghouse of HIV/AIDS-related legal resources.

2. Create an online list serve on HIV/AIDS legal issues.

γ  **Initiate a project to facilitate formal networking and sharing of HIV/AIDS legal materials.**

To facilitate the sharing of information, legal service programs need a mechanism for formally networking them. In addition, a clearinghouse for attorney and client educational and training materials would benefit providers and clients alike. The widespread use of computer tracking software suggests that it may be possible, and
relatively easy, to gather a great deal of data nationally about the types of HIV legal services being provided to clients living with HIV. Given such frequent use of computer and web resources among providers, the web could provide an effective means of networking and sharing information.
Options to accomplish this goal:

1. Create an online list serve on HIV/AIDS legal issues (similar to Recommendation 4).

2. Use SPNS funding for national activities including networking, list serves, conference calls, and meetings.
We contacted the following organizations in preparing this report. Those that provided information used in the report are noted in italics.

X Advocacy, Inc., Austin, TX
X AIDS Action Committee, Boston, MA
X AIDS Foundation of San Diego, AIDS Legal Services Program, San Diego, CA
X AIDS Law of Louisiana, New Orleans, LA
X AIDS Law Project of Middle Georgia, Macon, GA
X AIDS Law Project of Pennsylvania, Philadelphia, PA
X AIDS Legal Council of Chicago, Chicago, IL
X AIDS Legal Network for Connecticut, Hartford, CT
X AIDS Legal Referral Panel of the San Francisco Bay Area, San Francisco, CA
X AIDS Outreach Center Legal Network, Fort Worth, TX
X ACLU, AIDS Project, New York, NY
X ACLU of Illinois, AIDS Project, Chicago, IL
X Arizona Center for Disability Law, Tucson, AZ
Ensuring Access to Health Care for People with HIV/AIDS: The Role of Legal Services
X Protection and Advocacy, Sacramento, CA
X Protection and Advocacy Agency Inc., Honolulu, HA
X St. Louis University School of Law, Health Law Clinic, St. Louis, MO
X University of the District of Columbia, HIV Legal Clinic, Washington, DC
X University of Iowa College of Law, AIDS Representation Project, Iowa City, IA
X University of Maryland School of Law, AIDS Legal Clinic, Baltimore, MD
X Volunteer Attorneys for PWAs Legal Referral Project, SeattleKing Bar Association, Seattle, WA
X Volunteer Legal Services of Monroe County, AIDS Project, New York, NY
X Wayne County Neighborhood Legal Services, AIDS Law Center, Detroit, MI
X Whitman-Walker Clinic Legal Services Project, Washington, DC
X Wisconsin Legal Assistance Program, AIDS Resource Center, Milwaukee, WI
A variety of organizations and programs provide legal services to people living with HIV/AIDS. They include small independent 501(c)(3) non-profit organizations, departments within larger parent organizations, law school legal clinics, and often a hybrid of more than one type. Most HIV/AIDS legal service programs were founded in the late 1980s and early 1990s. The organizations typically have eligibility criteria that prospective clients must meet to receive services. They tend to have large caseloads of clients with multiple legal needs. Their budgets and resources vary, often by geographic location, as do their sources of funding. And they tend to rely on a mix of paid staff and volunteers to provide services.

**Clients and caseloads**

Most programs require that clients be infected or affected by HIV, live in a certain geographic area, and have limited incomes. The 25 organizations contacted for this
report reported a total of 21,965 HIV/AIDS cases\(^1\) during their most recent year. On average, programs that were housed in AIDS service organizations had the highest number of cases, with an average of 2,349 cases. The two largest programs in terms of cases were both housed in ASOs, the Legal Services and Advocacy Department of Gay Men’s Health Crisis in New York, New York (reporting 7,469 cases), and the HIV/AIDS Legal Services Alliance of Los Angeles, California (reporting 3,476 cases).

The independent 501(c)(3) non-profit organizations had the next highest average number of cases, 1,439; followed by the programs housed in legal services organizations, which had an average of 371 cases. The four Protection & Advocacys had an average of 183 cases for their most recent year. The three programs which did not have a separate HIV/AIDS legal services program only had an average of 57 cases, while the HIV/AIDS Advocacy Program of the Michigan Protection & Advocacy reported 559 cases for its most recent year. Both of the law school clinical programs reported having just over 100 cases for their most recent years. The impact litigation organizations reported the lowest number of cases, with an average of 74 cases for their most recent year.

\(^1\) For the purposes of the survey, an HIV case was defined as any legal service provided to a client infected with or impacted by HIV/AIDS, including referrals to other agencies and brief advice and counseling. Accordingly, a single client could have multiple cases.
Organizational structures

HIV/AIDS legal services programs\(^2\) have a variety of organizational structures, including:

- Department within a general legal services organization
- Department within an AIDS service organization (ASO)
- Clinical program at a law school
- Protection & Advocacy program
- Impact litigation organization
- Independent 501(c)(3)
- State or local bar lawyer referral panel
- Law & policy organization
- Public/government entity

While most HIV legal services programs are housed within a parent organization\(^3\) that provides either non-legal or non-HIV-related legal services, many HIV legal service programs are a hybrid of organizational types. These most frequently are HIV legal service programs with staff attorneys who also use attorney referral panels and clinical programs with area law schools to provide legal services, or programs that engage in impact litigation and policy work in addition to providing direct legal services.

Financial Resources

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\(^2\) For the purpose of this report, an HIV legal service program was defined as an organization’s legal services or programs for those infected with or impacted by HIV/AIDS, to the extent that such programs could be separated out from the organization’s other services or programs.

\(^3\) For the purposes of this report, a parent organization was defined as the organization that houses the respondent’s HIV legal services program. If an independent organization only provides HIV legal services, its parent organization and HIV legal services program are the same.
Many HIV legal services programs operate on relatively small budgets. Of the 25 organizations contacted for this report, the average total budget for the 21 respondents who provided this information was $310,000 for their most recent year.\(^4\) Ten of these programs, however, had budgets of $200,000 or less for their most recent year. Seven of them had budgets of $100,000 or less. Only one program had a budget of more than $1 million.

Legal service programs structured as independent non-profit organizations have the largest budgets, with an average budget of $883,333 for their most recent year. Programs housed within ASOs had an average annual budget of $439,335. The programs that had a general legal services provider for their parent organization had the smallest average annual budget, $112,426. Three of the four Protection & Advocacy programs contacted have no separate program or budget to provide HIV/AIDS legal services.

The primary indicator of budget size appears to be geographic location rather than organizational structure. The five contacted organizations with budgets over $500,000 were all located in large metropolitan areas with a high-incidence of HIV infection: Chicago, Los Angeles, New York (two programs), and Philadelphia. The organizations with the five smallest budgets were located in smaller cities with a lower incidence of HIV-infection: Kansas City, M0; Macon, GA; Madison, WI, Minneapolis, MN; and Oklahoma City, OK.

The average annual budget for parent organizations was more than $5 million, according to the 17 organizations that provided budget information for their parent

\(^4\) For the purposes of the survey, Amost recent year= was defined as the most recent year for which an HIV legal services program had collected or reported the requested data, regardless of whether that year was a calendar, fiscal, or contract year.
organizations. On average, the budgets of these HIV legal services programs represented nine percent of their parent organization’s total budgets. For programs housed within ASOs, on average, the program’s budget was three percent of their parent organizations’ annual budget. For programs housed in general legal services providers, on average, the program’s budget was nine percent of their parent organizations’ annual budget.

Programs receive funds from a variety of sources, including:

- Ryan White Care Act, Titles I & II
- Private foundations
- Individual donations
- State/local bar associations
- State government
- Local government
- HUD/HOPWA
- Protection & Advocacy funding
- Other federal government sources
- Fees for client services
- Attorneys Fees

In general, the HIV/AIDS legal programs were not supported by funding from diverse sources, with almost half (12) the organizations contacted reporting no more than two sources of funding. Only one in five receives funds from five or more sources; three of them are independent, non-profit organizations. For most, the federal government, state and local governments, private foundations, and individual donations were the principal sources of funding. Federal, state, and local government funding represented $2.85 million approximately 63 percent of the programs’ combined
budgets of just over $4 million. Federal funding alone accounted for 44 percent of the combined annual budgets, while 19 percent was from state and local government funding.

Nearly two in three of the organizations contacted that have separate HIV legal services program budgets receive Ryan White CARE Act funds. In fact, CARE act funds represent more than 40 percent of the total annual budgets of seven programs for the most recent year. Eight programs receive only Title I funds; two receive only Title II funds; and four programs receive funding from both Title I and Title II. One program, the Berkeley, CA HIV/AIDS Legal Project of the East Bay Community Law Center, also receives money from Title IV of the CARE act for legal services for women, youth, children, and the fathers of minor children.

Four programs receive funding from the Housing Opportunities for People with AIDS (HOPWA) program administered by the Department of Housing and Urban Affairs. One program receives a grant from the Abandoned Infants Assistance Program operated by the Administration on Children, Youth, and Families of the U.S. Department of Health and Human Services.

Independent non-profit organizations and impact litigation organizations rely strongly on private philanthropy. Private donations are particularly important for the impact litigation organizations. More than 30 percent of the most recent budgets of the three independent non-profits we contacted came from private foundation grants. Combined, they reported grants totaling $984,900. The three impact litigation organizations reported receiving a combined $148,000 from private foundations. The other five programs that received funding from private foundations received a total of $98,274 during their most recent year.
Ten organizations reported that their budgets included a combined $758,200 in donations from individuals, representing 12 percent of their combined budgets. Most of these donations, however, were given to the three impact litigation organizations. Individual donations also made up a significant percentage of the budgets for smaller programs with total annual budgets under $130,000: the AIDS Network Legal Services of Madison, WI (29 percent), the AIDS Legal Network of Fort Worth, TX (40 percent), and the AIDS Legal Resource Project of Oklahoma City, OK (90 percent).

**Human resources: staff and volunteers**

Most programs have small staffs and rely on volunteer attorneys. The average staff size in the organizations contacted was four staff members. The programs employed an average of just under two and a half full-time-equivalent attorneys. Just over half had the equivalent of one full-time attorney or less designated to their HIV legal services program. The independent non-profit organizations and those serving large metropolitan areas had significantly larger staffs. The three programs organized as independent non-profit organizations had an average staff size of 12.1 full-time equivalents. The staff size of the HIV/AIDS Legal Services Alliance in Los Angeles, CA and the Legal Services and Advocacy Department of Gay Men=s Health Crisis in New York, NY were both well above average with 12.5 and 16.6 full-time staff equivalents respectively.

Most programs rely on volunteer attorneys to augment the services provided by their paid staff. Altogether 534 volunteer attorneys serve the 11 organizations that provided this information. Seven of these organizations reported a total of 10,792 volunteer attorney hours. Two in three of the programs use volunteer law students to help provide HIV legal services. The eight organizations that provided the number of
volunteer hours reported a total of 15,676 law student volunteer hours. Most programs do not use paralegals, although the HIV/AIDS Legal Services Alliance reported using 30 volunteer paralegals who contribute approximately 3,000 volunteer hours.
Information Resources

All but one of the programs contacted report having access to the Internet, and three-quarters of them provide Internet access for each staff attorney. Nearly two-thirds have a program website. More than two in three use computer software programs to track cases. In addition to standard programs, four organizations used customized client tracking software.

Most of the organizations contacted report using four or five different methods for monitoring the quality and effectiveness of their services. Only the three impact litigation organizations and the one public entity reported using fewer than three methods to monitor the quality and effectiveness of their services. The most commonly used methods are client surveys, client grievance procedures, computer tracking of client cases, and case reviews by expert attorneys.

Services provided

Programs provide legal services to people living with HIV/AIDS in a broad range of legal areas, including:

- Health Care
- Housing Landlord/Tenant
- Discrimination
- Public Benefits
- Employment
- Private Insurance
- Confidentiality

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Within each legal area, the programs offer one or more of the following services:

- Brief advice and counseling
- Limited direct representation
- Referrals to other providers/programs
- Referrals to pro bono attorneys
- Client education
- Provider education
- Legislative and policy advocacy
- Litigation
- Impact litigation
- Administrative hearings/proceedings
- Preventive legal education
- Pro se/ self-help assistance

\(^5\)Other legal areas included domestic violence, de-institutionalization, education and special education, legal checkups, mental health, and notary public services. Four organizations listed education issues under the Other\(^5\) category.
HIV legal services programs offer a broad range of legal services. Services range from providing clients with referrals to other organizations to filing and litigating lawsuits on behalf of clients. Programs successfully handle most client problems through brief advice and counseling, which typically involves only one or two conversations with a client. Only a fraction of most programs' cases result in litigation. Below are descriptions of the types of legal services that HIV legal services programs most commonly provide to clients and their communities.

**Client Education**

Client education involves providing groups of clients or individuals with general information about their legal rights. It includes the publication of brochures on certain topics, as well as the publication of more comprehensive "HIV & the Law" guides, in
the languages and at reading levels that make them accessible to clients. Client education also includes presentations by legal staff to groups of clients and activities such as having information booths at HIV/AIDS conferences. Some programs have also produced videos that educate clients about their rights. Client education activities allow a limited number of staff to reach a large group of clients and empowers clients to address and prevent legal problems.

**Education of service providers and others**

HIV legal services programs also provide training and technical assistance to other attorneys, non-legal service providers, professional groups, and other organizations and individuals. For example, programs may give presentations or workshops to the staff of a hospital, school, or drug rehabilitation program about the rights of people living with HIV regarding confidentiality and discrimination. The goal of these education efforts is to protect the rights of persons living with HIV and prevent legal problems by educating providers serving those with HIV/AIDS. Programs also train case managers and the staff of AIDS services organizations (ASOs) about legal issues in order to increase their ability to recognize legal problems and make appropriate referrals to legal services programs.

**Websites**

Some HIV legal services programs have an organizational website. Information on these websites allows clients to learn about HIV/AIDS law and upcoming client education events, as well as how to access the program's services. Websites also
provide information to others about the activities of the program and how one can volunteer or offer other kinds of support.
Preventive Legal Services

Most HIV legal services programs attempt to prevent legal problems for clients through client and community education activities. A few programs have developed "HIV legal checkup" programs to provide individual clients with a service that is equivalent to a medical checkup. During a legal checkup, an advocate discusses with a client many of the legal issues a person living with HIV may encounter. This discussion allows the client and advocate to identify current legal problems and prevent future ones. During the legal checkup clients are given advice and referred to legal services as needed. Since several issues are frequently identified during a legal checkup, an action plan is created to assist the client and advocate in addressing the legal problems in an orderly manner. Legal checkups identify legal issues that the client may not otherwise raise through a program's intake process. They have the advantage of dealing with a client's legal issues in a holistic manner.

Referrals to Other Legal and Non-legal Service Providers

One important service that HIV/AIDS legal services programs provide is referring clients to other legal and non-legal service providers. By having knowledge of other services for the indigent, HIV/AIDS legal services programs help clients access and maximize the use of existing community resources. These referrals allow clients to learn about and access other legal services programs for the indigent, lawyer referral services, the private bar, and administrative agencies that can address clients' non-legal issues. Referrals are given when the legal issue presented is outside the scope of the HIV/AIDS legal services programs' areas of service, or when the client does not meet the program’s eligibility requirements. Referrals to case managers,
housing programs, public benefits programs, health care providers, and others also help clients meet their non-legal needs.

**Pro Se/ Self-Help Support**

HIV legal service programs provide services that empower clients to resolve their legal problems without attorney intervention. With these types of legal services, attorneys and legal staff train clients on how to advocate for themselves in administrative proceedings, the workplace, the health care system, and with other institutions and organizations. For example, programs can assist clients with applying for public benefits such as Social Security Disability Income (SSDI) and Medicare, preparing for small claims court actions, defending themselves in eviction proceedings, filing bankruptcy, and filing complaints with administrative agencies such as the EEOC or the Department of Labor. Programs may counsel clients on how to resolve issues with creditors or the IRS, or how to get a copy of their medical or personnel file. While the attorney is advising the client, the client is dealing directly with the administrative agency or the opposing party. Programs provide counseling and assistance to individual clients, as well as conduct self-help workshops and publish "how-to" packets on certain legal topics.

**Brief Advice and Counsel**

One of the most common types of services offered by HIV/AIDS legal services programs is brief advice and counsel. The majority of client problems can be handled through this type of service. Programs answer clients’ questions about specific legal issues and advise them on a course of action. Advice and counsel may involve explaining to clients how to protect the confidentiality of their HIV status in the

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workplace, how to apply for a job, or how to request reasonable accommodation or medical leave under federal or state law. Advice and counsel may also take the form of explaining to clients why the legal service provider does not have a legal remedy for their issue. This type of service does not involve representing the client to a third party and typically involves only one or two conversations with the client.

**Limited Direct Representation Short of Litigation**

These services involve direct representation in moderately time-intensive proceedings such as administrative hearings, settlement negotiations, and the preparation of documents. Services that fall into this category include representing a client at a Social Security benefits appeal hearing, negotiating the settlement of an HIV discrimination claim before a lawsuit is filed, drafting a client's will, writing a judgment proof letter to stop a collection agency from harassing a client, or negotiating with a landlord to prevent a client from being evicted. With these services, an attorney or advocate interacts with a third-party on behalf of the client. Many client problems can be handled through this type of service, which has the advantage of being less expensive and less time-consuming than litigation. These types of services represent the core activities of most HIV legal services programs.

**Referrals to Pro Bono Attorneys**

Most HIV legal services programs refer clients to a network of attorneys in the private bar who provide clients with brief advice and counseling, limited direct representation, and who also may litigate cases on behalf of clients. Programs educate attorneys through continuing education courses, workshops, and training manuals to increase
the private bar's knowledge of HIV/AIDS legal issues and encourage volunteers to take pro bono cases on behalf of persons living with HIV/AIDS. These attorneys offer free services to HIV-positive clients as part of their professional responsibilities as members of the bar. The use of pro bono attorneys helps programs with a small number of (or only one) paid staff to meet the needs of a large number of clients. While the staff can provide brief advice and counseling, and distinguish meritorious from non-meritorious claims, more time-consuming matters can be referred to a panel of pro bono attorneys.

**Litigation**

Most HIV legal services programs either conduct no litigation or litigate only a very small percentage of their cases. Litigation involves filing a complaint in state or federal court on behalf of a client. Only a small fraction of civil cases filed in court actually result in trial; most are settled out of court. HIV legal services programs may litigate HIV discrimination claims or cases against insurance companies that have unfairly denied clients benefits. Because litigation is expensive, many programs attempt to place cases that need to be litigated with pro bono attorneys or try to work in association with law firms or other legal services organizations.

**Impact Litigation**

Impact litigation involves filing a lawsuit for the purpose of not only advancing the rights of individual plaintiffs, but also changing or developing the law to benefit persons living with HIV/AIDS. These cases usually attempt to establish new law, serve as a vehicle for public education, or affect a large number of people. Impact litigation often involves class actions, in which a large group of HIV-positive people
are represented in a single lawsuit. Impact litigation may also involve only one plaintiff with a case that raises an important legal issue. For example, the case *Bragdon v. Abbott*, which GLAD of Boston, MA, brought on behalf of one HIV-positive woman, resulted in the United States Supreme Court’s ruling that persons with HIV infection, even if asymptotic, are protected by the Americans with Disabilities Act. Since impact litigation cases are expensive to litigate, require a high-level of expertise, and are very time-consuming, programs often pursue them in affiliation with law firms or other non-profit organizations.
**Legislative/ Policy Advocacy**

Some HIV legal services programs also work to develop laws and policies that benefit persons living with HIV-disease. Policy advocacy includes working with local, state, and federal legislatures and administrative agencies to develop laws or policies that are responsive to the needs of persons living with HIV/AIDS. HIV legal services programs can contribute to policy discussions their expertise in dealing with HIV/AIDS legal issues as well as their experience with providing direct services to a large number of HIV-positive clients.
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