

HIV & Civil Rights

A Report from the Frontlines
of the HIV/AIDS Epidemic

ACLU AIDS Project



ACLU

HIV & Civil Rights

A Report from the Frontlines of the HIV/AIDS Epidemic

by
Tamara Lange
Senior Staff Attorney

November 2003

ACLU AIDS Project
125 Broad Street, 18th Floor
New York, NY 10004
(212) 549-2627
getequal@aclu.org
aclu.org/hivaids

HIV & CIVIL RIGHTS

A Report from the Frontlines of the HIV/AIDS Epidemic

Over the past two years, the ACLU AIDS Project interviewed over 40 community-based AIDS service providers (CBOs) around the country to get a better picture of the civil rights and civil liberties issues facing people living with HIV/AIDS.¹ The survey cast a wide net in terms of geography, type of service provided (medical, basic care, policy), and race, class, age, ethnicity, and particular needs of clients. The results reflect what direct service providers already know from day-to-day experience: there is a lot of work to be done. That work requires better connections between CBOs and civil rights organizations like the ACLU. This report is the first step in the ACLU AIDS Project's work to forge those connections.

Discrimination adds to the daily struggles faced by the growing number of people living with HIV/AIDS in the United States – people who are predominantly poor and disproportionately African American or Latino/a. Almost every agency told us that the biggest problems facing their clients involve meeting basic needs – coping with poverty, hunger, illiteracy, inadequate medical care, lack of transportation, and homelessness. In addition to those basic needs issues, people with HIV face a series of critical civil rights problems. Individuals living with HIV/AIDS need to know their rights and need the resources to advocate for themselves when their rights are threatened. They also need national legal organizations like the ACLU AIDS Project to enforce their civil rights and civil liberties through litigation, public education and legislative advocacy.

This report provides a starting point for discussions among local providers and national advocacy groups. Our findings are based on interviews with CBOs and their colleagues on the frontlines of the epidemic. In the next section, we outline the problems that need immediate attention. The last section of the report describes how we plan to address some of the most pressing civil rights issues facing people living with HIV/AIDS.

THE PROBLEMS

Stigma and Fear of Disclosure

Recent estimates suggest that as many as 280,000 people living with HIV in the United States do not know they are infected because they have not been tested, and that only a third of people who know they are infected are receiving care.² CBOs reported that many people avoid testing

¹ In order to protect the participating organizations from potential political retribution, we have not identified them in this report. We are deeply indebted to the people at each organization who took time out of their busy schedules to meet with us.

² P. L. Fleming, R. H. Byers, P. A. Sweeney, D. Daniels, J. M. Karon, and R. S. Janssen "HIV Prevalence in the United States, 2000," *CDC* (Atlanta, GA) (estimating that one third of 670,000 persons diagnosed with HIV/AIDS may not be receiving ongoing care, that 180,000-280,000 people are undiagnosed, and that 400,000-500,000 people living with HIV may be untested, untreated, or both) (available at <http://63.126.3.84/2002/Abstract/13996.htm>).

and treatment because they are terrified about the potential consequences of a breach of confidentiality: social stigma, rejection by loved ones, being evicted from an apartment, losing a job, and suffering harassment or violence. Because of that fear, more people get infected, more people get sick, and more people die.

Particularly in rural areas and in African American, Latino/a and Native American communities, people say that they are afraid of being abandoned by their families and rejected by their churches. In the Florida panhandle, some churches ask members to leave the congregation if they discover they are HIV-positive. In many rural areas, there is still widespread fear of casual contact and people still think of HIV as a “gay disease.”³ In Montana, approximately 50% of people statewide did not know the possible methods of transmission. Very few people in these areas are open about their HIV status and most are afraid to use their own names even with AIDS service providers. People in rural areas are so closeted about their HIV status that complaints of discrimination are rare.

A Dallas provider said many people are afraid that there is some sort of national directory that lists every HIV-positive person’s name. In an AIDS 101 class, they get many questions about what happens to the information when someone tests positive. Many people who use anonymous testing wait to access care because they are afraid to be put in the database. Even for people who are proactive in seeking medical care, the fear of social retribution and discrimination is so extreme that they are willing to travel from Alabama to Georgia to get tested or to drive 350 miles in Montana for treatment. Unfortunately, the fear is not unfounded; violation of medical privacy was one of the most frequently reported civil liberties problems faced by people living with HIV/AIDS.

Privacy

Breaches of confidentiality can and do unravel people’s lives, forcing them to find new jobs, new schools, and new homes. Nearly every one of the providers interviewed reported serious violations of medical privacy.

- In New Mexico, a patient first learned that he was HIV-positive from a receptionist in front of a waiting room full of people.
- In Fort Worth physicians sometimes tell a family member about a person’s HIV status before telling the client. Many providers think HIV-positive people “should be forced to tell others.”
- In Florida, people refuse to pick up their medication from the health department because they are afraid someone will see them.

³ As a result, symbolic stigma based on preexisting attitudes toward groups of people disproportionately affected by HIV is compounded by instrumental stigma, which is based mainly on fear of HIV-transmission. See Herek, G.M., Capitanio, J.P., & Widaman, K.F., “HIV-related stigma and knowledge in the United States: Prevalence and trends, 1991-1999,” *American Journal of Public Health*, 92(3), 371-377 (2002).

- A Minnesota provider said most people do not understand the difference between confidential and anonymous testing and need to know what information will be released to insurers, employers, and family members.
- A teacher in Florida informed an entire class that a particular student was HIV-positive.
- A family counselor in Alabama told the school that a child's mother was HIV-positive.
- A school in Detroit threatened to disclose a child's HIV status to all teachers and administrators.
- Police in St. Louis found a young man's HIV medication when they searched his car and disclosed his HIV status to his father, saying the father had a right to know.
- The New York City Department of Health disclosed a person's HIV status to his employer in the course of making partner notification calls.
- A receptionist at a nursing home in Texas told a woman that the patient holding her baby might give it AIDS.
- A university hospital in New Mexico sent a client's bill to a collection agency and disclosed the client's HIV status on the bill.
- Medical charts in Fort Worth are labeled on the outside with a sticker indicating that the patient is HIV-positive.
- Clinic employees and pharmacists in Florida disclosed people's HIV status to others in the waiting area by shouting out information about their medications and identifying which doctors they were coming to see.
- In small towns, people are often in serious danger if their HIV status is revealed. One provider had to help three or four people get out of a small town in Texas because of hate mail and vandalism of their homes.

These incidents are likely the tip of the iceberg, for even people who reported egregious breaches of confidentiality were typically too afraid to confront the problem if it meant disclosing their HIV status to more people. All over the country, health care providers, pharmacists, law enforcement officials, government employers and schools are violating state and federal laws by disclosing HIV status without permission.

Names Reporting, Criminal Prosecutions and Mandatory Testing

Fear about unauthorized disclosure appears to be growing more acute now that most states require testing agencies to report the names of people who test positive or who seek treatment. Several CBOs expressed concern that people are avoiding testing and treatment specifically because of fear about the fact that the government keeps a list of people with HIV/AIDS.⁴

Public confidence in the local health department is damaged almost irreparably if people perceive a link between efforts to track the identities of people with HIV and efforts to prosecute people for transmission of HIV. Unfortunately, that perception already exists in at least one state. In South Dakota, after several widely-publicized prosecutions of men accused of exposing their sexual partners to HIV, the legislature authorized the health department to release a person's name and HIV-status to the state prosecutor whenever the department thinks a person may have been exposed to HIV intentionally or may have exposed someone else intentionally. In other states, enforcement of reporting laws undermines public confidence in health care providers.

Discrimination

Despite some advances, discrimination against people living with HIV is still pervasive and affects virtually every aspect of life from employment to housing to access to basic medical care.

Employment

Most service providers had stories of HIV/AIDS-based job discrimination. A CBO in Tallahassee receives at least 10 complaints a year from people who say they were fired because of their HIV status. An organization in Texas receives an average of one complaint a week about firings or demotions based on HIV status. People who take time off for medical care often lose their jobs, either because of absences or because they are forced to disclose their HIV status and are then fired. In Miami, most clients report that they are afraid of discrimination at work. A St. Louis provider said workplace discrimination is rampant. One Texas employer asked an employee to get an HIV test because the employee was gay and had been sick.

Much of the discrimination reflects employer ignorance about established law. Employers in Detroit and New York ask illegal questions on job applications, in interviews, and after making a job offer, including "what medications are you taking," and "have you been on disability?" A flight attendant had a job offer retracted because he failed to list HIV medications on an application form but disclosed his HIV status after being hired. Providers in St. Louis reported

⁴ It is difficult for CBOs to reassure their clients given that 35 states now have name-based reporting and five states have name-to-code based reporting, while only eight states and the District of Columbia have code-based reporting. See "50 State Comparisons: HIV Name/Code Based Reporting Policies" (available at www.statehealthfacts.kff.org/). The reauthorization of the Ryan White CARE Act of 2000 created additional incentives for states to increase HIV name reporting and partner notification programs; "ultimately driving more people away from HIV testing." See Collins, Chris. "HIV/AIDS Surveillance and Reporting in the United States," *HIV InSite* (February 2001) (available at <http://hivinsite.ucsf.edu/InSite?page=kb-08-02-02>).

that employers don't view HIV as a disability and that most people assume that anyone out as gay is HIV-positive. In Dallas and Ft. Worth, CBOs said it is "a given" that disclosure means a decision not to hire, particularly in the restaurant business. One Texas employer even required an HIV-positive employee to use a different bathroom, to eat in a separate location, and to wear long-sleeved clothing in the summer.

Child Custody and Visitation

Several providers reported that clients who were HIV-positive were prohibited from visiting their children, lost custody of their children, or were prohibited from providing foster care or adopting children. One provider in New Mexico said an HIV-positive man initially lost custody because of his HIV status and had to fight to obtain visitation. In Texas, several HIV-positive clients were denied visitation with their children. Another person was told that the presence of one HIV-positive child would bar future placement of children through foster care or adoption.

Medical Care

Medical and social services play a critical role in the daily lives of many HIV-positive people, but because of ignorance and discrimination this lifeline is often dangerously unreliable. All over the country, from Alabama to California, doctors, dentists, skilled nursing and psychiatric facilities, and drug treatment centers refuse to provide services to HIV-positive patients.

Emergency medical providers in Dallas and Fort Worth refuse to treat people who are HIV-positive, and police officers wear gloves to transport HIV-positive detainees. Migrant workers with HIV in South Florida are turned away from hospitals. At the county hospital in Dallas, people living with HIV/AIDS are refused service on a routine basis; instead they are referred to a nearby HIV clinic, even for standard care like cleaning a small cut. Staff at one Texas county hospital asked employees from an AIDS service program to move one patient with HIV to a gurney so that hospital staff would not have to touch him.

Another hospital in rural Texas tried on several occasions to send HIV-positive patients seeking emergency care to the local AIDS service organization, saying, "we've got one of yours." In the worst cases, people die as a result of discrimination in medical care. One man died a week after he was turned away from a Texas emergency room; although the man had no transportation, the doctor wrote on a prescription pad "go to JPS," referring to another hospital an hour away that had an AIDS unit. In a rural Texas hospital, a patient who was admitted because of vomiting and diarrhea was found lying in a hospital bed with nothing but a cup of water on the table. Staff from an AIDS service organization delivered medication to him and asked that he be given an IV and the appropriate medications. They returned the next day to find the man in the same neglected state. By the time he was transferred to another hospital it was too late, and he died there.

Skilled Nursing, Drug Treatment, and Psychiatric Facilities

Discrimination in residential nursing, drug treatment, and psychiatric facilities leaves many people with HIV/AIDS without any way of obtaining adequate care. Many facilities blatantly refuse to accept patients who are HIV-positive; others have unspoken rules. One AIDS

organization tried for three months to get a client into a skilled nursing care facility, calling almost every home in Arizona. Even in Los Angeles, many nursing homes and psychiatric facilities will not take clients with HIV. Some nursing homes say they do not have enough experience to care for patients who are HIV-positive, even when they are entirely asymptomatic.

In New Mexico, inpatient drug treatment facilities will not take anyone who takes medication of any kind, and some facilities say outright that they will not serve people who are HIV-positive. Several drug treatment facilities in Texas refuse admission to anyone who has had an opportunistic infection within the past 18 months. Others impose strict requirements for health status before allowing residence. In east Texas, one program has refused patients who are HIV-positive, arguing that they do not have access to a large hospital and that their on-site doctors are not equipped to treat people with HIV.

Housing and Shelters

People living with HIV and AIDS are particularly vulnerable to housing discrimination. Because a disproportionate number of people living with HIV/AIDS are poor, access to housing is a critical problem that is compounded by discrimination.

Organizations in Missouri, Arkansas, Florida, and Alabama said housing discrimination based on HIV status is commonplace. One landlord in Arkansas found out his tenant was HIV-positive and tore up the lease. Landlords often refuse to accept checks from social service programs, making it impossible for HIV-positive tenants receiving government subsidies to rent from them. In Dallas, even certain apartment complexes associated with social service programs refuse to allow anyone with HIV to live there. Neighborhood associations in Alabama and New Mexico recently opposed issuance of city and county permits for new housing facilities for people living with AIDS.

Discrimination in homeless shelters forces people to choose between adequate medical care and shelter. The Salvation Army shelter in Dallas requires people to turn in their medication to stay there, but does not allow sufficient access to the medication for residents to adhere to their regimens for HIV drugs and psychotropic medication. Gay bashing and discrimination continue to create problems at St. Louis shelters, making their services unavailable for many clients.

Medical Care in Rural Areas

In rural areas, even people who know that they are HIV-positive frequently receive no medical care. Many people in small communities and on reservations refuse to access services close to home because of fear of discovery. In Montana, this is particularly problematic for Native Americans because Indian Health Services will not pay if someone goes outside its system. Rural providers in Texas reported that in some parts of Oklahoma people who test positive are sent to a gay nurse practitioner with no resources to provide HIV care. In the Florida panhandle and in rural Texas, many patients are still being treated with AZT because doctors have never heard of triple combination therapy. Others are receiving no medication at all. For those

patients who do get triple combination therapy, treatment education is often nonexistent. As a result,

many people continue taking one drug when they run out of the other two, or, for financial reasons, they take their drugs once a day instead of three times a day.

Prevention education is also sorely lacking in rural areas. A recent study on high-risk sexual activity in rural areas found that at least one-half of sexually active men and women with HIV engaged in practices that created a high risk of HIV transmission even though one-third believed that their sex partners were HIV-negative.⁵

HIV in Prisons and Jails

Failing to adhere to a strict schedule when taking HIV medications can make the virus resistant to the medication, so depriving inmates of medication is a matter of life and death. Yet all over the country CBOs reported that prisons and jails are depriving inmates of medication, skipping doses, and providing one standard set of medications for triple combination therapy, even for inmates with resistance to one or more of the three drugs.

AIDS organizations in Los Angeles and Michigan reported that prisoners have a hard time getting medication and are subjected to dangerous interruptions in medication. An incarcerated man in St. Louis said he was deprived of HIV medication for four months and pre-trial detainees and arrestees frequently complain that they are not receiving their medications. A county jail in Texas reportedly refused to provide medication to one inmate for over two months, asserting that the local AIDS services organization was responsible for getting him medication. Several Texas prisons switch inmates to cheaper medications despite the danger that the virus will develop resistance to the medications that are keeping the inmates alive.

The most widespread problem is disruption in medication upon arrival at or departure from jail. In Dallas, the county jail reportedly confiscates medication on arrival and denies treatment until the prison doctor diagnoses the inmate and writes a new prescription, even if medication is provided to the jail by an AIDS service organization. In Santa Fe and Gallup, people with HIV who have been arrested and held over the weekend have begged for their medications to no avail because the jail does not see non-adherence as a medical emergency. Nearly everywhere, prisoners who are HIV-positive are released from jail without enough medication to tide them over until they can obtain follow-up care. It often takes as much as 45 days to qualify for Medicaid services after release from prison. In Dallas, it takes 60 days to get an appointment at the county hospital. In addition, many inmates with HIV are subjected to longer prison terms based on discriminatory policies that exclude them from rehabilitative programs, including work release programs, because of the cost of medical care.

⁵ Heckman, T. G., et al., "HIV transmission risk practices in rural persons living with HIV disease," 30 *Sexually Transmitted Diseases* 134-136 (2003).

Immigration and Language Barriers

Documented immigrants have difficulty accessing housing services in Dallas. Many eligible immigrants in Miami do not receive food stamps or SSI because they are afraid of being deported and are afraid the government will tell their families that they are HIV-positive. In New York, a provider reported that one client was eligible for food stamps for many months but did not know because he could not read the form, which was not provided to him in Spanish (although the benefits cut-off letter was provided in Spanish).

Undocumented immigrants living with HIV find it difficult to obtain even basic health care. In Texas, CBOs reported that undocumented indigent people are turned away from for-profit hospitals and cannot get treated at the county hospital because of an internal policy of refusing to use indigent funding for undocumented patients. Programs in Detroit that are supposed to provide drug treatment on demand require Social Security numbers, making the programs inaccessible to undocumented immigrants.

Needle Exchange

There are very few needle exchange programs, and hence very little education about or access to clean needles as a way to prevent the spread of HIV. Those programs that do exist are in imminent danger of having their funding pulled. New Mexico is the only state where providers talked about the availability of successful needle exchange programs. Even in the traditionally conservative city of Roswell, police have been open to needle exchange. Providers in Detroit and Missoula identified the ban on federal funding of needle exchange as a substantial problem. Of the groups interviewed, only one provider had needles and works-cleaning kits in public view with instructions clearly posted, and that provider explained that they were dismantling the program because of funding problems.

Censoring Education and Prevention

Meanwhile, the federal government is not focused on the epidemic spiraling out of control in poor communities of color or on how to protect young men who have sex with men. Instead, it is focused on preventing young people from learning the facts about HIV by concentrating funding in programs that teach only one message – abstinence until marriage – and that often mislead young people into thinking that condoms and other safe-sex practices are useless in preventing HIV transmission.

HIV service providers say the focus on abstinence is having a chilling effect on AIDS programming. Access to works exchange and bleach kits is limited or non-existent in most areas. Many providers believe the federal government has been auditing well-known CBOs that provide prevention and harm reduction education for gay, bisexual, and transgender clients as a scare tactic to discourage all CBOs from discussing safe sex and providing other meaningful services to that disfavored group of people living with HIV/AIDS.

Encouraging abstinence among young people may be a valuable way to build self-esteem and to promote emotional intimacy between young couples, but advocating abstinence until marriage is meaningless for gay and bisexual teenagers as long as same-sex couples are prohibited from marrying. Talking about abstinence without providing accurate scientific information about how to minimize the risk of sexual transmission is dangerous and shortsighted. The government should be teaching teenagers and young adults how to avoid infection instead of closing its eyes to the reality that most of them are not choosing abstinence.

EXPLORING SOLUTIONS

The survey of CBOs provided an overview of the contexts in which people living with HIV/AIDS confront discrimination, and an idea of which institutions are ignoring anti-discrimination and other laws that protect people with HIV. Some of the problems reflected by the survey do not generally lend themselves to the skills of lawyers, though it is important for us to fully understand what the people we are trying to help are facing. Other problems may suggest the need for a tactical shift in the movement, increasing the emphasis on education, advocacy, and enforcement over impact litigation and policy work aimed at creating new rules. The ACLU AIDS Project has identified several areas that seem the most pressing, both in terms of the number of people affected and the seriousness of the harms they face.

- **Discrimination in Residential Facilities.** Refusing to treat people with HIV is illegal, yet the survey suggested that many nursing, drug treatment and psychiatric inpatient facilities routinely refuse admission to people with HIV. These violations of the law are particularly distressing because the issue has been the subject of considerable industry-wide education. The Project is interested in finding the right case to challenge this practice and is seeking partners in new efforts to educate key players in inpatient care industries.
- **Deprivation of Parental Rights.** Several providers reported that people with HIV are being denied custody of their children and even visitation with their children. People are also categorically excluded both as foster parents and as adoptive parents solely because they or their family members are HIV-positive. The ACLU AIDS Project is interested in representing people whose families are being torn apart by this sort of illegal discrimination.
- **Discrimination in Food Service and Health Care Jobs.** Many employers, including some major food, retail and drug chains, are asking unlawful questions about disabilities and health on their job applications. Employment discrimination appears to be particularly concentrated in food service and health care, reflecting continuing ignorance about the mechanisms for HIV transmission. Litigation and public education to challenge myths about casual contact transmission are critical components in efforts to stop employment discrimination and reduce social stigma.
- **Censorship.** Local, state and federal governments may be breaking the law when they censor or distort HIV prevention messages. Schools teach students incorrect information

about how to prevent HIV transmission (including that condoms do not work), and other parts of the government provide inaccurate facts about HIV transmission and prevention. Such misinformation appears to be a significant problem in abstinence-only until marriage education programs in schools. Censorship may also take the form of restrictions along the lines of the federal government's faith-based initiative. For example, an HIV service provider may be denied a government grant because of funding restrictions that require affiliation with a faith-based organization. Likewise, the government may cross the line and allow faith-based CBOs to use government money to disseminate incorrect or distorted HIV treatment or prevention information based on the organization's religious views.

- **Violations of Privacy.** The law in most states already provides protection for medical privacy, so privacy violations appear to call primarily for education and training. The ACLU AIDS Project seeks partners in efforts to work with professional groups on peer education and to petition regulatory authorities to enforce the law. We are also interested in potential cases that could be used to reach specific audiences such as pharmacists, police officers, doctors and school administrators.
- **Discrimination in Medical Care.** The survey turned up alarming stories about people living with HIV/AIDS being denied critical medical and dental treatment. Over five years ago, the ACLU AIDS Project finished one of the first key cases under the Americans with Disabilities Act, which established that this kind of discrimination is illegal. We are interested in bringing cases that would initiate widespread public discussion about why it is both illegal and morally wrong for hospitals to refuse to treat people who are HIV-positive.
- **Inadequate Care in Jails and Prisons.** All over the country, prisoners and jail inmates are deprived of their HIV medications when they are first incarcerated and are denied a transitional supply of medication when they are released. We are interested in bringing lawsuits that would highlight the obligation of all jails and prisons to provide medication upon release and to provide prompt access to medication upon admission. One non-litigation effort we hope to build on was started by the ACLU of Southern California, which worked with the Los Angeles County Jail to educate its intake officers about which drugs were approved medications for HIV. This enabled inmates to keep their HIV medications and helped avoid interruptions in care.

CONCLUSION

In addition to making our impact litigation and public education work more effective by partnering with CBOs, the ACLU AIDS Project will focus significant resources on creating tools that CBOs and people living with HIV/AIDS can use to make the most of good laws that already exist. As with any toolkit, the goal is to provide simple do-it-yourself advocacy information. If you are interested in working with the ACLU AIDS Project on a particular issue, or if you have heard about a problem that we might be able to address, please let us know. We look forward to an ongoing collaboration.



AIDS Project

125 Broad Street, 18th Floor
New York, NY 10004
(212) 549-2627
getequal@aclu.org
aclu.org/hivaids