

HIV & Civil Rights



**A Report from the Frontlines
of the HIV/AIDS Epidemic**

ACLU AIDS Project

by
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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.

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.

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.

- 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

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
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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 liv

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

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).

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.

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.

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.

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.**

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.

