



Lambda
Legal

making the case for equality

The State of HIV Stigma and Discrimination in 2007: An Evidence Based Report

Since the onset of the U.S. HIV epidemic in 1981, stigma and discrimination have detrimentally affected people living with HIV (PLWH) in every aspect of their lives – including employment, education, housing, insurance, health care, and relationships with family, friends and sexual partners. This has resulted in harms including the erosion of social support networks, eviction from homes, loss of work, denial of healthcare, social isolation, depression and violence. Although confidentiality laws, the Americans with Disabilities Act and state antidiscrimination laws have provided some legal protection and relief against HIV-related discrimination, and the introduction of highly active antiretroviral therapy (HAART) in 1996 dramatically increased the life expectancy of those PLWH with access to care, too many PLWH in the United States continue to be harmed by stigma and discrimination.¹

Our Education Deficit

HIV stigma is fueled by ignorance about the basic modes of HIV transmission, unfounded fears of contagion, moral judgment and personal prejudice against the groups most affected by the epidemic.²

Far too many people still lack basic knowledge about how HIV is transmitted. According to a 2006 national survey conducted by Kaiser Family Foundation:

- 37% of the public mistakenly believed that HIV could be transmitted through kissing.
- 22% mistakenly believed that transmission could occur through sharing a drinking glass.
- 16% mistakenly believed that transmission could occur through touching a toilet seat.
- And more than 4 in 10 adults held at least one of the above misconceptions about HIV transmission.³

Our HIV education deficit continues to fuel stigma against and to ostracize PLWH. For example, the 2006 Kaiser survey found:

- Only 1 in 4 respondents reported that they would be very comfortable having a roommate with HIV.
- Only 29% reported that they would be very comfortable with their child having an HIV-positive teacher.
- And those with misconceptions about HIV transmission were much more likely to express discomfort about working with someone with HIV.⁴

Moral judgment continues to fuel discrimination against PLWH. Those who consider a person with HIV to be morally responsible for his or her HIV infection are more likely to harbor feelings of anger, blame and disgust towards PLWH and/or support coercive and discriminatory HIV policies.⁵ National surveys reveal that PLWH continue to experience significant levels of moral judgment by their peers:

- 40% of respondents agreed with the statement “In general, it’s people’s own fault if they get AIDS.”⁶
- 48.3% believed that “Most people with AIDS are responsible for having their illness.”⁷
- And 24.8% believed “People who got AIDS through sex or drug use have gotten what they deserve.”⁸

The Power of Prejudice

“I have always hidden my (homosexuality) from my family and friends. To now come out and say I am gay and I have AIDS, it’s a double stigma. Unfortunately, the stigma is attached to you at the time you need support, you are afraid of dying, and you are hurting pretty bad.”⁹

Scientifically, HIV is an infectious disease that is blind to the social status or characteristics of its host. Yet, prejudice and moral judgment have the power to redefine HIV as a deserved affliction or punishment. In this way, HIV serves as a vehicle for the expression of preexisting prejudice against particular socially marginalized groups, such as gay men and IDUs.¹⁰ Further, HIV stigma may function in tandem with racial prejudice, creating multiple layers of stigma for PLWH who are members of ethnic and racial minorities.¹¹

The perception of AIDS as a “gay disease” continues to fuel alarming misperceptions about sexual transmission of HIV.

- A 2005 national study revealed that 33% of male respondents and 46% of female respondents incorrectly believed that HIV transmission could occur through unprotected sex between two uninfected men.¹² Since HIV cannot be transmitted when neither sexual partner has the virus, this evidence suggests the persistence of a widely held misperception that men having sex with other men is in itself dangerous or unhealthy.
- Several national surveys indicate that stigmatizing attitudes towards PLWH appear to be greatest among heterosexuals who also express negative attitudes towards gay people.¹³

Injecting drug users are highly stigmatized and least likely to access care.

- For example, a national survey found that 72% of respondents agreed with the statement, “I think people who inject illegal drugs are disgusting.” Further, negative feelings towards IDUs directly correlated to increased attitudes of stigma towards PLWH.¹⁴
- IDUs are less likely to receive highly active antiretroviral treatment than non-IDUs. According to a 2005 study, this remained true after adjustment for patient use of services.¹⁵

Racial and sexual prejudices both contribute to health care disparities for black gay and other men who have sex with men.

- In a 2004 study, black men who have sex with men expressed external and internal barriers to their medical care, including racial prejudice, distrust of doctors and medical facilities, miscommunication and lack of cultural competence.¹⁶
- Recent studies have identified a pattern of ethnic and racial minorities receiving lesser quality health care than non-minorities, *even when they have the same type of health insurance.*¹⁷ For example, a 2005 multistate study found that black Americans were less likely to receive HAART than whites, and that this disparity was not due to lack of access to care.¹⁸

HIV Discrimination in the Third Decade of the Epidemic

Existing evidence shows that HIV stigma and discrimination persist and continue to have a severe impact on the lives of PLWH.

From 2002 to 2006, HIV-related employment discrimination claims have been filed with the U.S. Equal Employment Opportunity Commission (EEOC) at an average rate of about one per day.¹⁹

This is only a small decline from the number of claims filed during 1994 to 2001, which saw an average rate of 1.3 claims per day.²⁰ We still have a long way to go to meet our goal of ending HIV stigma and discrimination.

Discrimination also persists in the health care system. For example, a 2006 study of specific-service health care providers in Los Angeles County found HIV discrimination to be prevalent. The researchers surveyed 131 skilled nursing facilities, 98 plastic and cosmetic surgeons and 102 obstetricians in Los Angeles County to determine how many of these institutions practice a policy of blanket discrimination against PLWH. They found that of the institutions surveyed, 56% of the skilled nursing facilities, 26% of the plastic and cosmetic surgeons, and 47% of the obstetricians refused to treat PLWH and had no lawful explanation for their discriminatory policy.²¹

Current examples of HIV stigma and discrimination are pervasive. PLWH experience stigma and discrimination in all aspects of social existence including employment, health care, child custody matters, education, sports and accessing public benefits. The following are just a few examples of discriminatory policies practiced by our own government:

- The U.S. government bans individuals with HIV from entering the United States as tourists, workers or immigrants.²²
- The U.S. Foreign Service refuses to hire applicants with HIV.²³
- Sexual activity by people with HIV may subject them to criminal penalties in many states, even when the sexual activity is consensual, the activity involves little or no risk of transmission, there is no intention to transmit the virus and the activity does not result in HIV transmission.²⁴

HIV discrimination is underreported. Unfortunately, the number of claims reported and filed with EEOC represent only a small portion of the discrimination experienced by PLWH. Incidents of discrimination are not reported and/or pursued for a multitude of reasons including:

- A potential claimant cannot afford a lawyer.
- The discrimination is only one crisis among many the individual is facing, such as lack of access to housing or medical care.
- Bringing a claim forces a claimant to focus on the indignities that he or she has experienced and to reveal his or her HIV status to others.
- Legal standards and burden of proof can be very difficult to meet.

Underreporting of discrimination may be particularly likely among PLWH who are members of historically marginalized communities.²⁵

Many forms of stigmatization are not illegal – and may be impossible to quantify – yet they continue to profoundly affect the everyday lives of PLWH. Cathy Bowman, HIV Project Director at South Brooklyn Legal Services, put it this way:

“The law (in New York) does not prohibit family members, neighbors, friends, boyfriends, girlfriends, private landlords or the other clients you might run into at your HIV clinic, HIV case management program or other HIV-related program from telling anyone or everyone of your HIV status. It does not stop your family members from never speaking to you again. It does not prevent your neighbor from forbidding her children to play with your children. It does not bar gossiping, slurs, religious curses or hostile stares and has very limited efficacy against menacing behavior. The law does not advise us not to blame people with HIV for their status. It does not stop people from assuming that you are gay or promiscuous or use drugs. For some things the law offers no protection and unfortunately these are the traumas that I most often hear recounted in my practice.”²⁶

The Psychological and Physical Toll of Stigma

"I lost my wife and child. My father doesn't want anything else to do with me. My brother, who is in the medical profession, didn't want me living in the same community because it would affect his job. My own relatives would not give me a glass of water. Nobody wants to associate with me. Basically I died in 1989 when the diagnosis was made. I've kept on going and tried to carry on. That's why I am still here."²⁷

HIV stigma is a significant source of psychological damage and depression.²⁸

- A 2006 study found that higher levels of HIV stigma experienced by the respondent directly correlated with having symptoms of depression and/or having received psychiatric care in the previous year.²⁹
- Internalized HIV stigma is also strongly associated with levels of depression, anxiety and hopelessness.³⁰

HIV stigma and depression can deter PLWH from seeking medical care and lead to deterioration of health.

- Stigma has been linked to delays by HIV-positive individuals in seeking medical care,³¹ and at least one recent study has confirmed that a relationship between stigma and treatment nonadherence still exists.³²
- Depressive symptoms in PLWH have been correlated consistently with treatment nonadherence, suicidal ideation, disease progression and mortality.³³ Disturbingly, a 2004 study of nonmetropolitan PLWH found that "approximately 60% of participants reported moderate or severe levels of depressive symptomatology."³⁴
- In addition, research has shown a correlation between lower levels of social support and faster disease progression.³⁵

Tragically, stigma and discrimination are still prevalent in the third decade of the HIV epidemic and continue to have a very serious impact on the lives and health of people living with HIV in the United States.

Lambda Legal HIV Project
February 2007

--

¹ Vanable, P.A. et al., "Impact of HIV-Related Stigma on Health Behaviors and Psychological Adjustment among HIV-Positive Men and Women," *AIDS and Behavior*, 10(5), 473-482 (2006); Schuster, M.A. et al., "Perceived Discrimination in Clinical Care in a Nationally Representative Sample of HIV-Infected Adults Receiving Health Care," *Journal of General Internal Medicine*, 20, 807-813 (2005); American Civil Liberties Union, "HIV and Civil Rights: A Report from the Frontlines of the HIV/AIDS Epidemic," 2003, available at http://www.aclu.org/pdfs/hiv/hiv_civilrights.pdf; Herek, G. et al., "HIV-Related Stigma and Knowledge in the United States: Prevalence and Trends, 1991-1999," *American Journal of Public Health*, 92(3), 371-377 (2002); Studdert, D., "Charges of Human Immunodeficiency Virus Discrimination in the Workplace: The Americans with Disabilities Act in Action," *American Journal of Epidemiology*, 156(3), 219-229 (2002); Zierler et al., "Violence Victimization After HIV Infection in a US Probability Sample of Adult Patients in Primary Care," *American Journal of Public Health*, 90(2), 208-215 (2000); Chesney, M. & Smith, A.W., "Critical Delays in HIV Testing and Care: The Potential Role of Stigma," *American Behavioral Scientist*, 42(7), 1158-1170 (1999); Herek, G., "AIDS and Stigma," *American Behavioral Scientist*, 42(7), 1102-1112 (1999); Herek, G. & Capitano, J., "AIDS Stigma and Sexual Prejudice," *American Behavioral Scientist*, 42(7), 1126-1143 (1999); Laryea, M. & Gien, L., "The Impact of HIV-Positive Diagnosis on the Individual, Part 1," *Clinical Nursing Research*, 2(3), 245-266 (1993); Gostin, L., "The AIDS Litigation Project: A National Review of Court and Human Rights Commission Decisions, Part II: Discrimination," *Journal of the American Medical Association*, 263, 2086-93 (1990).

² Herek, G. & Capitano, J., "Symbolic Prejudice or Fear of Infection? A Functional Analysis of AIDS-Related Stigma Among Heterosexual Adults," *Basic and Applied Social Psychology*, 20(3), 230-241 (1998).

³ Kaiser Public Opinion Spotlight, "Attitudes about Stigma and Discrimination Related to HIV/AIDS," 2006, available at <http://www.kff.org/spotlight/hivUS/index.cfm>

-
- ⁴ Kaiser Public Opinion Spotlight.
- ⁵ Herek, G. et al., "Stigma, Social Risk, and Health Policy: Public Attitudes Toward HIV Surveillance Policies and the Social Construction of Illness," *Health Psychology*, 22(5), 533-540 (2003); Herek et al. (2002); Herek & Capitanio (1999).
- ⁶ Kaiser Public Opinion Spotlight.
- ⁷ Herek et al. (2002).
- ⁸ Herek et al. (2002).
- ⁹ Laryea & Gien (1993).
- ¹⁰ Devine, P. et al., "The Problem of 'Us' Versus 'Them' and AIDS Stigma," *American Behavioral Scientist*, 42(7), 1208-1224 (1999); Herek (1999).
- ¹¹ See Schuster et al. (2005).
- ¹² Herek, G. et al., "When Sex Equals AIDS: Symbolic Stigma and Heterosexual Adults' Inaccurate Beliefs about Sexual Transmission of AIDS," *Social Problems*, 52(1), 15-37 (2005).
- ¹³ Herek et al. (2003); Herek & Capitanio (1999); Herek & Capitanio (1998).
- ¹⁴ Capitanio, J. & Herek, G., "AIDS-Related Stigma and Attitudes Toward Injecting Drug Users Among Black and White Americans," *American Behavioral Scientist*, 42(7), 1144-1157 (1999).
- ¹⁵ Gebo, K.A. et al., "Racial and Gender Disparities in Receipt of Highly Active Antiretroviral Therapy Persist in a Multistate Sample of HIV Patients in 2001," *Acquired Immune Deficiency Syndrome*, 38(1), 96-103 (2005). See also Celentano, D.D. et al., "Self-Reported Antiretroviral Therapy in Injection Drug Users," *Journal of the American Medical Association*, 280, 544-546 (1998); Sherer, R., "Adherence and Antiretroviral Therapy in Injection Drug Users," *Journal of the American Medical Association*, 280, 567-568 (1998).
- ¹⁶ Malebranche, D. et al., "Race and Sexual Identity: Perceptions about Medical Culture and Healthcare among Black Men Who Have Sex with Men," *Journal of the National Medical Association*, 96(1), 97-106 (2004).
- ¹⁷ Institute of Medicine, "What Healthcare Consumers Need to Know about Racial and Ethnic Disparities in Healthcare," *National Academy of Sciences*, 2002, available at <http://www.nap.edu/catalog/10260.html>. Numerous studies have found that ethnic and racial minorities are more likely to be uninsured. See, e.g., Kaiser Family Foundation, "Key Facts: Race, Ethnicity, and Medical Care," 2003, available at <http://www.kff.org/minorityhealth/upload/Key-Facts-Race-Ethnicity-Medical-Care-Chartbook.pdf>; Institute of Medicine (2002).
- ¹⁸ Gebo et al. (2005).
- ¹⁹ Based on "ADA Charges Filed with EEOC and State and Local FEP Agencies Where the Alleged Basis Was HIV," obtained from EEOC by Lambda Legal on Dec. 15, 2006 (on file with Lambda Legal).
- ²⁰ "ADA Charges Filed with EEOC" (on file with Lambda Legal); Studdert (2002).
- ²¹ Sears, B. & Ho, D., "HIV Discrimination in Health Care Services in Los Angeles County: The Results of Three Testing Studies," *The Williams Institute*, UCLA School of Law, 2006, available at <http://www.law.ucla.edu/williamsinstitute/publications/Discrimination%20in%20Health%20Care%20LA%20County.pdf>
- ²² Immigration and Nationality Act, sSection 212(a)(1)(A)(i), 8 U.S.C. § 1182(a)(1)(A)(i).
- ²³ *Taylor v. Rice*, 451 F.3d 898 (D.C. Cir. 2006).
- ²⁴ See, e.g., Ga. Code Ann. § 16-5-60; Mich. Comp. Laws Ann. § 333.5210; Ark. Code. Ann. § 5-14-123..
- ²⁵ See Schuster et al. (2005); Burris, S., "Studying the Legal Management of HIV-Related Stigma," *American Behavioral Scientist*, 42(7), 1225-1239 (1999) ("For many people with HIV, law is less a source of protection than itself a source of significant social risk.").
- ²⁶ Testimony of Catherine F. Bowman, New York State Assembly Public Hearing on HIV Testing, Counseling, and Informed Consent, Dec. 20, 2006 (on file with Lambda Legal).
- ²⁷ Laryea & Gien (1993).
- ²⁸ Vanable et al. (2006).
- ²⁹ Vanable et al. (2006).
- ³⁰ Lee, R.S. et al., "Internalized Stigma Among People Living with HIV-AIDS," *AIDS and Behavior*, 6(4), 309-319 (2002).
- ³¹ See Chesney & Smith (1999) (discussing research relating stigma to delays in seeking HIV testing and care).
- ³² Vanable et al. (2006).
- ³³ Heckman, T.G. et al., "Emotional Distress in Nonmetropolitan Persons Living with HIV Disease Enrolled in a Telephone-Delivered, Coping Improvement Group Intervention," *Health Psychology*, 23(1), 94-100 (2004) (discussing studies with these findings).
- ³⁴ Heckman et al. (2004).
- ³⁵ Leserman et al., "Impact of Stressful Life Events, Depression, Social Support, Coping, and Cortisol on Progression to AIDS," *American Journal of Psychiatry*, 157(8), 1221-1228 (2000).