Almost thirty years after the first cases of infection by the human immunodeficiency virus (HIV) were reported, ignorance and fear about HIV and bias against people affected by HIV continue to fuel stigma and discrimination in this country. Individuals living with HIV have been detrimentally affected in every aspect of life, including experiencing denial and termination of employment; denial of needed medical care; loss of insurance coverage; erosion of social support networks; eviction from homes; disruption of family relationships; social isolation; depression; unwarranted criminal prosecution; and excessive criminal sentences.

And the harms go beyond the individuals directly affected. Stigma and discrimination continue to hinder the wider effort to combat the HIV/AIDS epidemic. As the National HIV/AIDS Strategy for the United States – issued by the White House Office of National AIDS Policy in July 2010 – states, “[t]he stigma associated with HIV remains extremely high[,] and fear of discrimination causes some Americans to avoid learning their HIV status, disclosing their status, or accessing medical care.”

This report summarizes current evidence of the sources and impact of HIV stigma and discrimination, including recent examples of such discrimination.

OUR HIV EDUCATION DEFICIT

HIV stigma is largely fueled by ignorance about the basic modes of HIV transmission and unfounded fears of contagion. As one set of researchers reported in 2008, “[l]arge segments of the public remain uneducated about HIV and how it is transmitted, which promotes fear and antipathy” that can “often translate into biased and discriminatory actions.”

Far too many people still lack basic knowledge about how HIV is transmitted. According to a 2009 national survey conducted by Kaiser Family Foundation, “levels of knowledge about HIV transmission have not improved since 1987.” In that survey:

- 27% of respondents mistakenly believed that transmission could occur through sharing a drinking glass.
- 17% mistakenly believed that transmission could occur through touching a toilet seat.
- 14% mistakenly believed that transmission could occur through swimming in a pool with someone who is HIV positive.

More than one-third (34%) of respondents held at least one of the above misconceptions about HIV transmission. The pervasiveness of these misconceptions varied by age and was most common among individuals 65 and older, but almost a third (32%) of those aged 18 to 29 years old held at least one of those false beliefs. The percentage of people who incorrectly believe that HIV can be transmitted by sharing a drinking glass is actually higher now than in 1987, and the percentage of people who incorrectly believe that transmission can occur by touching a toilet seat actually rose between 2006 and 2009.

Our HIV education deficit continues to fuel the ostracizing of people living with HIV. For example, the 2009 Kaiser survey found:

- Only 21% reported that they would be very comfortable having their food prepared by someone who is HIV-positive; 51% would be uncomfortable.
- Only 27% reported that they would be very comfortable having a roommate with HIV; 42% would be uncomfortable.
- Only 34% of respondents reported that they would be very comfortable with their child having an HIV-positive teacher; 35% would be uncomfortable.
- Only 44% reported that they would be very comfortable working with someone who had HIV or AIDS; 23% would be uncomfortable.

People who incorrectly believed that certain activities posed a risk for HIV transmission were significantly more likely to say they would be uncomfortable working with someone who has HIV or having their food prepared by someone with HIV.

Similarly, a survey of inmates and staff at a state prison in the southern United States found that inmates and prison staff who had inaccurate beliefs about HIV being transmissible through casual contact were more likely to have stigmatizing reactions to people with AIDS.
Family members of people with HIV reported experiencing avoidance and ostracism by other family members and friends, much of it due to unfounded fears of HIV infection. For example, during interviews conducted in 2004 and 2005 several interviewees reported that family members or friends disposed of utensils used by the person with HIV and/or refused to eat food prepared by the person with HIV.¹¹

HIV DISCRIMINATION IN THE THIRD DECADE OF THE EPIDEMIC

Ignorance about HIV and its transmission fuels stigma; in turn, ignorance and stigma lead to discrimination against PLWH. Although discrimination on the basis of HIV status is illegal in many contexts, such discrimination continues to occur throughout the U.S.

Employment

From FY 2000 through FY 2009, the U.S. Equal Employment Opportunity Commission received 2,175 complaints of discrimination based on HIV. More individuals claimed that they had experienced HIV-related employment discrimination during FY 2009 than in any year since FY 2002.¹² Examples of HIV discrimination in employment include the following.

▪ Bob Hickman was fired from his job at a Las Vegas sandwich shop in 2005 because he had HIV. He disclosed his HIV status in response to a question on a health insurance application and was fired the next day. His employer incorrectly believed that he posed a danger to customers, although medical researchers had determined more than a decade earlier that there is no risk of HIV transmission through food handling. Lambda Legal represented Mr. Hickman in his federal lawsuit.¹³

▪ Cirque du Soleil fired trained gymnast Matthew Cusick in 2003 because it incorrectly believed that his HIV posed a risk of harm to others. Lambda Legal filed a complaint with the EEOC on Mr. Cusick’s behalf. After the EEOC determined that the company likely had engaged in illegal discrimination, the matter settled.¹⁴

▪ Joey Saavedra, a skilled auto-glass installer, was working as a glass installer in Georgia in 2002, when he was fired because he had HIV. His termination notice informed him that the company believed that he posed a direct threat to others because he had HIV. After the EEOC concluded that the firing violated federal antidiscrimination law, Mr. Saavedra filed a federal lawsuit.¹⁵

Health Care

Lambda Legal’s 2009 survey of barriers to health care among LGBT and HIV communities in the United States found that nearly 63 percent of the respondents who had HIV reported experiencing one or more of the following types of discrimination in health care: being refused needed care; being blamed for their health status; and/or a health care professional refusing to touch them or using excessive precautions, using harsh or abusive language, or being physically rough or abusive. Almost 36 percent of those respondents reported that health care professionals had refused to touch them or had used excessive precautions and 19 percent reported being denied care.¹⁶

▪ As reported in 2007, almost 25% of a sample of people living in temporary emergency housing for people with HIV in New York City reported experiencing discrimination in the health care system due to their HIV status. The survey participants were residents of transitional emergency housing for homeless PLWH and thus were particularly vulnerable and in need of consistent HIV care.¹⁷

▪ In 2006, settlement was reached in a civil rights suit involving claims that paramedics refused to provide appropriate care to a man who had HIV. According to the complaint, paramedics responded to a call that John Gill Smith was experiencing chest pains, but then refused to help him into the ambulance after learning he had HIV. The suit was filed by the AIDS Law Project of Pennsylvania and joined by the U.S. Department of Justice.¹⁸

▪ High levels of discrimination against PLWH by health care providers in Los Angeles County were found in three studies conducted from 2003 to 2005. 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 had blanket policy of refusing to provide services to PLWH. Of the providers surveyed, 46% of the skilled nursing facilities, 26% of the cosmetic and plastic surgeons, and 55% of the obstetricians refused to accept any patient who had HIV—and did not have any lawful explanation for their discriminatory practice.¹⁹

Housing and Public Accommodations

▪ Robert Franke, a 75-year-old retired university provost and former minister, was abruptly ejected from an
assisted living facility in Little Rock, Arkansas in 2009 because he has HIV. Representing Dr. Franke and his daughter, Lambda Legal sued the company operating the facility, alleging violations of the ADA and the federal Fair Housing Act, as well as similar state antidiscrimination laws.20

- In the summer of 2007, an RV campground and resort in Alabama prohibited a toddler from using the resort’s common areas – including the swimming pool and showers – because he had HIV. The family, which had planned a month-long stay at the resort, explained that their son’s HIV posed no threat to others, but the facility refused to allow the two-year old full use of the facilities. The U.S. Department of Justice sued the resort operator on behalf of the family.21

- In 2004, a 10-year old boy was denied admission to a basketball camp in Rockland County, New York because he has HIV. The camp claimed that the boy posed a risk to others because he might transmit HIV through his use of the camp toilets or by playing basketball. In 2010, a federal district court rejected those excuses – which were not supported by objective medical evidence – and ruled that the camp had discriminated against the boy in violation of the ADA.22

Discrimination by Federal and State Governments and the Criminal Justice System

- The military imposes a number of limitations on individuals with HIV. For example, the Defense Department has a policy against enlisting into military service anyone who has HIV, and the Army requires that any active duty soldier who tests positive for HIV be barred from serving overseas.23

- The federal government continues to list HIV infection as a condition which will disqualify someone from employment in the U.S. Public Health Service Commissioned Corps.24

- Until recently, the U.S. Foreign Service refused to hire applicants with HIV. Lambda Legal sued the State Department on behalf of Lorenzo Taylor in 2003, challenging the blanket policy against newly-hired foreign service officers with HIV. In 2008, the federal government finally changed that policy and adopted guidelines for the individualized assessment of applicants with HIV required by federal law.25

- After the ACLU filed suit in 2008 on behalf of a veteran denied a job with a State Department contractor because he has HIV, the State Department agreed to policy changes to prevent PLWH from being automatically barred from working under Department contracts.26

People with HIV are subject to prosecutions and/or harsher sentencing for conduct that is not criminal if engaged in by someone who does not have HIV.

- In 2009, Daniel Allen was charged with violating a Michigan bioterrorism statute outlawing the use of harmful biological substances, based on allegations Mr. Allen had HIV and bit a neighbor. That charge was dismissed after his attorney and HIV advocates, including Lambda Legal, explained to the court that the science behind HIV transmission did not support such a charge.27

- In 2006, an HIV-positive man in upstate New York was convicted for aggravated assault on the grounds that his saliva was a dangerous instrument, despite the fact that saliva does not transmit HIV.28

- In recent years there have been many prosecutions across the country based on sexual activity by people with HIV, even when the sexual activity was consensual, there was no intention to transmit the virus, and the activity involved little or no risk of transmission and, in fact, did not result in HIV transmission.29

People living with HIV who enter the state prison systems in Alabama and South Carolina are subjected to multiple forms of discrimination based on their HIV status, which stigmatize them within the prison system. These medically unjustifiable policies include: being excluded from some in-prison jobs; limited (in Alabama) or barred (in South Carolina) from participating in work release programs; isolated and segregated from the general prison population; and forced to wear armbands, badges or uniforms that declare their HIV status to everyone, including visitors to the facilities.30 Not until 2009, after two decades of advocacy by the American Civil Liberties Union, did Alabama end its longstanding ban against any participation by prisoners with HIV in the Department of Corrections work release program.31

Discrimination is Pervasive and Underreported

In addition to the types of discrimination listed above, PLWH experience stigma and discrimination in other aspects of life, including child custody matters, education, and various social settings.
The number of claims filed with administrative agencies and lawsuits filed in courts 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: the expense of litigation; other crises, such as lack of access to housing or medical care; in the lives of many of those affected by HIV; being forced to focus on the indignities that one has experienced and/or to reveal one’s HIV status to others; and the difficulty of proving HIV discrimination. Underreporting of discrimination may be particularly likely among PLWH who are members of historically marginalized communities.32

FURTHER HARMS FROM HIV STIGMA AND DISCRIMINATION

Stigma results in harms – on the individual and societal levels – beyond those resulting from stigma-fueled discrimination.33

Psychological Damage and Depression

Internalized HIV stigma is strongly associated with levels of depression, anxiety and hopelessness.33 A study examining the impact of stigma-related experiences on PLWH confirmed that stigma contributes to psychological adjustment difficulties among individuals with HIV. The researchers found that experiencing higher levels of HIV stigma directly correlated with having symptoms of depression and/or having received psychiatric care in the previous year.34 Depressive symptoms in PLWH have been correlated consistently with treatment nonadherence, suicidal ideation, disease progression and mortality.35

One study of nonmetropolitan PLWH found that “approximately 60% of participants reported moderate or severe levels of depressive symptomatology.”36

A recent study of HIV-positive African-American men found that HIV stigma could have “a huge effect” on reducing quality of life.37

Interviews of multiple family members in families living with HIV conducted in 2004 and 2005 revealed high levels of fear of being discriminated against due to HIV status, which resulted in fears of serostatus disclosure. Those who hid their HIV status from others experienced stress, loneliness and social isolation.38

Deterrent to Accessing Medical Care

Stigma has been linked to delays by HIV-positive individuals in seeking medical care.39 One reason that people do not get tested for HIV is their fear of HIV-related stigma and discrimination.40 A strong association between experiencing HIV stigma and reporting poor access to medical care exists.

Approximately one-third of the participants in a 2007 study of HIV-positive adults in Los Angeles reported experiencing high levels of internalized stigma and those respondents were four times more likely than others to report poor access to health care.41

Studies demonstrate that persons experiencing high levels of stigma are more likely to have suboptimal adherence to their HIV medication regimen.42 In addition, research has shown that faster disease progression is associated with lower levels of social support.43

Public Health Consequences

Failure to get tested for HIV, delays in seeking medical care, failure to obtain such care, nonadherence to antiretroviral treatment, and resulting disease progression all have public health consequences, in addition to harming the individual.44 Negative attitudes towards both HIV and homosexuality have had a detrimental effect on HIV prevention efforts; for example, such attitudes are a contributing factor to low participation by men of color in HIV prevention services.45 The Centers for Disease Control and Prevention’s strategic plan for HIV prevention for the years 2007 to 2010 recognized the continuing importance of interventions to reduce both HIV stigma and discrimination, noting the need “to change the community perceptions that inhibit those at risk from seeking early HIV diagnosis and treatment and adopting healthy behaviors that prevent the spread of HIV.”46

CONCLUSION

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 and on public health in the United States. As the National HIV/AIDS Strategy correctly asserts, “[w]orking to end the stigma and discrimination experienced by people living with HIV is a critical component of curtailing the epidemic.”47 That vital work must include an aggressive and ambitious public education campaign to dispel HIV ignorance and fear; eradication of policies and practices that discriminate against people based on their HIV status; vigorous enforcement of antidiscrimination laws to protect the civil rights of PLWH; and vigilance on the part of all stakeholders. And the work must be undertaken by all levels of government; private businesses; organizations and individuals who serve and advocate for PLWH; and individuals with HIV.

Lambda Legal HIV Project November 2010
antidiscrimination training and altered its employment policies worldwide.

7 Id. at 4, 21 (Chart 27).

9 Id. at 5, 23 (Chart 31).


11 Laura M. Bogart et al., HIV-Related Stigma among People with HIV and their Families: A Qualitative Analysis, 12 AIDS & Behav. 244, 249 (2008).


13 Lambda Legal, Hickman v. Donna Curry Investments, LLC, http://www.lambdalegal.org/in-court/cases/hickman-v-donna-curry-investments.html (last visited Nov. 17, 2010). As part of the settlement reached in 2006, the company agreed to institute new policies and training on HIV issues. Id.

14 Lambda Legal, Matter of Mathew Cusick and Cirque du Soleil, http://www.lambdalegal.org/in-court/cases/matter-of-mathew-cusick-and-cirque-du-soleil.html (last visited Nov. 17, 2010). The settlement – under which Cirque paid $600,000 to Mr. Cusick, initiated companywide antidiscrimination training and altered its employment policies worldwide concerning PLWH – was the largest monetary settlement ever for an HIV-discrimination complaint settled with the EEOC. Id.


32 See, e.g., Mark A. Schuster et al., Perceived Discrimination in Clinical Care in a Nationally Representative Sample of HIV-Infected Adults Receiving Health Care, 20 Journal of General Internal Medicine 807, 809-10 (2005) (reporting lower rates of reporting by Latino and African American respondents compared to white respondents).

33 Rachel S. Lee et al., Internalized Stigma Among People Living with HIV/AIDS, 6(4) AIDS & Behavior 309 (2002); see also, e.g., Waite et al., supra note 3.

34 Peter A. Vanable et al., Impact of HIV-Related Stigma on Health Behaviors and Psychological Adjustment among HIV-Positive Men and Women, 10(5) AIDS & Behavior 473 (2006).

35 Timothy G. Heckman et al., Emotional Distress in Nonmetropolitan Persons Living with HIV Disease Enrolled in a Telephone-Delivered, Coping Improvement Group Intervention, 23(1) Health Psychology 94 (2004) (discussing studies with these findings).

36 Id. at 97.


38 Laura M. Bogart et al., supra note 11 at 248-249.


40 White House Office of National AIDS Policy, supra note 39 at 22-23, 52 (reporting that community members informed the federal Office of National AIDS Policy that HIV stigma deters some people from getting tested); Derlega et al., supra note 10 (finding that prison inmates and staff reported that concern about being treated differently or discriminated against if they tested positive for HIV would influence their decision whether to be tested for HIV); Vanable et al., supra note 34 at 473-74 (summarizing research); Chesney & Smith, supra note 39 at 1159-60; see also Sean D. Young et al., Potential Moral Stigma and Reactions to Sexually Transmitted Diseases: Evidence for a Disjunction Fallacy, 33(6) Personality & Social Psychology Bulletin 789 (2007) (reporting on study finding that people are less likely to get tested for a disease that is perceived as stigmatized).


42 See, e.g., Mahajan et al., supra note 41; Sayles et al., supra note 41 at 1103-05; Waite et al., supra note 3; Lance S. Rintamaki et al., Social Stigma Concerns and HIV Medication Adherence, 20(5) AIDS Patient Care & STDs 359, 364 (2006); Vanable et al., supra note 34 at 478-80.


44 See, e.g., Mahajan et al., supra note 41; Chesney & Smith, supra note 39.


47 White House Office of National AIDS Policy, supra note 1 at 36.