
INCREASING ACCESS TO VOLUNTARY HIV TESTING: THE CONTINUING RELEVANCE OF STIGMA AND DISCRIMINATION

INTRODUCTION

Because an estimated 500,000 people with HIV are not in regular care¹ and an estimated 1 in 4 people with HIV do not know that they have HIV,² there are forceful and compelling arguments for HIV policy change on the federal and state levels. With its revised recommendations for HIV testing in health care settings,³ the federal Centers for Disease Control and Prevention (CDC) rightfully seeks to expand testing in the U.S. As health care providers, government entities and others consider whether and how to implement the CDC's revised recommendations, they should consider the persistence of HIV stigma and discrimination. Although HIV stigma should not prevent the expansion of testing efforts, stigma is a significant factor that must be considered in any HIV policymaking. Contrary to some recent assertions,⁴ the social risks of HIV diagnosis are still multiple and significant.⁵ Because HIV stigma and discrimination continue to have a forceful impact on people with HIV, policymakers must consider how stigma impacts any intervention and how any intervention promotes or attacks stigma.

The CDC acknowledges that stigma and discrimination present profound challenges to disease control and prevention efforts and to people with HIV. For example, the CDC notes that individuals may decline HIV testing because of concerns about “partner violence or potential stigma or discrimination.”⁶ The CDC also cautions that, due to risk of stigma and discrimination, health care providers should not use family or friends as interpreters when providing positive test results.⁷

In some respects, however, the CDC's recommendations do not account adequately for the persistent stigma and discrimination confronting people living with HIV, which is discussed below. Taking a closer look at stigma reveals the need to strengthen the CDC's recommendations in at least three ways:

- 1. Clarify that general consent for medical care is not sufficient to encompass consent for HIV testing.**

In its recommendation regarding consent for an HIV test, the CDC fails to weight adequately the effects of stigma and other factors that make HIV tragically different from most other medical conditions. The CDC's recommendation that “general consent for

medical care should be considered sufficient to encompass consent for HIV testing”⁸ is not appropriate because the risks associated with a positive test result are not at all routine. As the AIDS Coordinating Committee of the American Bar Association has said: “The risks and benefits of an HIV test ... involve complex physical, emotional, social and legal consequences, and thus cannot be encompassed by a general medical consent.”⁹ The American Academy of HIV Medicine (AAHIVM) agrees: “[A] general consent to care does not meet the legal standard of informed consent for agreeing to have an HIV test in most instances.”¹⁰ Localities and health care providers should retain or adopt a requirement of specific consent for an HIV test, including written consent and some verbal or visual communication about HIV¹¹ and the meaning of test results,¹² and ensure that health providers are in compliance with state law regarding informed consent.

2. Ensure that patients tested for HIV have basic information about HIV and its transmission.

Indisputably, stigma advances the HIV epidemic. Fortunately, patient education about HIV and its transmission – including how HIV is not transmitted – can help reduce stigma.¹³ However, the CDC’s revised recommendations underemphasize the utility of patient education about HIV in health care settings. Expanded testing will be most productive if localities retain or adopt laws requiring that basic information about HIV and its transmission be provided to all patients before an HIV test.¹⁴

3. Maintain referrals to legal counseling for those who test positive.

The CDC should recommend, as it did previously, that individuals who test positive be referred to legal counseling on how to prevent discrimination by maintaining confidentiality of HIV test results.¹⁵ Such counseling will reduce opportunities for discrimination and therefore encourage more individuals to be tested. With expanded testing comes greater responsibility; states should ensure that those who test positive have the resources they need to protect themselves.

Finally, it is important to recognize that, although expanded HIV testing is needed and desirable, HIV testing is not a panacea. HIV testing alone will not reduce stigma or debunk HIV transmission myths. Testing will not resolve our social prejudices around sexual orientation and drug use. Merely administering a test will not help a person to know if he or she is at risk for HIV. Further, testing is not an adequate intervention for those who are at high risk for HIV. (In fact, AAHIVM and others have raised a concern that routine screening may have the unintended consequence of affirming current risk behaviors for those who are at high risk but test negative.)¹⁶ Testing is also not an adequate intervention for those who test positive and need care, support, and prevention education. And testing will not guarantee access to treatment. It is clear that we need to do more in all of these areas, not just testing.

STIGMA STILL MATTERS

“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.”¹⁷

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. Confidentiality laws, the Americans with Disabilities Act and state antidiscrimination laws have provided some legal protection and relief against HIV-related discrimination. Further, the introduction of highly active antiretroviral therapy (HAART) in 1996 dramatically increased the life expectancy of those PLWH with access to care. However, too many PLWH in the United States continue to be harmed by stigma and discrimination.

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.¹⁸ We desperately need to expand HIV testing and access to treatment, but in doing so we must be cognizant of the roles that ignorance and prejudice play in fueling the epidemic itself. Moreover, although expanded testing is needed, it has not been shown that widespread testing will reduce stigma that is based on fear of contagion or personal prejudice against marginalized populations such as men who have sex with men and injecting drug users.

THE GENERAL PUBLIC LACKS BASIC INFORMATION ABOUT HIV TRANSMISSION

Far too many people still lack basic knowledge about how HIV is and is not transmitted. According to a 2006 national survey conducted by Kaiser Family Foundation:

- 37% 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.¹⁹

Lack of HIV education fuels stigma against and marginalizes PLWH. For example, the 2006 Kaiser survey also 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.²⁰

To debunk HIV transmission myths, we need to increase funding for prevention and education programs in our communities, our homeless shelters, and our prisons. We also need to provide our youth with medically accurate, comprehensive sexuality education in our schools. And with expanded testing we need to ensure that those who are tested for HIV receive information about how the disease is and is not transmitted.

MORAL JUDGMENT AND PREJUDICE CONTINUE TO PROMOTE MISUNDERSTANDING AND HARM PEOPLE WITH HIV

“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.”²¹

Testing alone is not going to end the significant social prejudice against men who have sex with men, injecting drug users, and other populations disproportionately impacted by HIV. These prejudices are completely intertwined with HIV stigma and advance the epidemic.²²

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.²³ 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.”²⁴
- 48.3% believed that “Most people with AIDS are responsible for having their illness.”²⁵
- And 24.8% believed that “People who got AIDS through sex or drug use have gotten what they deserve.”²⁶

HIV stigma is still linked to homophobia and sexual prejudice. Several national surveys indicate that stigmatizing attitudes towards PLWH appear to be greatest among heterosexuals who also express negative attitudes towards gay people.²⁷

The perception that HIV is a “gay disease” can lead to serious misunderstanding about HIV transmission. A 2005 national study revealed that 33% of male respondents and 46% of female respondents mistakenly believed that HIV transmission could occur through unprotected sex between two *uninfected* men.²⁸ 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 men is in itself dangerous or unhealthy.

HIV stigma also is linked directly to stigma surrounding drug use. Injecting drug users (IDUs) are highly stigmatized and marginalized. One national survey found that 72% of respondents agreed with the statement, “I think people who inject illegal drugs are disgusting.”²⁹ It is also clear that the public associates PLWH with IDUs. At least one study found that negative feelings towards IDUs directly correlated to increased attitudes of stigma towards PLWH.³⁰ The marginalized status of IDUs affects their access to health care. IDUs are less likely to receive highly active antiretroviral treatment than non-IDUs.³¹

HIV DISCRIMINATION CONTINUES TO HAVE A SEVERE IMPACT ON PEOPLE LIVING WITH HIV

We must continue to address HIV discrimination, which remains prevalent. In addition to protecting individual rights and liberties, strong antidiscrimination and confidentiality protections help reduce stigma and discrimination and make it safer for individuals to learn their diagnosis and seek care. Contrary to some assertions,³² stigma around HIV testing itself is not a concern for most people.³³ However, concerns about confidentiality have been identified as a significant reason why some individuals avoid testing.³⁴ Presumably, confidentiality concerns are linked to fears of stigma and discrimination that could result from the disclosure of an individual’s HIV status. Roughly half of those surveyed by Kaiser Family Foundation said that there is a lot of discrimination against people with AIDS.³⁵

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.³⁶ 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.³⁷ We still have a long way to go to meet our goal of ending HIV discrimination.

Amazingly, discrimination persists in the health care system itself. For example, a 2006 study of specific-service health care providers in Los Angeles County found significant evidence of HIV discrimination. 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.³⁸ The findings of a 2005 study measuring levels of discrimination perceived by PLWH corroborate that health care settings remain sites of discrimination. In that study, 26% of adults with HIV believed that they had experienced discrimination by a health care provider since HIV diagnosis.³⁹ When asked which providers had discriminated against them, 54% of respondents named physicians, 39% named nurses or other clinical staff, 31% named hospital staff, and 32% named dentists. Moreover, the researchers noted that these numbers may be low due to underreporting by black Americans and Latinos.⁴⁰

Indeed, 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.⁴¹
- The U.S. Foreign Service refuses to hire applicants with HIV.⁴²
- 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.⁴³

HIV discrimination is also underreported. Unfortunately, the number of claims reported and filed with EEOC represents 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 HIV discrimination may be particularly likely among black Americans and other members of historically marginalized communities.⁴⁴

Further, 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.”⁴⁵

The human impact of stigma is great. HIV stigma is a significant source of psychological damage and depression.⁴⁶ 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.⁴⁷ Internalized HIV stigma is strongly associated with levels of depression, anxiety and hopelessness.⁴⁸

HIV stigma and depression can also deter PLHW from seeking medical care and lead to deterioration in health. Stigma has been linked to delays by HIV-positive individuals in seeking medical care.⁴⁹ Further, at least one recent study has confirmed that a relationship between stigma and treatment nonadherence still exists – with lapses in treatment adherence being associated with more frequent stigmatization and people who missed clinic appointments more likely to report stigma-related experiences.⁵⁰

The psychological damage associated with stigma is also correlated to deterioration in health. Increased levels of depressive symptoms in PLWH have been correlated consistently with increased treatment nonadherence, suicidal ideation, disease progression and mortality.⁵¹ Disturbingly, a 2004 study of nonmetropolitan PLWH found that “approximately 60% of participants reported moderate or severe levels of depressive symptomatology.”⁵² In addition, research has shown a correlation between lower levels of social support and faster disease progression.⁵³

IF HIV TESTING AND THE PROVISION OF POSITIVE TEST RESULTS ARE HANDLED INAPPROPRIATELY, HEALTH CARE PROVIDERS WILL UNDERMINE PATIENT TRUST, INCLUDING AMONG THOSE WHO ALREADY EXPERIENCE ALIENATION FROM HEALTH CARE SYSTEMS

Because HIV stigma and discrimination tragically remain prevalent in today’s society, and have a profound psychological impact on people with HIV from the moment of diagnosis, an HIV diagnosis is in no way routine. Health care providers should not treat an HIV test or diagnosis like they would treat other medical conditions such as hypertension, high cholesterol, and cancer. Using general consent for medical care as license to test for HIV will result in individuals being tested without their knowledge⁵⁴ and could cause psychological harm to the patient, damage the patient-provider relationship, and undermine patient trust in the health care system.⁵⁵

Furthermore, because black Americans, who represent 50% of new infections each year, already experience significant racial prejudice within and alienation from health care systems, the removal of patient protections in HIV testing would be a serious mistake.⁵⁶

- In a 2004 study, black gay and other 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.⁵⁷
- Also, 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*.⁵⁸ 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.⁵⁹

CONCLUSION

We agree that the federal government must reinvigorate its efforts to address the HIV epidemic, particularly given the gross disparities in infection rates in communities of color. We hope that federal agencies and their local partners will adopt policies that account for the stigma and discrimination that still confront people living with HIV and help perpetuate the epidemic. Acknowledging and addressing continued HIV stigma and discrimination within a public health strategy cannot be dismissed as merely a “civil liberties approach.”⁶⁰ A rights-based approach and a public health approach need not and should not be mutually exclusive. A more productive analysis recognizes that addressing stigma, safeguarding individual rights, and preserving human dignity are essential components of any public health strategy to reduce HIV incidence and bring individuals into care.

¹ Institute of Medicine, “Public Financing and the Delivery of HIV/AIDS Care: Securing the Legacy of Ryan White,” 2005. See also Public Health Watch, “HIV/AIDS Policy in the United States: Monitoring the UNGASS Declaration of Commitment on HIV/AIDS,” 2006, at 55.

² Centers for Disease Control and Prevention, “Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings,” *MMWR* 55 (RR14), 1-17 (2006) available at <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5514a1.htm> (hereinafter “CDC, Revised Recommendations”), at 2.

³ CDC, Revised Recommendations.

⁴ See, e.g., Gostin, L.O., “HIV Screening in Health Care Settings: Public Health and Civil Liberties in Conflict?” *Journal of the American Medical Association*, 296(16), 2023-2025 (2006); Frieden, T.R. et al., “Applying Public Health Principles to the HIV Epidemic,” *New England Journal of Medicine*, 353(22), 2397-2402 (2005).

⁵ 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, S. 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. & Capitanio, J., “AIDS Stigma and Sexual Prejudice,” *American Behavioral Scientist*, 42(7), 1126-1143 (1999).

⁶ CDC, Revised Recommendations, at 9.

⁷ CDC, Revised Recommendations, at 10.

⁸ CDC, Revised Recommendations, at 1. The CDC recommends that all HIV testing be informed and voluntary, but also recommends that general consent to medical care should be deemed sufficient consent to HIV testing. This is somewhat of a mixed message. In light of pervasive statements that HIV testing must be voluntary and informed (*see, e.g.*, CDC, Revised Recommendations, at 4, 7, 8), we do not believe the CDC is suggesting that a doctor may test a patient for HIV with nothing more than general consent to treatment. Rather, read together, the CDC is indicating its belief that specific written consent should not be required, but patients must still give their consent to HIV testing.

⁹ Letter from Shelley D. Hayes, Chair, and Richard T. Andrias, Immediate Past Chair, AIDS Coordinating Committee, to Bernard M. Branson, M.D. dated Aug. 22, 2006, *available at* <http://www.abanet.org/AIDS/Letter%20to%20Dr.%20Branson.pdf> (hereinafter “AIDS Coord. Comm. Comments”).

¹⁰ AAHIVM Comments on the Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health Care Settings dated Mar. 27, 2006, *available at* http://64.177.16.246/web/images/stories/pdfs/cdc_testing_aahivm_comments.pdf (hereinafter “AAHIVM Comments”).

¹¹ AAHIVM recommends that patients be told that if they test negative, they will be provided with “referrals to services where you can receive additional information and support to help you stay negative.” AAHIVM Comments, at 5. Patients should also be told that if they test positive, they will receive referrals for counseling, treatment, and prevention. *Id.* Further, patients testing for HIV should be informed about names and transmission category reporting, except in the instance of anonymous testing.

¹² Because typical HIV screening tests do not identify acute HIV infection, when the likelihood of transmission is greatest, pre-test information must include that a test may not detect infections acquired within the six months preceding the test. *See* Pope, M. & Haase, A.T., “Transmission, Acute HIV-1 Infection and The Quest for Strategies to Prevent Infection,” *Nature and Medicine*, 9, 847-852 (2003); Pilcher, C.D. *et al.*, “Acute HIV Revisited: New Opportunities for Treatment and Prevention,” *Journal of Clinical Investigation*, 113, 937-945 (2004); Cates, W. *et al.*, “Primary HIV Infection: A Public Health Opportunity,” *American Journal of Public Health*, 87(12), 1928-1930 (1997); Wawer, M.J. *et al.*, “Rates of HIV-1 Transmission per Coital Act, By Stage of HIV-1 Infection, in Rakai, Uganda,” *Journal of Infectious Diseases*, 191, 403-409 (2005).

¹³ *See, e.g.*, Herek *et al.* (2002).

¹⁴ Some interpret the CDC’s recommendations to suggest that any state laws requiring pre-test counseling of any kind must be eliminated to implement “routine” testing. In fact, the CDC is not recommending that there be no counseling prior to testing, but rather recommends that a very specific form of counseling – focused on individualized risk assessment and reduction – not be provided. Moreover, the CDC recommends that information such as an explanation of HIV infection and the meanings of test results be provided prior to HIV testing. CDC Revised Recommendations, at 2, 7-8, 13.

¹⁵ *See* CDC, “Revised Guidelines for HIV Counseling, Testing and Referral,” *MMWR* 50(RR19), 37 (2001). For a discussion of the CDC’s legal service referral recommendation, *see generally* AIDS Coord. Comm. Comments.

¹⁶ AAHIVM Comments, at 5; Senterfitt, W., “A Test of our Commitment: what it would really take to fix HIV testing,” *HHS Watch*, Sept. 2006, at 2, *available at* <http://www.champnetwork.org/media/HHSWatch0906.pdf>.

¹⁷ Laryea, M. & Gien, L., “The Impact of HIV-Positive Diagnosis on the Individual, Part 1,” *Clinical Nursing Research*, 2(3), 245-266 (1993).

¹⁸ 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).

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- ¹⁹ Kaiser Public Opinion Spotlight, “Attitudes about Stigma and Discrimination Related to HIV/AIDS,” 2006, available at <http://www.kff.org/spotlight/hivUS/index.cfm>.
- ²⁰ Kaiser Public Opinion Spotlight (2006).
- ²¹ Laryea & Gien (1993).
- ²² Devine, P. et al., “The Problem of ‘Us’ Versus ‘Them’ and AIDS Stigma,” *American Behavioral Scientist*, 42(7), 1208-1224 (1999); Herek (1999).
- ²³ 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).
- ²⁴ Kaiser Public Opinion Spotlight (2006).
- ²⁵ Herek et al. (2002).
- ²⁶ Herek et al. (2002).
- ²⁷ Herek et al. (2003); Herek & Capitanio (1999); Herek & Capitanio (1998).
- ²⁸ 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).
- ²⁹ 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).
- ³⁰ Capitanio & Herek (1999).
- ³¹ 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). In a 2005 study, this disparity remained true after adjustment for outpatient utilization, Gebo et al. (2005), which suggests that the disparity cannot be blamed on individual failure to seek treatment.
- ³² See, e.g., *New York Times*, op. ed. (contending that HIV testing consent requirements “beyond the general consent forms signed by patients all too often scares patients away from a test that would help them”) (Sept. 25, 2006).
- ³³ Kaiser Public Opinion Spotlight (2006), see “Perceptions of Whether Stigma Follows Testing.”
- ³⁴ Kaiser Public Opinion Spotlight (2006), see “Reported Reasons for Not Being Tested.”
- ³⁵ Kaiser Public Opinion Spotlight (2006), see “Discrimination Against People with HIV/AIDS.”
- ³⁶ 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).
- ³⁷ “ADA Charges Filed with EEOC” (on file with Lambda Legal); Studdert (2002).
- ³⁸ 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>.
- ³⁹ Schuster et al. (2005).
- ⁴⁰ Schuster et al. (2005).
- ⁴¹ Immigration and Nationality Act, Section 212(a)(1)(A)(i), 8 U.S.C. § 1182(a)(1)(A)(i).
- ⁴² *Taylor v. Rice*, 451 F.3d 898 (D.C. Cir. 2006).
- ⁴³ See, e.g., Ga. Code Ann. § 16-5-60; Mich. Comp. Laws Ann. § 333.5210; Ark. Code. Ann. § 5-14-123.
- ⁴⁴ 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.”).
- ⁴⁵ 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). Some

state confidentiality laws are broader than the law in New York and do prohibit some of the types of disclosures mentioned here.

⁴⁶ Venable *et al.* (2006).

⁴⁷ Venable *et al.* (2006).

⁴⁸ Lee, R.S. *et al.*, "Internalized Stigma Among People Living with HIV-AIDS," *AIDS and Behavior*, 6(4), 309-319 (2002).

⁴⁹ See Chesney & Smith (1999) (discussing research relating stigma to delays in seeking HIV testing and care).

⁵⁰ Venable *et al.* (2006).

⁵¹ 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).

⁵² Heckman *et al.* (2004).

⁵³ 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).

⁵⁴ See, e.g., CDC, "HIV Testing of Pregnant Women – United States and Canada, 1998-2001," *MMWR*, 51, 1013-1016 (2002).

⁵⁵ Studies show that patients' adherence to prescribed treatment correlates with increased physician disclosure. Etchells, E. *et al.*, "Bioethics for Clinicians: 1. Consent," *Canadian Medical Association Journal*, 155(2), 177-180 (1996) (citing Hall, J.A. *et al.*, "Meta-Analysis of Correlates of Provider Behavior in Medical Encounters," *Medical Care*, 26(7), 657-75 (1988)).

⁵⁶ See Hanssens, C., "Racial Disparities in HIV Care and Outcome: A Call for an Evidence Based Response," May 2006, available at

http://www.hivlawandpolicy.org/resources/RACIAL_DISPARITIES_IN_HIV_CARE.pdf (arguing that eliminating patient-provider communication and written proof of informed consent will worsen racial disparities in care).

⁵⁷ 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).

⁵⁸ 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).

⁵⁹ Gebo *et al.* (2005).

⁶⁰ Gostin (2006).