INCREASING ACCESS TO VOLUNTARY HIV TESTING:

THE CONTINUING RELEVANCE OF STIGMA AND DISCRIMINATION

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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

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]

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

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

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.

[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

[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*

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

[46] Vanable *et al.* (2006).

[47] Vanable *et al.* (2006).

[48]