



## **Harlem United Community AIDS Center, Inc.**

*Testimony before the New York State Assembly Social Services Committee*  
*Re: HIV Testing & Counseling*

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I am Executive director of Harlem United Community AIDS Center, Inc., an HIV/AIDS service organization, founded in 1988, which provides healthcare, housing and prevention services, including HIV testing, in upper Manhattan and the Bronx.

I am also a person who has been testing regularly and in a variety of settings for 15 years and, I dare say, that until I found a physician who now routinely tests me in violation of current regulations, I would rather endure multiple dental extractions or even attend a day-long public hearing than endure another mandated pre- and post-test counseling interview.

That being said, 25 years ago, AIDS activists blocked entrance to the offices of the Federal Drug Administration to gain speedier access to potentially life-saving treatments. This meant removing government protections intended to reduce risk. Our mantra then was "Do not let the ideal be the enemy of the good!" as we sought to remove all barriers to care and treatment.

Today, we are discussing the removal of other possible barriers to care and treatment; optional HIV testing, with mandatory pre-test counseling containing certain required elements and a mandatory separate written consent. These HIV testing and counseling protections were put in place when there was more reason *not* to test than to test. Remember that when the HIV/AIDS epidemic started, those suffering from the disease faced both certain death and a high probability of discrimination in employment, housing, and in society, at large. Now, however, the medical and social situations have changed dramatically. HIV/AIDS is a chronic, if manageable disease. Discrimination and social stigma are still prevalent, of course, but they have lessened considerably over the last quarter of a century, while other legal protections against discrimination have been enacted. It is in this very different social, legal, and medical context that changes are being suggested in HIV testing and counseling as part of a movement away from risk-based testing and towards routinized testing.

Certainly, our current healthcare system requires fixing. For example, bias must continue to be attacked, and doctors need much further training in order to be comfortable speaking about sex and drug use with their patients and in eliciting honest discussion of high-risk behavior. While we should insist upon these changes, we must not once again let the ideal become the enemy of the good. This particularly true now for the following three reasons:

- 1) to repeat, effective medical treatment for HIV/AIDS is now available;
- 2) health outcomes for those with HIV/AIDS decline dramatically with late diagnosis; and
- 3) an individual's ignorance of his HIV-positive status contributes to an increased likelihood of his infecting others.

In this latter regard, the federal Centers of Disease Control (CDC) recently presented the results of a study that evaluated potential explanations for why HIV prevalence among black gay and bisexual men (collectively, known as "men-who-have-sex-with-men" or MSM's) in the United States remains dramatically and consistently higher than among other men who have sex with men—despite far fewer sexual partners and risk behaviors.<sup>1</sup>

The theories that have the most empirical support both relate to health care access and knowledge of HIV status—hence their relevance to today's topic of discussion.

Though black men are just as likely as non-blacks to have been tested once for HIV, one study showed they were less likely to be re-tested – i.e. tested as regularly as once a year.<sup>2</sup> Black MSM who are HIV positive tend to test later in their infection than whites and Latinos—and therefore are more likely to be sick and have a poorer long-term prognosis.<sup>3</sup> A 2004 CDC publication presented findings that 66% of black MSM were unaware of their positive status versus 48% of Latinos and only 18% of whites. The picture is even worse among the youngest men – 91% of infected black gay or bisexual men under 22 or younger were unaware of their status versus 60% of whites.

Harlem United recently conducted a survey of 200 residents of east and central Harlem on attitudes towards HIV testing:

- despite the fact that the survey was conducted in 2 neighborhoods with exceedingly high HIV prevalence and incidence, 85% of those surveyed say they are probably not at risk – and presumably not likely to seek out a test.
- 84% cite embarrassment as an obstacle to asking for an HIV test; 82% did not want to be asked about their sexual practices prior to receiving an HIV test.
- 87 % wanted more routine HIV testing.
- 75% would choose to be tested for HIV if tests were easier to obtain .

- 87% said we should treat HIV tests the same as other diagnostic tests.

This survey, and the studies I've cited, reinforce the need to routinize testing—especially re-testing—with as few obstacles as possible. In practice—though not necessarily in theory—current pre-test counseling requirements, which must be documented in the required separate written consent, also entail specialized training of HIV test providers and segregate testing away from other routine medical diagnostic tests. This has the practical effect of reducing the number of individuals who receive HIV testing.

Our current risk-based approach (based on either the patient's own often inaccurate perception of risk or the provider's often equally inaccurate perception of her patient's risk) is not working. Take a look at routine HIV testing during pre-natal care, for example. This initiative has been successful in a context where pregnant women are routinely offered HIV testing while still permitting them to opt out of such testing, should they choose to do so.<sup>4</sup> Furthermore, studies such as ours show both that patients prefer routine testing to risk-based testing<sup>5</sup> and that routine testing decreases the stigma associated with being offered an HIV test and/or with accepting an HIV test.<sup>6</sup>

Current counseling practices need to be changed for successful implementation of routine HIV testing. In practical (not ideal) terms, the performance of routine testing in a setting with high patient volume, such as a primary health care office, does not really allow for extensive pre-test and post-test counseling, regardless of test results. For routine HIV testing to be successful, strategies for connecting those who test HIV positive to care are absolutely key. In-depth counseling should always occur when someone receives a positive HIV test, when counseling is requested by the patient, or when counseling is deemed appropriate by the healthcare provider.

Viewed in isolation from our practice of risk-based testing—with required elements of pre-test counseling in all instances and post-test counseling regardless of results—the mere requirement of separate written consent seems inconsequential. As of today, it is difficult not to view the requirement for a separate written consent as part of a broader HIV prevention strategy that is failing.

To summarize, I would urge that legislative changes should focus upon broader HIV prevention strategies and promote changes that will result in greater routinization of HIV testing and a movement away from specialized and segregated, risk-based HIV testing. As I've made argued, vastly improved medical options should change how we test, identify, and treat those at risk of HIV/AIDS. Harlem United advocates a full paradigm shift in HIV testing and the adoption of universal screening regulations. Needless to say, we also vigorously advocate enforcement and strengthening of laws that penalize discrimination, violations of confidentiality, and testing without consent in order to prevent civil rights abuses.

For more information on Harlem United's prevention, testing, education and outreach programs & related public policy issues, please contact:

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<sup>1</sup> Gregorio Millet PhD, John L. Peterson PhD, Richard J. Wolitski PhD, and Ron Stall, MPH. June 2006, American Journal of Public Health.

<sup>2</sup> Gregorio Millet PhD, John L. Peterson PhD, Richard J. Wolitski PhD, and Ron Stall, MPH. June 2006, American Journal of Public Health.

<sup>3</sup> Gregorio Millet PhD, John L. Peterson PhD, Richard J. Wolitski PhD, and Ron Stall, MPH. June 2006, American Journal of Public Health.

<sup>4</sup> Lindsay MK, Adefris W, Peterson HB, Williams H, Johnson J, Klein L, Determinants of acceptance of routine voluntary human immunodeficiency virus testing in an inner-city prenatal population. *Obstet Gynecol* 1991;78: 678-80.

<sup>5</sup> Hutchinson AB, Corbie-Smith G, Thomas SB, Mohanan S, del Rio C, Understanding the patient's perspective on rapid and routine HIV testing in an inner-city urgent care center. *AIDS Educ Prev* 2004;16:101-14.

<sup>6</sup> Barbacci M, Repke JT, Chaisson RE, Routine prenatal screening for HIV infection, *Lancet* 1991;337:709-11.

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