



**Testimony before the
New York State Black, Puerto Rican,
Hispanic & Asian Legislative Caucus
On Proposed Changes to
NY State HIV Testing, Counseling, and Informed Consent Laws**

**Hadiyah Charles
Community Organizer
HIV Law Project**

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The New York State Black, Puerto Rican, Hispanic and Asian Legislative Caucus

On behalf of the HIV Law Project, I appreciate the invitation to testify before you today at this hearing on written informed consent, pre- and post-test HIV counseling and other proposed statutory changes to Article 27-F.

The HIV Law Project was founded in 1989 in response to the growing need for legal and advocacy services for low-income people living with HIV/AIDS in New York City.¹ In addition to our policy advocacy and impact work, we have handled nearly 20,000 individual legal cases for our clients. Over 92% of our clients are people of color; approximately 34.5% are women; 38% self-identify as Lesbian, Gay, Bisexual or transgender; and 75.6% are new or recent immigrants. The overwhelming majority of our clients receives public assistance and depends on Medicaid or ADAP to obtain access to HIV primary care. Most come from New York City's poorest communities and frequently have few educational, familial and community resources at their disposal.

The HIV Law Project strongly supports the proposition that the earlier more people know their HIV status, the better – both from a clinical perspective and from a behavioral modification perspective. Like all of us here today, we believe it unacceptable that so many people continue to learn of their HIV-status concurrent with an AIDS diagnosis. Thus, we support the expansion of access to routine **voluntary HIV testing** throughout the general population.

The solution, however, should be tailored to the problem while seeking to preserve the rights of individuals to give written, informed consent under Article 27-F of the Public Health Law. Unfortunately, the problem continues to be mischaracterized in order to ramp up testing at the completely unnecessary expense of individual rights.

The Problem

The debate up to this point is a classic example of how a mischaracterized social problem can lead to the development of seriously flawed policy interventions. It should be clear at this point that no one – not even the former Commissioner of New York City Department of Health and Mental Hygiene (DOHMH) – believes that counseling and written informed consent to HIV testing are significant barriers to people consenting to an HIV test. ***The real problem to increasing the rate of early HIV testing and diagnosis is, succinctly put, medical providers' discretion in deciding who should be offered an HIV test.***

There is presently no peer-reviewed study or other evidence to support the proposition that the statutory requirements for written informed consent and counseling under Article 27-F create a real barrier HIV testing uptake by patients. While one or two studies may show a connection between written

informed consent and HIV testing rates, neither of the studies identify the source of the connection. Does a connect exist because doctors do not offer if the test if they have to obtain written informed consent, or that patients decline the test after their medical providers offers the test? Past anecdotal information from the NYC DOHMH supports the proposition that written consent is a barrier to testing actually points to the real problem: the failure of medical professionals to offer their patients HIV tests as a matter of routine medical care. In fact, the NYC DOHMH Commissioner has previously acknowledged that the leading reason people are not learning their HIV status earlier is that medical providers are not offering the test.

The Solution: Mandate the Offering of HIV Tests

We can never hope to achieve the legitimate public health goal of making HIV testing a routine part of medical care without the active involvement of medical professionals in affirmatively offering HIV tests to all their patients on a routine basis. By offering HIV tests just those individuals the provider (mis)perceives to be categorically at risk, the provider is doing his/her patients a severe injustice. Such discretionary basis for offering the test is both over- and under-inclusive, and further helps to create a stigma by singling out certain (already marginalized) individuals.

The Center for Disease Control (CDC) has long recommended that HIV testing for all people, ages 13-64, be integrated as a routine part of medical care – regardless of categorical risk. This policy by the CDC requires medical provider cooperation to be actualized. There are three basic methods for securing wide-spread medical provider cooperation: 1) through education and voluntary changes in clinical practice; 2) statutory changes directed at making the offering of an HIV test a routine part of medical care by licensed providers and in licensed medical facilities; or 3) regulatory change directed at making the offering of an HIV test a routine part of medical care by licensed providers and in licensed medical facilities. Three of the four bill concerning the amendment of Article 27-F propose a statutory change that would mandate the offering of an HIV test.

HIV Law Project strongly supports the mandated offering of an HIV test but vigorously opposes amending Article 27-F to achieve this goal.

Alternative to Proposed Bills to Amend Article 27-F

First, HIV Law Project finds it unacceptable to unnecessarily deprive historically disenfranchised members of our citizenry of rights – the right to receive basic information and the right to give written informed consent – long enjoyed by the majority when the epidemic was largely white and male. Second, the universal offering of HIV tests can be achieved just as easily and effectively through a regulatory change as has been successfully shown in the area of prenatal HIV testing.

Studies assessing the barriers to voluntary prenatal HIV testing reveal several reasons women do not routinely test for HIV. For example, in a study assessing barriers to testing, the most common reasons pregnant women declined to test for HIV were they had no perceived need for the test and they had been tested before.² In another study, women who were not provided information about HIV were an astounding four times more likely to refuse HIV testing.³ These results confirm the well-settled notion that information is power—that, when provided with the knowledge about the risks and benefits of HIV testing and about transmission, exposure, and the need to test periodically, women – and men – will choose to test.

Barriers to routine prenatal HIV testing may also be overcome through recommendations by physicians that all women test for HIV. Not surprisingly, a study assessing barriers to HIV prenatal testing revealed that proportions of women who voluntarily tested increased incrementally with the increased perception that the provider considered testing to be important. Among women who perceived that their provider wanted very much for them to be tested, over 90% opted to test.⁴

Since August 1999 New York State regulations have required medical providers of prenatal services to provide HIV counseling to all pregnant women and recommend HIV testing as a routine part of prenatal care.⁵ If a woman accepts HIV testing, the regulations provide that it be conducted consistent with the requirements of Article 27-F, including written informed consent. Data for 2000 indicates that just one year after the regulations were implemented, voluntary HIV testing among pregnant women increased by 13%.⁶ Rates of voluntary testing among pregnant women are now at an all time high of near 95-96%.

Given the success of this regulatory intervention in increasing the rate of voluntary testing among pregnant women, it should be expanded to cover all medical settings. At worst, medical providers may need to spend a few minutes longer with their patients or develop a process for having such services provided by designated members of their staff. At best, we could achieve near record HIV testing rates while still preserving and protecting the

² Royce, R., Walter, E., Fernandez, I., et al., “Barriers to Universal Prenatal HIV Testing in 4 US locations in 1997.” *American Journal of Public Health* 91 (2001) 727-733.

³ Aynalem, G., Medoza, P., Frederick, T., et al., “Who and Why? HIV-Testing Refusal During Pregnancy: Implication for Pediatric HIV Epidemic Disparity.” *AIDS and Behavior* 81 (2004) 25-31.

⁴ Royce, R., Walter, E., Fernandez, I., et al., “Barriers to Universal Prenatal HIV Testing in 4 US locations in 1997.” *American Journal of Public Health* 91 (2001) 727-733

⁵ Title 10 NYCRR § 405.21(h)

⁶ In 2000, 90% of HIV-infected women giving birth knew their HIV status prior to delivery, up from 77% in 1997 prior to the passage of the regulation. Pulver, Wendy, Glebatis, Donna, Wade, Nancy, et al. “Trends from an HIV Seroprevalence Study Among Childbearing Women in New York State From 1988 Through 2000.” *Archives of Pediatrics & Adolescent Medicine* 158 (2004): 443-448.

rights of individuals to have basic information and give written informed consent.

Recommendations

- Preserve Article 27-F of the Public Health Law in its present form(see HIV Law Project's Guiding Principles for HIV Testing see addendum attached);
- Consider alternate regulatory intervention(s) aimed at requiring all medical facilities and providers licensed by the state to offer all patients – regardless of perceived risk – routine voluntary HIV tests; and
- Institute mandatory continuing professional education for medical providers on the recently streamlined HIV counseling and testing process, and any subsequent changes in regulations in HIV testing.

Conclusion

There is little dispute that we need to develop new public health policies to further prevent the spread of HIV. There is no need, however, to trample the rights of those already most marginalized in our communities in a misguided attempt to “feel” like we are doing something new and therefore better. The HIV Law Project supports the expansion of access to Routine Voluntary HIV Testing. We do not believe it necessary, however, to amend Article 27-F to eliminate certain rights in order to achieve that goal. Sound health policy is consistent with and accounts for individual rights – this is especially true when the health threat is one most often spread by intimate human contact not easily regulated by the State.

We urge you to take our comments and recommendations into consideration as you consider proposals to amend the State's HIV/AIDS law.