The NYCLU strongly opposes S.4484/A.7757 and any piece of legislation that aims to eliminate written consent for HIV testing. The proposed legislation would eliminate important protections that ensure people who choose to be tested for HIV do so with the full knowledge and understanding of the meaning and implications of either a positive or negative HIV test result.

Another bill before the legislature—S.3293/A.7610—would address the same goals without eviscerating patients rights and undermining meaningful communication between health care providers and their patients. Therefore, the NYCLU urges legislators to vote for S.3293/A.7610 (Duane/Gottfried) and against S.4484/A.7757 (Huntley/Robinson).

New York health care providers serve the highest concentration of persons at risk for or living with HIV in the nation. It is therefore important to remove unreasonable burdens that compromise efforts to make HIV testing widely available and efficiently administered. However, the streamlining of HIV testing procedures need not—and should not—require abandoning the informed consent regarding the nature and consequences of a medical test before it is administered.

1 S5660/A 7892A (Monserrat/Towns) and A.4016 (Mayersohn) present the same substantive concerns as A.7757/S.4484.

2 Current New York State Law requires that prior to being tested for HIV, a person to be tested sign a statement consenting to such testing, which includes information about the test, an explanation that the test is voluntary and that anonymous testing is available, and an explanation of the confidentiality protections afforded HIV-related information. N.Y. Public Health Law 2781(2) (McKinney 2007).

3 The NYCLU issued a memorandum in opposition to S.3298 in January 2009. While we still have concerns about the opt-out consent scheme that S.3298/A.7610 adopts, of the two bills, S.3298/A.7610 is the better approach and we hereby amend our position as to this bill, which we now support with qualification.
Great strides have been made in reducing the stigma associated with HIV/AIDS and in treating those with the virus. But a positive test for HIV is a life-altering event, with ramifications unlike those for any other type of medical test. People diagnosed with HIV are still subject to harassment and discrimination in the workplace\(^4\) and in health care settings;\(^5\) still subject to prosecution under criminal laws because of their status;\(^6\) and still subject to extreme social aversion.\(^7\) In light of these facts, the failure to inform and counsel persons tested for HIV is not only unwise, it is irresponsible.

Testing is not an end in itself, but rather a diagnostic intervention that is intended to prevent and treat disease. A majority of experts agree that the most effective public health models for preventing and treating HIV/AIDS, in all racial and ethnic groups, is to empower people through education to join the effort. In short, the goal of such a program is not merely to test, but to reduce the incidence of infection. And this objective may be subverted if HIV testing procedures fail to require written informed consent before administering the test.

I. Eliminating meaningful consent for HIV testing harms marginalized communities

Proponents of eliminating written informed consent from HIV testing point to the disproportionately high HIV/AIDS infection rate among communities of color in New York State. Indeed, of all racial and ethnic groups in New York State, HIV/AIDS hits African Americans the hardest. According to the CDC, blacks accounted for about 44 percent of all

\(^4\) From 2002-2006, HIV-related employment discrimination claims were filed at an average rate of one per day, according to data obtained from the U.S. Equal Employment Opportunities Commission (EEOC). This is only a small decline from the number of claims filed during the period 1994-2001. See ACLU AIDS Project & Lambda Legal, Increasing Access to Voluntary HIV Testing: A Summary of Evidence of the Importance of Specific Written Consent and Pre-test Counseling in HIV Testing (undated), available at http://www.aclu.org/images/asset_upload_file15_30248.pdf.

\(^5\) In a 2005 study published in the Journal of General Internal Medicine, 26% of adults with HIV believed that they had experienced discrimination from a health care provider since being diagnosed with HIV. Mark A. Schuster, et al., Perceived Discrimination in Clinical Care in a Nationally Representative Sample of HIV-Infected Adults Receiving Health Care, 20 J. Gen. Internal Med. 807 (2005). In addition, 56% of the skilled nursing facilities, 26% of the plastic and cosmetic surgeons, and 47% of the obstetricians surveyed in Los Angeles County from 2003-2005 refused to treat any people living with HIV. Brad Sears & Deborah Ho, HIV Discrimination in Health Care Services in Los Angeles County: The Results of Three Testing Studies, The Williams Institute, UCLA School of Law (Dec. 2006), available at http://www.law.ucla.edu/williamsinstitute/publications/Discrimination%20in%20Health%20Care%20in%20Los%20Angeles%20County.pdf.


\(^7\) In a 2006 study, 46% of those surveyed agreed that “people often behaved negatively around them once they learned of their HIV status.” 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 and Behavior 473-482 (2006). In addition, another 2006 study found that only 1 in 4 respondents reported feeling that they would be very comfortable having an HIV+ roommate and only 29% reported that they would be very comfortable with their child having an HIV+ teacher. Kaiser Public Opinion Spotlight, Attitudes About Stigma and Discrimination Related to HIV/AIDS (2006), available at http://www.kff.org/spotlight/hivUS/index.cfm.
AIDS cases in the state through 2007 even though blacks represent only about 17 percent of the state’s population. Latinos account for about 30 percent of AIDS cases but compose only 16 percent of the population. Blacks and Latinos are also more likely to be tested for HIV, but have less access to medical care generally, and HIV treatment in particular. Under the proposed legislation, health care practitioners will no longer be required to explain anything about HIV beyond the fact that they are administering a test.

Reducing required communication between health care providers and their patients will only increase the disparities in access to health education and care. According to a study in New York City last year, more than one third of individuals who test positive for HIV are not linked to care within three months. Those who are less likely to be linked to care included people of color, people in high-poverty areas, and immigrants. Marginalized individuals already mistrustful of the health care system, particularly those living in high risk situations, may lose a crucial connection in counseling, and may be less likely to seek further treatment. Failure to follow-up with treatment after receiving a positive test result can only be addressed by counseling and education provided both before and after testing.

II. Informed consent requires that a patient agree in writing to be tested for HIV

Public health authorities estimate that nearly one-quarter of New Yorkers with HIV do not know that they have the virus. It is appropriate, then, that the current debate over HIV testing has centered on removing barriers to testing. But the analysis of this issue has been flawed by misinformation and distortion.

The argument that requiring written consent creates a barrier to testing is a red herring. Simply requiring health care providers to offer HIV testing would dramatically increase the numbers of people who choose to have the test performed. For example, New York City’s Health and Hospitals Corporation (HHC), the city’s public hospital system, was able to increase the number of patients tested by 63 percent in 2006 by expanding testing sites, increasing the use of

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8 70% of African Americans reported having been tested for HIV and reported a result, compared to 57% of Latinos, and 52% of whites. From 2005-2006, 41% of African Americans, 28% of Latinos, and 16% of whites. Kaiser Family Foundation, *Survey of Americans on HIV/AIDS*, 2006.


10 The informed consent language in the bill reads; “Informed consent to an HIV related test shall consist of informing the person of the purpose of the test and its means while offering an opportunity for questions.”


rapid HIV tests, and streamlining counseling and consent procedures.\textsuperscript{13} They reported that written consent was not a barrier.\textsuperscript{14} Reports of this nature are not unique to New York City. Making testing more routine and streamlining consent procedures has been shown to increase the rates of testing in other states that require written informed consent.\textsuperscript{15}

While the 2006 CDC issuance of revised guidelines for HIV testing provided the impetus for streamlining New York’s HIV testing scheme, the proposed legislation contravenes the CDC’s recommendation that practitioners inform patients of “the risks and benefits of testing [and] the implications of HIV test results.”\textsuperscript{16}

**III. Pre-test counseling is critical to informed consent**

A.7757/S.4484 would eliminate the requirement that health care providers give those who are considering being tested for HIV critical information about the test itself, the benefits of early diagnosis and medical intervention, the availability of anonymous testing, and about confidentiality and anti-discrimination protections that exist for those who test positive.

As a practical matter there is a tension between two important objectives: efficiency versus effective pre-test counseling. In the proposed legislation efficiency trumps informed consent, based on the premise that pre-test counseling is unduly burdensome. However, there is little if any evidence to support this assertion. Several studies have shown that health care professionals do not find pre-test counseling prior to obtaining written consent to an HIV test to

\begin{itemize}
\item \textsuperscript{14} “Written informed consent has not been a significant barrier to achieving exceptional increases in the number of unique patients testing for HIV.” Joanna Omi, “Integration of HIV testing with medical care in a large public hospital system,” New York City Health and Hospitals Corporations, Slide Presentation, Nov. 2008, p. 11, available at www.hivforum.org/storage/hivforum/documents/HIV%20Summit/Presentations/1120_tr_a_3_01_aberg_track.pdf
\item \textsuperscript{16} CDC Revised Recommendations, supra note 15 at 2. The CDC Recommendations define “informed consent” as:

A process of communication between patient and provider through which an informed patient can choose whether to undergo HIV testing or decline to do so. Elements of informed consent typically include providing oral or written information about HIV, the risks and benefits of testing, the implications of HIV test results, how the test results will be communicated and the opportunity to ask questions.
be a barrier to efficiency. In fact, a pre-test counseling session can take as little as five minutes. The success of the HHC in the example above was attributed in part to expanding the number of staff trained to do pre-test counseling, as well as to providing pre-test counseling information in educational videos and pamphlets.

Eliminating counseling requirements will also leave patients without an understanding of the social and legal consequences of the test. Among the pieces of information that practitioners will no longer be required to provide patients is the fact that upon testing positive, the patient’s name is reported to the Department of Health under the HIV Reporting and Partner Notification Law.

IV. Post-test counseling is key to reducing the incidence of infection

The Huntley/Robinson bill eliminates the requirement that health care providers counsel patients who test negative for HIV. This scheme creates a new risk to public safety, and presents an ineffective approach to public health, limiting the ability of health practitioners to stem the spread of infection. An individual being tested under this model would receive no education about HIV prior to testing, and no counseling after the fact. Individuals who have never learned about HIV, its causes and its consequences, may go through the health care system without ever learning what behavior would put them at risk of infection. Consider, for example, a woman with little to no information about HIV transmission who is in a relationship that she mistakenly believes to be monogamous. She is routinely tested for HIV and informed that the result is negative. Under the proposed legislation, she would leave her doctor’s office without receiving any information whatsoever about HIV transmission risks. The one opportunity for reaching someone at risk of HIV would be squandered if the law is amended to eliminate the post-test counseling requirement.


18 “ACTS: Advise, Consent, Test, Support,” provided by the Adolescent AIDS Program at the Children's Hospital at Montefiore Medical Center. Available at http://www.actshivtest.org/.

19 CDC Revised Recommendation, supra note 15 (citing Rothman at 33).


V. Legislators have a better option before them

Legislation sponsored by Senator Duane and Assemblymember Gottfried (S.3293/A.7610) differs from the Huntley/Robinson bill in three key ways: it requires providers to 1) obtain written consent for HIV testing, thereby ensuring that a patient understands that he or she is submitting to the test; 2) provide information on the risks and benefits of an HIV test before performing the test; and 3) provide post-test counseling to all of their patients who are tested, regardless of whether they test positive or negative.

The written consent required by the Duane/Gottfried bill is not a separate affirmative consent, but rather an “opt-out” option on a general medical consent form. The NYCLU strongly believes in maintaining separate, affirmative consent for HIV testing. It is well known that when engaging an individual in a contractual or similar administrative relationship, the most effective way to gain passive acceptance – or inaction – is to offer an individual the choice of “opting out.” Despite this critical flaw, we believe the Duane/Gottfried bill is far superior to the alternative legislation in safeguarding patients’ rights.

Conclusion

It is the position of the NYCLU—a position shared by most health professionals with experience in treating HIV/AIDS—that it is possible to increase the number of people who are tested for HIV without eliminating assurances that people consent to HIV-related testing with full information about what the test means. This involves providing clear, accessible information that treatment is available for those who test positive, that testing is voluntary and can be done anonymously, that the law protects the confidentiality of HIV-related test information, that the state Department of Health has access to HIV-related test information when a person tests positive, that the law prohibits discrimination based on HIV status, and that services are available to those who experience discrimination.

For these reasons, NYCLU opposes A.7757/S.4484, and urges legislators to include in any HIV testing bill (1) a requirement that test subjects consent in writing to testing for HIV; (2) a requirement that essential information regarding the nature and consequence of the test is provided in writing before an individual elects to be tested; and (3) a requirement that individuals who are tested receive information regarding HIV prevention regardless of the test result. For these reasons, the NYCLU recommends that the legislature pass S.3293/A.7610, the Duane/Gottfried bill.

23 For instance, according to a 2002 study conducted by the CDC, nearly 16 percent of pregnant women tested in Arkansas under an opt-out procedure without a written consent requirement did not even know that they had been tested for HIV CDC, HIV Testing of Pregnant Women—United States and Canada, 1998-2001, MMWR 51, 1013-1016 (2002).
24 The NYCLU has been a critic of the Duane/Gottfried bill, and, in fact, we issued our written opposition to this bill in January 2009. Given our recognition of the strong desire across the state to see HIV testing procedures streamlined and incorporated into routine medical care, we now believe that it is time to amend our position on the Duane/Gottfried bill, and we announce our qualified support of the bill and urge legislators to move for its passage. As between those bills that would all but eliminate informed consent to HIV testing and the “opt-out” procedure offered patients in the Duane/Gottfried bill—we endorse the latter approach. For the record, however, we would prefer an amendment to the Duane/Gottfried bill that provides for affirmative, opt-in consent for testing.