

HIV Testing and Informed Consent: Legislative History, Policy and Issues for Consideration

Funders Concerned About AIDS Funders Briefing
March 23, 2010

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Need to “Routinize” HIV Testing

- *One in four New Yorkers living with HIV is unaware of his or her status. Up to 70% of new infections are caused by people who are unaware of their HIV status. How can New York State increase the number of New Yorkers who know their HIV status?*

What New York has done since 2005

- Unacceptably high rates of HIV infection and illness that were ravaging the City's communities of color galvanized calls to action to increase HIV testing and reduce AIDS related deaths.
- The New York City Health Commissioner's 2005 World AIDS Day editorial in the New England Journal of Medicine called for the end of "AIDS exceptionalism" in public health laws and policies.
- CDC developed revised recommendations, issued in 2006, urging states to adopt universal "opt-out" HIV screening in all health care settings.

2005

- New York State DOH also recognized and responded to the need to address HIV testing rates.
- In 2005, NYSDOH simplified and streamlined HIV testing process and consent forms.

2006

- The City's Health Commissioner began pressing for fundamental changes to be made to New York's laws regarding HIV testing, reporting, partner notification, and public health monitoring of people with HIV and AIDS.
- Chief among the changes he advocated were proposals to amend Article 27-F of the Public Health Law to eliminate its current requirement for written informed consent for HIV testing and, instead, adopt CDC recommendations for "opt out" testing.
- CDC "opt out" testing recommendations: allow health care providers to conduct HIV testing with oral (provider-documented) consent.

2006

- In response to these developments, in the spring of 2006 Assembly members Mayersohn and Towns, respectively, drafted and introduced two bills proposing to amend New York's HIV testing law to eliminate its current requirement for written, informed consent for HIV testing.
- Both bills were designed to answer the CDC's call for states to implement universal "opt-out" HIV screening in health care settings.

2006

- LAC conceived of and began promoting consideration of an alternative approach – which has since become known as the “mandatory HIV test offer” approach – to amending Article 27-F.
- LAC proposed to amend the law to make the offer of HIV testing to patients seen in most health care settings a mandatory component of medical care.

2006

- LAC wrote the original language that became the core of Assembly Health Committee Chair Richard Gottfried's first-in-the-nation "mandatory test offer" bill, which Assemblyman Gottfried drafted and began circulating in early 2007.
- Neither the Gottfried bill nor the other bills were passed by the end of the 2006-2007 session.

2007

- A.2095 (Gottfried)/S.6326 (Hannon) was introduced in both the Assembly and Senate in the final days of this year's legislative session.
- This bill would have preserved the requirement for written, informed consent to HIV testing that has been a fundamental provision of the state's HIV testing and confidentiality law since Article 27-F was first enacted in 1988, while simultaneously simplifying and streamlining the testing process and, for the first time requiring, require health care practitioners in many medical settings to offer HIV testing to their patients on a universal basis.
- The sponsors worked closely with DOHMH and City officials and adopted several of the City's recommendations.
- The Assembly passed the bill on the last day of the 2007 session, but the Senate adjourned without taking final action.

2008

- As the legislative session opened in January 2008, the New York State Department of Health (DOH) became actively involved in efforts to promote a sound legislative outcome in the Article 27-F debate.
- The NYSDOH embraced the “mandatory test offer” approach taken by the original Gottfried/Duane bill, and developed its own program bill incorporating those mandatory test offer provisions.
- The DOH then worked closely with LAC, other community-based HIV service providers and advocates in the following months to improve the “mandatory offer” and other key provisions of its draft legislation.

2008

- The legislative session ended in 2008 without enactment of any of the competing bills.

2009

- The 2009 legislative session saw 4 competing bills that were introduced to amend Article 27-F.
 - Duane/Gottfried/NYS DOH bill (A.7610/S.3293)
 - Towns/Monserrate (A.7892/S.5660)
 - Robinson/Huntley (A.7757/S.4484)
 - Mayersohn (A.4016)

What does routine HIV testing look like?

- Since 1996, routine offer of HIV testing in prenatal settings has been standard of care.
- Offer of HIV testing in broad array of GYN/OB settings = women consenting to testing = almost no new Pediatric AIDS cases in the State.
- Testing in these settings is done with written, informed consent as required by current law.

Current Law

NEW YORK STATE DEPARTMENT OF HEALTH
AIDS Institute

Informed Consent to Perform HIV Testing

My health care provider has answered any questions I have regarding HIV testing and has given me written information with the following details about HIV testing:

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- HIV is the virus that causes AIDS.
- The only way to know if you have HIV is to be tested.
- HIV testing is important for your health, especially for pregnant women.
- HIV testing is voluntary. Consent can be withdrawn at any time.
- Several testing options are available, including anonymous and confidential.
- State law protects the confidentiality of test results and also protects test subjects from discrimination based on HIV status.
- My health care provider will talk with me about notifying my sex or needle-sharing partners of possible exposure, if I test positive.

I agree to testing for the diagnosis of HIV infection. If I am found to have HIV, I agree to additional testing which may occur on the sample I provide today to determine the best treatment for me and to help guide HIV prevention programs. I also agree to future tests to guide my treatment. I understand that I can withdraw my consent for future tests at any time.

For pregnant women only:

In addition to the testing described above, I authorize my health care provider to repeat HIV diagnostic testing later in this pregnancy. I understand that my health care provider will discuss this testing with me before the test is repeated and will provide me with the test results. The consent to repeat diagnostic testing is limited to the course of my current pregnancy and can be withdrawn at any time.

Signature: _____ Date: _____
(Test subject or legally authorized representative)

If legal representative, indicate relationship to subject: _____

Printed Name: _____

Medical Record #: _____

Except for expedited HIV testing on labor units, this form replaces other HIV testing consent forms as of June 1, 2005.

NOTE: this form is intended to be used in conjunction with DOH-2556I, Part A.

DOH-2556 (5/05)

Stand-alone or combined consent works

- Written, informed consent can be part of a general consent form under current NYS law.
- NYC DOHMH uses this kind of consent form in all STD clinics and elsewhere.
- See NYC DOHMG STD/HIV consent form.

Currently Approved Wording:

I hereby grant permission to the New York City Department of Health and Mental Hygiene to obtain specimens, perform tests and/or procedures including HIV testing unless I decline below, administer treatment, and release information to Medicaid or other third-party health care reimbursers if the information is necessary to pay for my medical care. Any questions I have regarding HIV testing have been answered, and I have been provided information with the following details about HIV testing:

- HIV is the virus that causes AIDS.
- The only way to know if you have HIV is to be tested.
- It is important for you and your medical provider to know your HIV status to properly care for you and prescribe the right drugs for you.
- HIV testing is voluntary. Consent can be withdrawn at any time.
- Several testing options are available, including anonymous testing.
- State law protects the confidentiality of HIV test results and also protects persons from discrimination based on HIV status.
- Your provider will talk to you about notifying your contacts of possible exposure, if you test positive.

I agree to testing for the diagnosis of HIV infection. I will be informed if a diagnostic HIV test is ordered. If I am found to have HIV, I agree to additional testing to determine the best treatment for me and to help guide HIV prevention programs. I understand that I can withdraw my consent for future tests at any time.

Patient:

Date:

Witness:

Check box and sign below if you are requesting that the HIV test not be performed. You may request HIV testing in the future.

I DO NOT want an HIV test at this time. Signature _____