HIV/AIDS TESTING, CONFIDENTIALITY & DISCRIMINATION

WHAT YOU NEED TO KNOW ABOUT NEW YORK LAW



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HIV/AIDS TESTING, CONFIDENTIALITY & DISCRIMINATION

WHAT YOU NEED TO KNOW ABOUT NEW YORK LAW

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The Legal Action Center wishes to thank the AIDS Institute of the New York State Department of Health, whose generous support made this manual possible, and has enabled the Center to provide legal assistance, training, and technical assistance to New Yorkers concerned with HIV/AIDS for more than two decades.

FOREWORD

The Legal Action Center has written this manual to help health and social service providers and individuals in New York State navigate some of the complex legal and practical issues raised by the HIV/AIDS epidemic: HIV testing, confidentiality, and discrimination.

The Legal Action Center is a leading expert in New York on these issues. The Center has authored many publications and provided training and advice to thousands of agencies and individuals throughout the state on the laws governing HIV testing and confidentiality and protecting people from HIV-based discrimination. The Center also provides legal representation to HIV-positive individuals on these issues. The Center is the only non-profit law and policy organization in the country whose mission is to fight discrimination against and protect the dignity of people with HIV/AIDS, alcohol/drug histories, and criminal records.

QUESTIONS ABOUT TOPICS IN THIS MANUAL?

CALL THE LEGAL ACTION CENTER, (212) 243-1313 or (800) 223-4044.

The Center offers FREE legal advice and help about HIV-related issues to HIV-positive individuals and their families as well as their service providers. Call (212) 243-1313 for information. Many of the Center's training materials are available at www.lac.org (click on "free publications" and/or "training/technical assistance").

Helpful resources are also available from —

NEW YORK STATE DEPARMTENT OF HEALTH, AIDS INSTITUTE http://www.health.ny.gov/diseases/aids/

The AIDS Institute also has an HIV confidentiality hotline at (800) 962-5065.



SUPPLEMENT to

HIV/AIDS Testing, Confidentiality & Discrimination: What You Need to Know About New York Law September 2024

Summary

New York's HIV confidentiality and testing law has been amended several times since this manual was published in 2012. Key changes include:

- Eliminating the requirements for "informed consent" and written consent for an HIV test.
- Eliminating the requirement to be "orally advised" about the performance of an HIV test, and replacing it with the requirement to, "at a minimum," be provided "notice" by means accessible in many languages, which could be orally, in writing through prominent signage, electronically, or through other communications.
- Eliminating the requirement to be informed about the option for anonymous HIV testing; if individuals *request* information about anonymous testing, referrals to anonymous test sites must be provided.
- **Adding a requirement that post-test counseling** include information about pre- and post-exposure prophylaxis medications to prevent HIV infection.
- **Changing the age for the mandatory test offer** to 13 and over.
- Adding exceptions to the non-disclosure rule, to allow-
 - the Department of Health to use and redisclose HIV-related information for purposes of linkage, retention in care, and care coordination, and
 - o confidential HIV-related information to be disclosed to medical researchers in some circumstances.

Health Department regulations also were amended in April 2017 to enable minors to consent to HIV treatment and prevention.

Updates To the Text of the Manual

The following updates supplement the Legal Action Center's book, *HIV/AIDS Testing, Confidentiality & Discrimination: What You Need to Know About New York Law:*

Part 1 – HIV Testing

Pages 2-3: **Definitions**

The section entitled "**informed consent to HIV testing**" should be deleted because Article 27-F no longer specifically requires "informed consent" to an HIV test.

Page 4: Sec. I.A. – Basic Rule

Article 27-F establishes the general rule that no individual may be given an HIV test –

- 1. unless the person ordering the test first provides, at a minimum, "notice by means readily accessible in multiple languages" to the person undergoing the test (or the person authorized to make health care decisions for that person) that an HIV-related test is being performed; such notice may be provided "orally, in writing by prominently displayed signage, by electronic means or other appropriate form of communication." The notice must include information that HIV testing is voluntary.
- 2. over the objection of the person being tested (or person authorized to make health care decisions for that individual); or
- 3. without required pre-test information (details are on page 13).

Refusal of an HIV-related test must be noted in the medical record. Situations where individuals may be subject to an HIV test without notice are outlined in Part 1, Sec. III.

Pages 4-5: Sec. I.B.2 – Confidential Testing

Confidential testing means that the health care provider that orders or performs an HIV test will collect identifying information about the person tested and will record it and HIV-related counseling and testing information (including the test request and results) in the individual's medical record. The testing is "confidential" because the information is protected by law from unauthorized disclosure. If a confidential HIV test is positive, the state's HIV/AIDS case reporting law requires that the person's name and diagnosis be reported to the State Department of Health (see page 51).²

However, all providers who are not authorized to conduct anonymous testing — except in the insurance context noted below — must refer those who request anonymous testing to such a site.³

¹ N.Y. Pub. Health Law §§ 2781(1)-(2).

² N.Y. Pub. Health Law § 2130.

³ N.Y. Pub. Health Law § 2781(4).

Page 5: Sec. I.B.3 – Insurance: no anonymous option

Insurers may legally ask people applying for life insurance to undergo an HIV-related test as a condition of applying for coverage. Although applicants are theoretically free to refuse testing, their application for insurance will probably be denied unless they consent.

People who are tested in connection with insurance applications are not required to receive referrals to anonymous testing, upon request,⁴ and the counseling requirements are less stringent than those in Article 27-F. ⁵ However, people cannot be tested for insurance purposes without written informed consent – a requirement that is no longer in Article 27-F. ⁶

If applicants for insurance are tested, their identifying information and their HIV test results will go to the insurance company — and to a centralized computer, the Medical Information Bureau (MIB), to which most other insurance companies have access. Although the law requires insurers reporting to the MIB to use general codes to indicate "abnormal blood test" results (rather than reporting the specific HIV test result), those codes are generally understood and can be further investigated by other potential insurers. ⁷

One way to deal with this dilemma is for persons who want to apply for life insurance to undergo an anonymous HIV test before they begin the insurance application process. Then, knowing their test results, they can decide whether or not to go ahead with the application.

Pages 9-10: Sec. I.C.4.b.iv – Minors: Consent to HIV Treatment and Prevention

Since April 12, 2017, minors have been able to consent to their own HIV treatment and prevention. Previously, minors with capacity to consent could consent to their own HIV test, but not to treatment. However, in 2017, amendments to New York State Department of Health regulations re-classified HIV as a sexually transmitted infection (STI). Because New York law permits minors to consent to their own treatment and prevention of STIs, by extension, minors can now consent to their own treatment and prevention of HIV.

Page 12: Sec. I.D – Pre-Test Information Requirements

1. General rule -

Before anyone decides whether to consent to any HIV-related test, that person must receive the information about HIV required by the Public Health Law. This information must be provided "either orally or by prominently displayed signage, by printed materials, by electronic means or other appropriate form of communication. If the

⁴ N.Y. Pub. Health Law § 2781(4).

⁵ N.Y. Pub. Health Law § 2611(b).

⁶ Id.

⁷ N.Y. Ins. Law § 321(d).

⁸ N.Y. Pub. Health Law § 2305(2).

individual lacks capacity to consent, the information must be given to the person authorized by law to consent on his/her behalf.⁹ (The exceptions to the general rule requiring this information, and the special rules that apply to applicants for insurance, are discussed at pages 20-23.)

2. Content of required information

Prior to testing, the following information must be provided:

- 1. HIV causes AIDS and can be transmitted through sexual activities and needle-sharing, by pregnant women to their fetuses, and through breast feeding infants;
- 2. there is treatment for HIV that can help an individual stay healthy;
- 3. individuals with HIV or AIDS can adopt safe practices to protect un-infected and infected people in their lives from becoming infected or multiply infected with HIV:
- 4. testing is voluntary and can be done anonymously at a public testing center;
- 5. the law protects the confidentiality of HIV related test results;
- 6. the law prohibits discrimination based on an individual's HIV status and services are available to help with such consequences;
- 7. the law requires that an individual be notified before an HIV-related test is performed, and that no test shall be performed over their objection;
- 8. pre- and post-exposure prophylaxis medications (PrEP and PEP) are available to protect persons at risk of HIV infection. ¹⁰

Page 13: Sec. I.E. -- Consent for an HIV Test

[Sections 1 (Rapid HIV Testing), 4 (Duration of Consent to an HIV Test, and 5 (Revoking Consent to an HIV test) from the 2012 manual should be deleted]

1. HIV Testing Generally

Individuals must be notified prior to being subject to an HIV test, and the test cannot be performed over their objection. Individuals do not have to affirmatively consent to the test, however. They merely need to be notified and not object.¹¹

Notification does not need to be oral. As noted in the discussion on page 4, "at a minimum," it may be provided "orally, in writing by prominently displayed signage, by electronic means or other appropriate form of communication. Such notice shall include information that HIV testing is voluntary. ¹²

2. People with Language Barriers

It is imperative that the notification of an HIV test (regardless of whether it is oral, written, or through other means), which contains the required pre-test information, be

¹¹ N.Y. Pub. Health Law § 2781(1).

⁹ N.Y. Pub. Health Law § 2781(2).

¹⁰ *Id*

¹² N.Y. Pub. Health Law §§ 2781(1)-(2).

in a language understood by the individual being tested (or person authorizing health care). ¹³ The Department of Health, AIDS Institute, website has "expect the test" and other materials in several languages.

Page 15: Sec. F.1

1. General Rule

a. Positive Test Results

Post-test counseling (or referral for such counseling) must be provided whenever a test indicates evidence of HIV infection. The counseling must be provided to a person who has been tested, or if the individual tested lacks capacity to consent, then to the person who provided consent and, to the extent it is beneficial, to the person tested.57 While Article 27-F does not mandate that post-test counseling always be done in person, good, sensitive practice generally requires it when the test is positive.

Post-test counseling for *confirmed* positive results must include information about:

- 1. how to cope with the emotional consequences of learning the result;
- 2. discrimination that could result from disclosure of the test result;
- 3. the importance of precautions to prevent HIV transmission to others;
- 4. the ability to release or revoke the release of confidential HIV-related information;
- 5. HIV reporting requirements for epidemiologic monitoring of the HIV/ AIDS epidemic;
- 6. the importance of notifying contacts in order to prevent transmission and to allow early access to HIV testing, health care and prevention services, and a description of notification options and assistance available; though not required, providers should advise people that their refusal to reveal contacts or otherwise cooperate with contact notification efforts is not illegal, and there are no penalties for not providing contacts' names; 14
- 7. an assessment of the risk of domestic violence resulting from notification of any partner will be assessed, through a domestic violence screening conducted during post-test counseling (pages 54-60 discuss the contact reporting and notification rules);
- 8. the requirement that known contacts (including a known spouse) will be reported and that protected persons will also be requested to cooperate in contact notification efforts and may name additional contacts they wish to have notified with the assistance of the provider or authorized public health official;
- 9. that the tested person's name or other identifying information is not disclosed to anyone during the contact notification process;
- 10. the provider's responsibility for making an appointment for newly diagnosed persons to receive follow-up HIV medical care (discussed below);

¹³ N.Y. Pub. Health Law § 2781(1).

¹⁴ N.Y. Pub. Health Law § 2136.

- 11. available medical services, including the location and telephone numbers of treatment sites, information on the use of HIV medications for prophylaxis and treatment and peer group support, access to prevention services and assistance, if needed, in obtaining these services;
- 12. prevention of perinatal transmission;
- 13. the importance of remaining in care to maintain good health and reduce the likelihood of transmission to others, and that if the individual appears not to be receiving HIV medical care, health care providers, entities engaged in care coordination or local and state health departments may contact them to help address challenges or barriers that may be affecting their ability to initiate and remain in care; and
- 14. pre- and post-exposure prophylaxis medications available to sexual partners to prevent HIV infection. ¹⁵

b. Negative test results.

When a test does not indicate evidence of HIV infection, the subject of the test (or, if the subject lacks capacity to consent, to the person authorized to consent to health care for that person) must be provided with information concerning the risks of high-risk sexual or needle-sharing behavior and pre- and post-exposure prophylaxis medications available to prevent HIV infection. The negative result and required information may be provided in-person, by mail, electronic messaging, or telephone, provided that patient confidentiality is reasonably protected. The information concerning behavior risks may be given by oral or written reference to materials previously provided. ¹⁶

Part 2 – Confidentiality and Disclosure of HIV-Related Information

Page 52: Sec. III.E.3 – When the Report Must be Made

The report of a determination or diagnosis of HIV, HIV-related illness, and AIDS must be made "as soon as possible but no later than seven (7) days after the provider's receipt of a positive laboratory result or after diagnosis, whichever is sooner." Acute HIV infection must be reported within 24 hours of the determination or diagnosis. 18

Page 53: Sec. III.E.6 – Confidentiality of Case Reports

State and local public health officials must keep confidential all reports and information they obtain in connection with case reporting and contact notification activities, with limited exceptions. They may only use the information:

o to track and monitor the HIV epidemic or facilitate partner notification efforts (where merited to protect public health); and

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¹⁵ N.Y. Pub. Health Law § 2781(5)(a); 10 N.Y.C.R.R. § 63.3(e).

¹⁶ N.Y. Pub. Health Law § 2781(5)(b); 10 N.Y.C.R.R. § 63.3(f).

¹⁷ 10 N.Y.C.R.R. § 63.4(a)(1).

¹⁸ *Id*.

o for patient linkage and retention in care.

They may only re-disclose the information:

- within New York State: (1) to other public health officials if, in the public health official's judgment, the disclosure is necessary for monitoring the HIV/AIDS epidemic, to conduct notification activities (see page 56), or for purposes of patient linkage and retention in care; and (2) to health care providers currently treating the patient for purposes of patient linkage and retention in care.
- outside New York State: contact names and locating information may be disclosed to public health officials in other states if necessary to notify the contact or for purposes of de-duplication, but the identity of the protected individual may not be disclosed.¹⁹

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¹⁹ N.Y. Pub. Health Law §§ 2134; 2135; 10 N.Y.C.R.R. § 63.4(c).

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INTRODUCTION

APPLICABLE LAWS AND REGULATIONS

Article 27-F of the New York State Public Health Law (N.Y. Pub. Health Law §§ 2780-2787) regulates virtually all HIV-related testing of individuals in New York state. It also establishes the basic rules regarding confidentiality of HIV-related information (see Part 2). Article 27-F, commonly called the HIV Testing and Confidentiality Law, went into effect in 1989 and has been amended several times. Section 2781 of this law establishes the basic rules regarding HIV testing. New York's 1998 HIV Reporting and Partner Notification Law (Public Health Law Article 21, Title III, §§ 2130-2139), whose rules went into effect in June 2000 and have since been amended, also contains provisions that affect HIV testing.

The State Department of Health is the "lead agency" responsible for setting statewide standards for and implementing these laws. Its regulations on HIV Testing, Reporting and Confidentiality of HIV-Related Information are contained in 10 New York Code of Rules and Regulations ("N.Y.C.R.R.") Part 63. The state agencies that monitor or fund most health and social service providers in New York have also issued regulations implementing the requirements of Article 27-F. Health and human service providers must become familiar with both the law and the regulations that apply to them. The Department of Health has a comprehensive website that provides additional materials about these laws at www.health.ny.gov/diseases/aids/regulations.

A separate law (Insurance Law § 2611) governs some aspects of HIV testing for insurance purposes. Its special rules are discussed below.

POLICY UNDERLYING ARTICLE 27-F

Testing rules

One of the major purposes of Article 27-F is to encourage individuals to come forward voluntarily for HIV testing, so that they can —

- make decisions about appropriate treatment, if infected with HIV; and
- change the behavior that puts themselves or others at risk of contracting or transmitting HIV infection.

The law reflects a legislative recognition that the most effective strategy to promote both the public health and individuals' health encourages individuals to make voluntary, informed decisions about HIV testing. The Legislature determined that the best way to accomplish this is to ensure that individuals have the option of being tested either anonymously or confidentially, get information prior to the test and post-test counseling, and receive assurances of confidentiality.

Confidentiality protections

When it enacted Article 27-F, the Legislature also said that strictly protecting the confidentiality of HIV testing and other HIV-related information about individuals is needed to limit the risk of discrimination and harm to an individual's privacy that may result from the inappropriate disclosure and misuse of that information. The law's confidentiality and disclosure rules are intended to do this.¹

KEY DEFINITIONS

"HIV-related test or testing" means any laboratory test(s) or series of tests approved for the diagnosis of HIV. This includes HIV antibody tests (which indirectly reveal HIV by looking for its antibodies) and viral load tests (including a PCR, or polymerase chain reaction, test), which directly detect the HIV virus. This manual refers to all of these tests as "HIV tests."²

Note that the definition of "HIV-related test" does not include CD4 or T-cell tests, because they are used to check an individual's immune system; they do not detect the HIV virus itself. So Article 27-F's HIV test consent and counseling requirements do not apply to these tests. The law often does protect the confidentiality of this information, though (see page 25).

"Rapid HIV test or testing" means any laboratory screening test(s) approved for detecting antibodies or antigens to HIV that produces results in no more than sixty minutes and includes a confirmatory HIV related test if the screening test is reactive.³

"Capacity to consent" means an individual's ability, determined without regard to age —

- to understand and appreciate the nature and consequences of a proposed health care service, treatment or procedure (i.e., HIV test) or proposed disclosure of confidential HIV-related information, and
- to make an informed decision about whether to allow the proposed HIV test or disclosure.⁴

Pages 5-12 explain how this applies to HIV testing, and pages 39-41 explain how it applies to disclosures of HIV-related information.

¹ L. 1988, c. 584, § 1.

² N.Y. Pub. Health Law§ 2780(4).

³ N.Y. Pub. Health Law § 2780(4-a).

⁴ N.Y. Pub. Health Law § 2780(5).

Informed consent to HIV testing means a decision to allow HIV testing to be done, made after the person to be tested (or individual authorized pursuant to law to consent to health care for that person) has been given information the law requires be given to enable an informed decision to be made about whether to allow the HIV test to be performed.⁵

- **Oral informed consent** means consent provided orally for a rapid HIV test. Such consent shall be documented in the test subject's medical record by the person ordering the performance of the test.⁶
- **Written informed consent** means consent provided in a statement consenting to HIV related testing signed by the subject of the test who has capacity to consent or, when the subject lacks capacity to consent, by a person authorized pursuant to law to consent to health care for the subject after the subject or such other person has received the information described in the law.⁷

"Authorized pursuant to law to consent to health care" for another individual refers to a person who has specific legal authority to make health care decisions for the other person. The practical meaning and application of this term is explained in the sections of this manual that discuss "capacity to consent" for purposes of testing and disclosures (see pages 5-12 and 39-41).

⁵ N.Y. Pub. Health Law § 2781(1),(2),(2-a-2-c),(3).

⁶ N.Y. Pub. Health Law § 2781(1).

⁷ N.Y. Pub. Health Law. § 2781(3).

I. GENERAL RULE: NO HIV TESTING WITHOUT INFORMED CONSENT

A. BASIC RULE

Article 27-F establishes the basic rule that no individual may be given an HIV test unless that individual first:

- is told about and given the opportunity to choose either *anonymous or confidential* HIV testing;
- receives pre-test information the law requires be given to enable the person tested to make an informed decision about whether to be tested; and
- then gives voluntary, informed consent to be tested, either orally (for rapid testing only) or in a signed, written consent (in all cases except in rapid HIV testing).8

If the person to be tested lacks "capacity to consent" to the HIV test (see discussion at pages 5-12), then the requirements for testing must be directed to the person authorized by law to consent to health care for the patient instead of the patient. The following sections explain each of these concepts and requirements.

B. ANONYMOUS OR CONFIDENTIAL TESTING

1. ANONYMOUS TESTING

Anonymous testing means that no information linking the individual's identity to the test request or results will be gathered or kept. Records and blood specimens are identified by codes, not names. The results of anonymous HIV tests are not reported to the State Department of Health (see page 53).

Only public health agencies may offer anonymous counseling and testing. The main anonymous counseling and testing sites in New York are:

- New York City Department of Health Anonymous HIV Counseling and Testing Sites (call 311 or 212-639-9675 for the site locations) and
- New York State Department of Health Anonymous HIV Counseling and Testing Sites (call 1-800-541-AIDS for the sites in your area).

2. CONFIDENTIAL TESTING

Confidential testing means that the health care provider that orders or performs an HIV test will collect identifying information about the person tested and will record it and HIV-related counseling and testing information (including the test request and results) in the individual's medical record. The testing is "confidential" because the information is protected by law from unauthorized disclosure. If a confidential HIV test is positive, the state's HIV/AIDS case reporting law requires that the person's name and diagnosis be reported to the State Department of Health (see page 51).¹⁰

⁸ N.Y. Pub. Health Law § 2781.

⁹ N.Y. Pub. Health Law § 2781(4).

¹⁰ N.Y. Pub. Health Law § 2130.

Most health care providers (except those listed above) can only offer confidential testing on site. However, all providers — except in the insurance context noted below — must either directly or through a representative inform every person considering testing that anonymous testing is available, and must refer those who wish to be tested anonymously to such a site.¹¹

3. INSURANCE: NO ANONYMOUS OPTION

Insurers may legally ask people applying for health or life insurance to undergo an HIV-related test as a condition of applying for coverage. Although applicants are theoretically free to refuse testing, their application for insurance will probably be denied unless they consent.

People who are tested in connection with insurance applications are not required to receive the option of anonymous testing. Less stringent counseling and informed consent requirements than those in Article 27-F apply. 13

If applicants for insurance are tested, their identifying information and their HIV test results will go to the insurance company — and to a centralized computer, the Medical Information Bureau (MIB), to which most other insurance companies have access. Although the law requires insurers reporting to the MIB to use general codes to indicate "abnormal blood test" results (rather than reporting the specific HIV test result), those codes are generally understood and can be further investigated by other potential insurers.¹⁴

One way to deal with this dilemma is for persons who want to apply for insurance to undergo an anonymous HIV test before they begin the insurance application process. Then, knowing their test results, they can decide whether or not to go ahead with the application.

C. CAPACITY TO CONSENT TO AN HIV TEST

Article 27-F establishes the basic rule that any person with the "capacity to consent" has the right to decide whether to take an HIV test.

1. WHAT IS "CAPACITY TO CONSENT"?

Age, by itself, does not determine whether a person has "capacity to consent" to an HIV test (defined at page 2)¹⁵. An individualized assessment of capacity should be made in each case, by asking these two questions:

- Is this person able to understand and appreciate the nature and consequences of undergoing an HIV test?
- Is this person able to make an informed decision about whether to be tested?

If the answer to both of these questions is yes, then the individual has capacity to consent and the right to decide whether to be tested.

 $^{^{11}}$ N.Y. Pub. Health Law $\S~2781(4).$

¹² Id.

¹³ See N.Y. Ins. Law § 2611 and pages 22-23.

¹⁴ N.Y. Ins. Law § 321(d).

¹⁵ N.Y. Pub. Health Law § 2780(5).

2. WHAT TO DO IF SOMEONE LACKS CAPACITY TO CONSENT?

If the person lacks capacity to consent to an HIV test based on the two-part test, above, then those with responsibility for assessing the individual's capacity should either:

- determine whether another person is legally authorized to consent to health care for the individual. Possibilities include the parent/guardian of a minor (see pages 6-10), "agent" designated through a health care proxy (see page 11), "surrogate" selected to make decisions under the Family Health Care and Decisions Act (see pages 11-12); or court appointed guardian (see page 10); or
- defer or decide against testing of the individual in question.

Whenever a question arises about a particular individual's capacity to consent to an HIV test, the provider should document in the medical record that an assessment of capacity was done and, if the individual is deemed to lack capacity, the reasons for that conclusion.

3. WHO ASSESSES CAPACITY TO CONSENT?

Article 27-F does not specify who determines whether a person has the capacity to consent to an HIV test. All health and human service agencies that offer on-site HIV testing should designate the staff with responsibility for making such assessments.

Note, however, that if the provider believes that the patient does not have capacity to consent to an HIV test and wants to invoke the provisions of the health care proxy law or Family Health Care Decisions Act so that someone else can authorize the test (see pages 11-12), additional procedures are required, including the involvement of an attending physician (see pages 11-12).

4. APPLICATION TO SPECIFIC GROUPS: MINORS, PEOPLE ADJUDICATED INCOMPETENT, AND OTHER INDIVIDUALS WITH IMPAIRMENTS

a. NEWBORNS, INFANTS AND VERY YOUNG CHILDREN

i. DO THEY HAVE CAPACITY?

Infants and very young children will not have the capacity to consent to an HIV test because they lack the ability to understand or make an informed decision about the test. Except for newborn testing (which is done whether or not the mother consents, as explained at page 20), the following rules apply to infants and young children.

ii. WHO MAY CONSENT ON THEIR BEHALF?

The "person authorized pursuant to law to consent to health care for such [child]" has the sole right to consent to testing of the infant or young child.¹⁶

In intact families, the birth parent(s) of the child generally have the legal authority to consent to health care for the child. This is so even if the parent is

¹⁶ N.Y. Pub. Health Law § 2781(1)

also a minor.¹⁷ Thus the consent must be signed by a parent or in very limited cases another person designated by the parent.¹⁸

In cases where both parents have legal authority to consent to health care for their child, either may consent.¹⁹ If the two parents disagree, the provider has a dilemma. Consent authorizes but does not compel any provider to perform an HIV test. So, in these cases, a provider may want to look into the facts before deciding to test, and may decide to do so only if it serves a legitimate clinical purpose. Also, if a provider is not sure whether a parent has legal authority to consent to his or her child's health care, the provider may wish to verify this before proceeding with the test. This question is only likely to arise if the parents are separated or divorced; if only one parent has been given legal custody and health care decision-making authority for the child, that parent's consent will be needed.

When the infant or child is in foster care, the foster care agency must conduct an HIV risk assessment.²⁰ If this assessment identifies an HIV risk for the child, consent for the HIV test can be obtained in different ways depending on how the child was placed in foster care:

• <u>voluntary placement.</u> When a child has been placed in foster care voluntarily by his or her birth parent(s) or guardian, or placed as a Person In Need of Supervision (PINS) or Juvenile Delinquent, the parent's or guardian's consent to the test is required unless a court orders otherwise. If the parent or guardian does not consent or cannot be located, the child may not be tested unless a court order authorizes the test.²¹

According to guidelines issued by the state agency responsible for overseeing foster care (formerly the Department of Social Services, now the Office of Children and Family Services (OCFS)), courts may order HIV testing of a foster child upon a finding of "urgent medical necessity," which OCFS says may exist when –

- » a child entering care has previously tested positive and/or has symptoms related to HIV infection requiring immediate medical attention,
- » an infant or pre-school child has been abandoned, or
- » the child's parent has HIV/AIDS or has died from HIV/AIDS.²²
- <u>involuntary placement.</u> When a child has been placed in foster care as a result of child abuse or neglect proceedings, anyone wishing to test the child must seek the birth parent's or guardian's consent. If the parent/guardian refuses or is unable to consent within 10 days

¹⁷ See N.Y. Pub. Health Law § 2504(2): anyone who has borne a child may give consent for "medical, dental, health and hospital services for his or her child."

 $^{^{18}}$ N.Y. Pub. Health Law $\S~2504.$

¹⁹ *Id*.

²⁰ 18 N.Y.C.R.R. § 441.22.

²¹ Id.

²² Foster Care: Assessment of Foster Children for Capacity to Consent and HIV Risk; Counseling of Adolescents; Legal Consent for HIV Testing; Documentation and Disclosure, 97 ADM-15, issued July 24, 1997; see pp. 16, 24-26.

of the request, the local social services commissioner may consent.²³ (See pages 40-41 for a discussion of who can authorize the disclosure of HIV test results of a minor who lacks capacity to consent.)²⁴

When a child has been adopted, the adoptive parents generally assume all parental rights; thus they (not the birth parents) have the legal authority to consent to health care for, and to decide about HIV testing of, the adopted infant or young child. Before an adoption is finalized, the rules governing children in foster care generally apply. (See page 40 regarding disclosure of HIV-related information about adopted children.)

Note: These guidelines govern consent for testing only while a birth, foster or adoptive child is so young as to lack capacity to consent. Once a minor has the capacity to consent (as discussed next), s/he alone has the right to decide whether or not to be tested.

b. OLDER MINORS (UNDER THE AGE OF 18)

i. DO THEY HAVE CAPACITY?

A legal minor (under age 18) may have the capacity to consent and, thus, the right to decide whether to be tested. Since age itself does not determine capacity, an individualized assessment must be done of every older child's or adolescent's actual ability to understand the nature and consequences of being tested for HIV and to make an informed decision.

ii. WHO MAY CONSENT FOR THOSE WHO LACK CAPACITY?

Only if an individualized evaluation leads to the conclusion that a particular minor lacks capacity to consent to an HIV test may a provider consider whether to seek consent instead from a person legally authorized to consent to health care for the minor. Ordinarily, this will be the minor's parent(s) or legal guardian. In the following special cases, however, parents and guardians do not have the legal authority to consent to HIV testing of their minor children.

iii. SPECIAL CASES WHERE ONLY THE MINOR CAN DECIDE

In New York, certain minors have the right to make some health care decisions for themselves (or for their own children). Parental consent is neither required, nor legally effective, to authorize testing of these minors.

Married minors and minor parents: testing themselves. Any person (even if under the age of 18) who has married or is the parent of a child may give effective consent for "medical, dental, health and hospital services for him/herself, and the consent of no other person shall be necessary."²⁵

²³ 18 N.Y.C.R.R. § 441.22.

²⁴ These rules are discussed in detail in a manual issued by the New York State Office of Children and Family Services, entitled Working Together: Health Services for Children in Foster Care, issued March 9, 2009, available at: http://www.ocfs.state.ny.us/main/sppd/health_services/manual.asp.

 $^{^{25}}$ N.Y. Pub. Health Law $\S~2504(1).$

Thus a minor who is married or a parent (even if not married) is probably the only person who has the right to decide whether to consent to an HIV test. If a married minor or minor parent decides not to be tested, consent by his or her parent(s) or guardian cannot override that decision. If such a minor lacks capacity to consent, that person is treated as an adult without capacity to consent as discussed below.

Pregnant minors. Any person who is pregnant may give effective consent for "medical, dental, health and hospital services relating to prenatal care." Consequently, if HIV testing is offered or considered in the context of prenatal care, a pregnant minor has the right to decide whether or not to be tested. If that minor refuses to consent, no test may be done. Her parents may not be contacted or asked to consent to have her tested (see page 49). If the minor lacks capacity to consent, she should be treated as an person without capacity to consent, as described below.

Minor parents: testing their child. Any person (even if under the age of 18) who has been married or has borne a child may give effective consent for "medical, dental, health and hospital services for his or her child."²⁷

Since the minor in these special cases is the only person "authorized pursuant to law to consent to health care" for the child, the minor alone has the right to decide whether his or her child should undergo an HIV test. The minor's parent or legal guardian cannot be asked to consent instead.

iv. MINORS: CONSENT TO HIV TREATMENT VERSUS HIV TESTS

While Article 27-F gives minors who have capacity to consent the right to decide whether to be tested for HIV, it does not govern who may authorize a minor's treatment for HIV/AIDS.

Under New York law, a parent's (or guardian's) consent is generally required before a minor may be given medical, dental, health or hospital services. The law, however, does allow a minor to receive medical treatment without parental consent if the minor is married, pregnant, or has borne a child, or if in a physician's judgment an emergency exists that requires immediate medical attention, and an attempt to get parental consent would delay treatment, increasing the risk to the minor's life or health.²⁸ Some people have interpreted this "emergency" exception as authorizing providers to treat minors for HIV without the consent of a parent or guardian.

Other provisions of New York law give minors the legal authority to consent to treatment for particular health problems, including sexually transmitted diseases²⁹

 $^{^{26}}$ N.Y. Pub. Health Law $\S~2504(3).$

²⁷ N.Y. Pub. Health Law § 2504(2).

 $^{^{28}}$ N.Y. Pub. Health Law $\S~2504.$

²⁹ N.Y. Pub. Health Law § 2305(2).

and, within limits, mental health problems³⁰ or drug or alcohol problems.³¹ These laws recognize that, given the highly personal and stigmatizing nature of these health problems, minors might not seek needed treatment if parental consent were required. But no comparable law explicitly allows minors to be treated for HIV/AIDS without parental involvement or consent.

So, while Article 27-F gives minors who have capacity to consent the right to decide about HIV testing on their own, it does not address whether parental consent is needed to authorize a minor's treatment for HIV/AIDS. Health care providers must look to the general rules of Public Health Law § 2504, just noted, to figure this out in each minor's case. (The rules governing when doctors may tell parents their minor child's HIV status, for instance to obtain needed parental consent to treat the minor for HIV, are described on pages 49-51.)

c. INDIVIDUALS WHO HAVE BEEN ADJUDICATED INCOMPETENT

i. DO THEY HAVE CAPACITY?

A person whom a court has declared to be incompetent to make health care or other decisions about him/herself will probably not have "capacity to consent" for purposes of HIV testing. The fact that a person may have psychiatric problems, physical illnesses or disabilities does not, by itself, mean that he lacks capacity to consent. Only if there has been a judicial adjudication of incompetency may a provider forego the individualized assessment of capacity required by Article 27-F, and seek consent from the person authorized to act for the individual.

ii. WHO MAY CONSENT ON THEIR BEHALF?

If the court has appointed someone to serve as such a person's legal guardian and has authorized that legal guardian to make health care decisions for the individual, then the legal guardian has the right to consent to HIV testing of that person. Alternatively, if the individual has signed a health care proxy, the health care "agent" named in the proxy may be authorized to consent to HIV testing of that person. (See "Health care proxies," below.)

d. OTHER INDIVIDUALS WITH TEMPORARY IMPAIRMENTS

i. DO THEY HAVE CAPACITY?

In some instances, questions about an individual's capacity to consent to an HIV test may arise either because of conditions that temporarily impair the person's cognitive abilities or judgment, or because of other physical or mental conditions. For example, a client might be intoxicated or under the influence of drugs, experiencing stress or other psychiatric problems, unconscious or comatose.

ii. WHO MAY CONSENT ON THEIR BEHALF?

If the individual has a temporary impairment (e.g., intoxication), it may be prudent to defer testing until the person has regained capacity to consent. In

 $^{^{30}}$ N.Y. Mental Hyg. Law \S 33.21.

³¹ N.Y. Mental Hyg. Law § 22.11.

other circumstances, however, if such a person has *not* been judicially declared incompetent, then the person with authority to consent to an HIV test might be:

- parents or guardians of minor children, as discussed above and on pages 39-41,
- a health care agent named in a health care proxy (see next section), or
- the "surrogate" decision maker as authorized by the Family Health Care Decisions Act (see section 6, below).

5. HEALTH CARE PROXIES

Under New York's "health care proxy" law (Public Health Law Article 29-C, §§ 2980-2994), a competent adult may designate another person as his/her "health care agent" for purposes of making health care decisions on his/her behalf in the event of the loss of ability to do so, as defined by statute.³² An adult includes a person 18 years of age or older (or, as discussed above, a minor who is the parent of a child or is married).³³ Adults are presumed "competent" to appoint a health care agent unless adjudged incompetent "or otherwise adjudged not competent to appoint a health care agent" or if the court appointed a guardian.³⁴

The person making a "health care proxy" may authorize the health care agent to make decisions about particular medical procedures and treatments (such as HIV testing specifically), or may give the agent general authority to make any and all health care decisions, which would allow the agent to consent to HIV testing or treatment even if the proxy did not mention HIV.

As was explained previously, Article 27-F provides that when a patient lacks capacity to consent to an HIV test, consent may be obtained from "a person authorized pursuant to law to consent to health care for [that] individual." A health care proxy is simply an effective way of authorizing another person to provide that consent. If the patient who has signed the health care proxy regains the ability to make those medical decisions, though, the authority to decide whether to be tested shifts back to the patient. The attending physician makes the determination of whether the patient has the capacity to make the decision, though in specific circumstances the physician may be required to consult with a specialist. The determination must be documented and notice of it must be provided in accordance with the statute.

6. FAMILY HEALTH CARE DECISIONS ACT

Under the Family Health Care Decisions Act (the "FHCDA"), if a person becomes mentally incapacitated, health care decisions while the person is in a hospital or residential care facility can be made by an individual called a "surrogate." It is not necessary to invoke the FHCDA if the patient has a guardian or a health care proxy. While the FHCDA currently only applies in a hospital or residential care facility, the Legislature directed a task force to consider applying

 $^{^{32}}$ N.Y. Pub. Health Law $\S~2980(3).$

³³ N.Y. Pub. Health Law § 2980(1).

³⁴ N.Y. Pub. Health Law § 2981(1)(b).

³⁵ N.Y. Pub. Health Law § 2781(1).

 $^{^{36}}$ N.Y. Pub. Health Law \S 2983.

³⁷ N.Y. Pub. Health Law §§ 2983(1) and (3).

 $^{^{38}}$ N.Y. Pub. Health Law §§ 2994-a, 2994-d.

³⁹ N.Y. Pub. Health Law §§ 2994-b(2) and (3)(a).

it in other settings.⁴⁰ The attending physician makes an initial determination that the patient lacks decision-making capacity, though in specific circumstances, may be required to consult with another medical professional. The determination must be documented and notice of it must be provided in accordance with the statute.⁴¹

If a patient is incapacitated, a surrogate or the health care facility can make medical decisions for the patient, including HIV testing, following the procedures laid out in the FHCDA. If, however, the patient objects to the determination of incapacitation, to the choice of surrogate, or to a health care decision made on the patient's behalf, the patient's decision must prevail unless there is a finding by a court or other legal basis to override the patient's decision.⁴²

The surrogate should be assigned based on the order in the following list. If the person whose relationship is highest on the list is not reasonably available, willing or competent to act, that person can designate any other person on the list as the surrogate as long as someone with higher priority does not object. Otherwise, the next highest person on the list is surrogate.

- Guardian specifically authorized by the court to make such decisions
- Spouse (if not legally separated) or domestic partner
- Son or daughter 18 years of age or older
- Parent
- Sibling 18 years of age or older
- Close friend.43

Additionally, if a surrogate is not available for the patient, the patient can still receive HIV-related testing (considered a "major medical procedure" under the FHCDA) when physicians recommend the testing for the patient following the procedures set out in the FHCDA.⁴⁴

Decisions made for the patient under FHCDA must be made in accordance with the patient's wishes, including religious or moral beliefs. If the patient's wishes are not known and cannot be reasonably determined, decisions should be based on the patient's best interests, considering the factors laid out in the statute. 45

D. PRE-TEST INFORMATION REQUIREMENTS

1. GENERAL RULE

Before anyone decides whether to consent to any HIV-related test, that person must receive the information about HIV required by the Public Health Law. This information can be given directly

⁴⁰ New York State Bar Association Frequently Asked Questions about the Family Health Care Decisions Act, revised January 9, 2011, available at www.nysba.org/Content/NavigationMenu/PublicResources/ FamilyHealthCareDecisionsActInformationCenter/FAQ_HTML.htm.

 $^{^{41}}$ N.Y. Pub. Health Law \S 2994-c.

⁴² N.Y. Pub. Health Law §2994-c(6).

⁴³ N.Y. Pub. Health Law § 2994-d.

⁴⁴ N.Y. Pub. Health Law § 2994-g(4); Department of Health, *Fact Sheet: Family Health Care Decisions Act & HIV/ AIDS*, available at http://www.health.ny.gov/diseases/aids/regulations/fhcda/ai_fact_sheet.htm ("DOH Fact Sheet: FHCDA").

⁴⁵ N.Y. Pub. Health Law § 2994-d(4); DOH Fact Sheet: FHCDA http://www.health.ny.gov/diseases/aids/regulations/fhcda/ai_fact_sheet.htm.

or through a representative, and it can be in oral, written or electronic form. ⁴⁶ For example, the requirement can be satisfied by use of an HIV test consent form that contains the required pretest information (see page 14 regarding model forms available from the Department of Health), or by use of a video loop shown in a waiting area. If the individual lacks capacity to consent, the information must be given to the person authorized by law to consent on his/her behalf. (The exceptions to the general rule requiring this information, and the special rules that apply to applicants for insurance, are discussed at pages 20-23.)

2. CONTENT OF REQUIRED INFORMATION

Prior to testing, the following information must be provided:

- HIV causes AIDS and can be transmitted through sexual activities and needle-sharing, by pregnant women to their fetuses, and through breast feeding infants;
- there is treatment for HIV that can help an individual stay healthy;
- individuals with HIV or AIDS can adopt safe practices to protect un-infected and infected people in their lives from becoming infected or multiply infected with HIV;
- testing is voluntary and can be done anonymously at a public testing center;
- the law protects the confidentiality of HIV related test results;
- the law prohibits discrimination based on an individual's HIV status and services are available to help with such consequences; and
- the law allows an individual's informed consent for HIV related testing to be valid for such testing until such consent is revoked by the subject of the HIV test or expires by its terms.

Providers must have protocols in place to ensure compliance with these requirements.⁴⁷

E. CONSENT FOR AN HIV TEST

1. RAPID HIV TESTING

Oral consent is sufficient for rapid HIV testing (but written consent is required in correctional facilities) and must be documented in the individual's medical record by the person ordering the test. ⁴⁸ DOH guidance suggests that in non-medical settings, consent should be noted in the program's "testing documentation." ⁴⁹ "Rapid HIV test or testing" means any laboratory screening test(s) approved for detecting antibodies to HIV that produce results in sixty minutes or less, and that includes a confirmatory HIV related test if the screening test is reactive. ⁵⁰

⁴⁶ N.Y. Pub. Health Law § 2781(3); 10 N.Y.C.R.R. § 63.3 (b).

⁴⁷ N.Y. Pub. Health Law § 2781(3).

⁴⁸ N.Y. Pub. Health Law § 2781(1) and (2-c).

⁴⁹ DOH HIV Testing FAQs Dec. 2010,

http://www.health.ny.gov/diseases/aids/testing/law/faqs.htm.

⁵⁰ N.Y. Pub. Health Law § 2780(4-a).

2. HIV TESTING GENERALLY

Written consent is required for all HIV tests except rapid tests. (As discussed above, however, written consent is required for rapid tests performed in correctional facilities). Written consent can be in the form of:

- a simple signed statement consenting to the test after the person has received the required pre-test information; or
- a signed general written consent for medical care or any health care service, but only if the form has a clearly marked place next to the signature where the individual (or the person legally authorized to consent) can specifically decline in writing the HIV related testing.⁵¹

The Department of Health has developed model forms (see Appendices A and B), but providers may create their own forms consistent with these models and do *not* need Department of Health approval for these forms. The forms must be written clearly using words with common meanings.⁵²

Certification of consent does *not* need to be provided to the laboratory.

3. PEOPLE WITH LANGUAGE BARRIERS

HIV test consent forms contain crucial information that must be fully understood by those who are deciding whether to undergo HIV testing, or to consent to testing on another's behalf. If an individual's ability to read is questionable, the consent form should be read to that person. Forms written in a person's preferred language should be used. The Department of Health website provides consent forms in many languages.⁵³ The pre-test HIV information should also be provided in the person's preferred language.

4. DURATION OF CONSENT TO AN HIV TEST

Written or oral informed consent for HIV related testing can be for a single test, for a specified period of time until expiration, or open-ended. When an HIV related test is subsequently ordered based on ongoing consent, the person ordering it must orally notify the test subject (or, if the test subject lacks capacity to consent, then the individual authorized to consent to care for such individual) that an HIV test will be conducted at such time, and must document that notification in the patient's record.⁵⁴

5. REVOKING CONSENT TO AN HIV TEST

Consent to an HIV test may be revoked or withdrawn at any time.⁵⁵ People may revoke their consent either orally or in writing; it is not permissible to require or honor only written revocations. However, if the original consent form is retained in the medical or other records the client's revocation must also be noted in the record, including the date of revocation and the name of the person making the note. The revocation should be either on the consent form itself or in another way that ensures no one will perform any HIV test in reliance on the revoked consent.⁵⁶

 $^{^{51}}$ N.Y. Pub. Health Law §§ 2781(2) and (2-a).

⁵² N.Y. Pub. Health Law § 2786(1).

⁵³ Consent forms in many languages are available at: http://www.health.ny.gov/diseases/aids/testing/index.htm.

⁵⁴ N.Y. Pub. Health Law § 2781(2-b).

 $^{^{55}}$ Id

⁵⁶ DOH HIV Testing FAQs Dec. 2010, http://www.health.ny.gov/diseases/aids/testing/law/faqs.htm.

F. POST-TEST COUNSELING

1. GENERAL RULE

a. POSITIVE TEST RESULTS.

Post-test counseling (or referral for such counseling) must be provided whenever a test indicates evidence of HIV infection. The counseling must be provided to a person who has been tested, or if the individual tested lacks capacity to consent, then to the person who provided consent and, to the extent it is beneficial, to the person tested.⁵⁷ While Article 27-F does not mandate that post-test counseling always be done in person, good, sensitive practice generally requires it when the test is positive.

Post-test counseling for *confirmed positive results* must include information about:

- how to cope with the emotional consequences of learning the result;
- discrimination that could result from disclosure of the test result;
- the importance of precautions to prevent HIV transmission to others;
- the ability to release or revoke the release of confidential HIV-related information;
- HIV reporting requirements for epidemiologic monitoring of the HIV/ AIDS epidemic;
- the importance of notifying contacts in order to prevent transmission and to allow early access to HIV testing, health care and prevention services, and a description of notification options and assistance available;
- though not required in post-test counseling, providers should advise people that their refusal to reveal contacts or otherwise cooperate with contact notification efforts is not illegal, and there are no penalties for not providing the names of contacts;⁵⁸
- the possible risk of domestic violence resulting from notification of any partner will be assessed, through a domestic violence screening conducted during post-test counseling (pages 54-60 discuss the contact reporting and notification rules);
- the requirement that known contacts (including a known spouse) will be reported and that protected persons will also be requested to cooperate in contact notification efforts and may name additional contacts they wish to have notified with the assistance of the provider or authorized public health official;
- that the tested person's name or other identifying information is not disclosed to anyone during the contact notification process;
- the provider's responsibility for making an appointment for newly diagnosed persons to receive follow-up HIV medical care (discussed below);
- available medical services, including the location and telephone numbers of treatment sites, information on the use of HIV medications for

⁵⁷ N.Y. Pub. Health Law § 2781(5); 10 N.Y.C.R.R. 63.3(d).

 $^{^{58}}$ N.Y. Pub. Health Law $\S~2136$.

prophylaxis and treatment and peer group support, access to prevention services and assistance, if needed, in obtaining these services; and

prevention of perinatal transmission.⁵⁹

b. NEGATIVE TEST RESULTS.

When a test does not indicate evidence of HIV infection, information concerning the risks of high-risk sexual or needle-sharing behavior must be provided to the subject of the test (or, if the subject lacks capacity to consent, to the person authorized to consent to health care for that person). The negative result and required information may be provided in-person, by mail, electronic messaging, or telephone, provided that patient confidentiality is reasonably protected. The information concerning behavior risks may be given by oral or written reference to materials previously provided.⁶⁰

2. FOLLOW-UP CARE

The person who ordered the HIV test (or his/her representative) must provide or arrange with a health care provider for an appointment for follow-up HIV medical care for the person who tested positive, with that person's consent. According to the Department of Health, that consent may be oral or written. Simply providing the patient with contact information for follow up care is not sufficient. The name of the provider or facility offering the follow up appointment must be documented in the patient's record. This requirement applies to any provider who provided the HIV test resulting in a diagnosis, even if the provider was not mandated to offer the test (with limited exceptions such as testing to obtain body parts for transplant or in a blinded research protocol). Ea

3. PERSONS WHO DO NOT WISH TO LEARN THEIR HIV TEST RESULTS

Individuals who have undergone HIV testing have a legal right to choose not to be told the results of the test. When individuals test positive but do not return for their test results, however, providers may contact the New York State Department of Health's HIV Partner Services (PS) program or New York City Department of Health Contact Notification Assistance Program (CNAP) (see page 57), who can assist the provider in locating the individual to advise them to return to the provider for the test results.

a. LIABILITY FOR TELLING OR NOT TELLING HIV TEST RESULTS

Health care providers who have performed or know the results of an HIV test often ask whether they have a legal obligation to tell their patient the specific test results if the patient does not want to know.

The answer is no: providers do not have a legal duty to disclose the results to the tested person — although ethical, therapeutic or professional concerns may make them wish to do so. Health and mental health professionals generally have a legal duty to take reasonable care of their patients. This includes an obligation to give patients sufficient information (known to the health care provider) to make informed decisions about

⁵⁹ 10 N.Y.C.R.R. § 63.3(e).

 $^{^{60}}$ *Id*.

 $^{^{61}}$ N.Y. Pub. Health Law $\ 2782(5-a);\ 10$ N.Y.C.R.R. $\ 63.3(e).$

⁶² DOH HIV Testing FAQs Dec. 2010,

http://www.health.ny.gov/diseases/aids/testing/law/faqs.htm.

their health care, and take proper care of themselves and protect others from their transmissible illness.

But it is possible to relay this kind of information to a patient without giving the specific test result or diagnosis, if the patient does not want to know the specific result. To force specific medical information upon an unwilling patient might subject health professionals to possible legal claims for malpractice or professional misconduct, intentional infliction of emotional distress, or related claims (though no such cases have come to the authors' attention).

A person's decision not to receive his test results, and information about any post-test counseling that was performed, should be documented in that person's medical record.

b. SOME PRACTICAL SUGGESTIONS

Article 27-F mandates post-test counseling only "at the time of communicating the test result to the subject of the test." Thus, such counseling may not be legally mandated for persons who choose not to know their test results. However, it is advisable to offer them post-test counseling anyway For example, the patient could be counseled to act "as if" he were HIV-infected, and be educated about HIV transmission and risk reduction behaviors.

In addition, if the test was done on a confidential, as opposed to anonymous, basis, it is advisable to tell the individual that the test results will be recorded in his or her medical record. Arrangements should also be made to ensure that others who may have access to the individual's medical records and/or the HIV test result know that the individual does not wish to know the test results.

Finally, even when tested persons remain ignorant of their own test results, their names and known contacts must be reported to public health authorities (see pages 51-60).

 $^{^{63}}$ N.Y. Pub. Health Law $\S~2781(5).$

⁶⁴ N.Y. Pub. Health Law § 2782(8).

II. REQUIRED OFFER OF HIV TESTING

HIV testing must be offered to all persons between the ages of 13 and 64 receiving hospital or primary care services with limited exceptions noted in the law.⁶⁵ The specifics about who must offer an HIV test and who must be offered the test are described below.

A. WHO MUST OFFER HIV TESTING?

An HIV test must be offered in the following settings and by the following providers:

- emergency departments or providers of inpatient services in general hospitals;
- outpatient departments of such hospitals when they provide primary care services;
- "diagnostic and treatment center[s]" when they provides primary care services; and
- physicians, physician assistants, nurse practitioners or midwives who provide primary care services. This includes primary care service providers in settings such as nursing homes, school-based clinics, college health services, retail clinics, urgent care centers, employee health services, and family planning sites.⁶⁶

Note: Primary care services include family medicine, general pediatrics, primary care, internal medicine, primary care obstetrics, or primary care gynecology, regardless of board certification. ⁶⁷

B. WHO MUST BE OFFERED HIV TESTING BY THE PROVIDERS LISTED ABOVE?

The following individuals must be offered an HIV test in the settings noted above.

- everyone between the ages of 13 and 64; and
- people younger or older if there is indication of risk activity.

The only exceptions are where the medical practitioner reasonably believes one of the following:

- the patient is being treated for a life threatening emergency;
- the patient has previously been offered or been the subject of an HIV-related test;
- and the need for a test is not otherwise indicated; or
- the patient lacks the capacity to consent to an HIV related test. 68

The offer of testing must be made in "culturally and linguistically appropriate" ways. ⁶⁹ After the initial offer, the test should be offered again annually to people whose behavior indicates increased risk

 $^{^{65}}$ N.Y. Pub. Health Law $\S~2781\text{-a}.$

⁶⁶ Id. and DOH HIV Testing FAQs Dec. 2010, http://www.health.ny.gov/diseases/aids/testing/law/faqs.htm.

⁶⁷ N.Y. Pub. Health Law § 2781-a(2).

⁶⁸ N.Y. Pub. Health Law § 2781-a (1).

⁶⁹ N.Y. Pub. Health Law § 2781-a (3).

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such as sexual or drug use activity, and more often for those with very high-risk behaviors such as unprotected anal intercourse. Providers should consider setting a low threshold for recommending the test as many patients may not fully disclose their risk activities. Though not legally required, it may be prudent to document the offer of a test. The Department of Health's model form for documenting the offer of testing is attached as Appendix C.

⁷⁰ DOH HIV Testing FAQs, Dec. 2010 at http://www.health.ny.gov/diseases/aids/testing/law/faqs.htm.

III. HIV TESTING WITHOUT CONSENT AND OTHER SPECIAL RULES

A. EXCEPTIONS: HIV TESTING WITHOUT CONSENT

Article 27-F specifies the following situations in which HIV testing may be done without providing pretest information or obtaining consent.⁷¹

1. NEWBORN TESTING

All newborns must be tested for HIV, whether or not the mother consents.⁷² Although consent is not needed, a mother/parent must be informed about the purpose and need for newborn testing.⁷³ If there is no available HIV test result for the mother obtained during this pregnancy, expedited newborn testing must be done. An immediate screening test of the mother should be arranged with her consent, or a test of the newborn must be arranged as soon as possible but no longer than 12 hours after the mother consents or after the birth of the child.⁷⁴ Efforts to provide counseling to the mother and obtain her consent should be documented in the newborn's medical record.

Testing of pregnant women, on the other hand, is voluntary and may be done only with the woman's informed consent. The Department of Health does require all prenatal care providers to:

- counsel and encourage pregnant women to be tested as early as possible during the pregnancy; and
- inform pregnant women about the mandatory newborn testing requirements.

Additionally, the Department of Health urges prenatal providers in areas where HIV seroprevalence is high to recommend repeat HIV testing in the third trimester of pregnancy in case the mother became infected after early testing.⁷⁵

2. OCCUPATIONAL EXPOSURE AND HIV TESTING

Under 2010 amendments to Article 27-F, individuals who believe that they may have been exposed to HIV in the course of performing their job (e.g., through a needle stick) may test the source of an occupational exposure to determine his or her HIV status if all of the following conditions exist:

 the person who is the source of the exposure is deceased, comatose, or determined to lack mental capacity to consent to an HIV related test and is not reasonably expected to recover in time for the exposed person to receive appropriate medical treatment; and

⁷¹ N.Y. Pub. Health Law §§ 2781(1) and 2781(6).

⁷² N.Y. Pub. Health Law §§ 2500-f; 2781(6)(d); 10 N.Y.C.R.R. § 69-1.2.

⁷³ 10 N.Y.C.R.R. § 69-1.5.

⁷⁴ 10 N.Y.C.R.R. § 69-1.3(1)(2).

⁷⁵ For more information, see the Department of Health's January 2004 Letter Regarding Regulatory Changes for Expedited HIV Testing in Labor and Delivery, available at www.health.ny.gov/diseases/aids/testing/perinatal/expedited/2004_prenatal_hiv_testing_letter.htm.

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- the exposure created a significant risk of transmitting HIV as defined by 10 N.Y.C.R.R. § 63.10; and
- no one with the legal authority to consent to the HIV related test is available or likely to become available in time for the exposed person to receive appropriate treatment; and
- the exposed person will benefit medically by knowing the source's HIV test results, (which must be documented in that person's medical record).⁷⁶

When these conditions are met, a provider may test the source person. If an HIV test is done, it must be done anonymously; only the test results – not the identity of the source – may be disclosed to the exposed person's health care professional, and only for the limited purpose of assisting that person with making decisions regarding treatment. The test results shall not be disclosed to the source person or put in that person's medical record.⁷⁷

Note: if the Family Health Care Decisions Act applies and a surrogate is available, then this procedure would not apply.

If the possible "source" of the exposure has the capacity to consent to such a test and declines testing, that person cannot be required to undergo an HIV test. Not even a court has the authority to mandate such a test. If the source patient was previously tested for HIV, in some situations those results may be disclosed to the exposed person (see pages 62-64).

3. MEDICAL RESEARCH; TRANSPLANTATION

Health care providers and health facilities may perform HIV tests without consent when they get or use human body parts or fluids for medical research or therapy, or for transplantation. However, if they disclose the HIV test results to the person tested, they must provide that person with post-test counseling, as outlined above.⁷⁸

4. RESEARCH (WITHOUT IDENTIFYING INFORMATION)

HIV testing may be done without counseling or consent for the purpose of research, but only if the testing is done in a manner that ensures the identity of the subject is not known and may not be retrieved by the researcher.⁷⁹

5. DECEASED PERSONS

HIV tests may be performed on people who have died, when the test is done to determine the cause of death, or for epidemiological purposes. In these two circumstances, no counseling or consent is required for anyone (including surviving family members).⁸⁰

6. INDIVIDUALS WITH SEX OFFENSE CONVICTIONS AND INDICTMENTS

When an adult or juvenile is convicted of or indicted for certain sex offenses, the victim may request the court to mandate the convicted/indicted person to undergo an HIV test.

⁷⁶ N.Y. Pub. Health Law § 2781(6)(e). For additional information, see DOH HIV Testing FAQs Dec. 2010, http://www.health.ny.gov/diseases/aids/testing/law/faqs.htm.

 $^{^{77}}$ Id

⁷⁸ N.Y. Pub. Health Law § 2781(6)(a).

⁷⁹ N.Y. Pub. Health Law § 2781(6)(b).

⁸⁰ N.Y. Pub. Health Law § 2781(6)(c).

The court must issue the order upon such request.⁸¹ (See page 74 for a discussion of who has access to the test results.)

7. COURT-ORDERED TESTING WHERE PARTY'S HIV STATUS IS "IN CONTROVERSY"

A court may order HIV testing without consent under § 3121 of the Civil Practice Law and Rules. S2 This provision allows a court to order a party in a civil court case to undergo medical tests or examinations if that party's "mental or physical condition" is "in controversy" in that case.

This rarely occurs because a party's HIV status is rarely "in controversy." But one type of case where this issue can arise is a tort case based on a sexual partner's non-disclosure of HIV status. This arises when person A sues person B for money damages, claiming that A contracted HIV from B because B knew, but did not divulge, his or her HIV infection prior to having sex. Because a court may decide that each party's HIV status is central to these claims, both the plaintiff and defendant in these cases could be ordered to undergo an HIV test.

CPLR § 3121's medical examination provisions can only be invoked after an action has been commenced.⁸³ It appears that § 3121 cannot be used by someone who wants to force another person to undergo an HIV test but has no independent legal claim to pursue.

8. TESTING "SPECIFICALLY AUTHORIZED OR REQUIRED BY A STATE OR FEDERAL LAW"

Article 27-F provides that non-consensual HIV testing may be "specifically authorized or required" by other state or federal laws. Article 27-F would not override such other state or federal laws. 84

New York laws As of the publishing of this manual New York had no laws (other than the provisions described above) specifically authorizing or mandating HIV testing without consent. Some courts have nonetheless ordered defendants in certain criminal cases to undergo HIV testing. These have primarily involved defendants charged with sexual assault crimes, prostitution, or assaults on law enforcement officers alleging bites or contacts with the defendant's blood or body fluids. Article 27-F does not expressly allow such testing, and its legality is hotly debated.

Federal law Federal laws and regulations authorize mandatory HIV testing in certain circumstances, including:

- prisoners in federal correctional facilities; and
- the military

B. HIV TESTING IN CONNECTION WITH INSURANCE APPLICATIONS

Special, less stringent rules apply when an insurance company asks or requires an applicant for health or life insurance to undergo an HIV test as a condition of coverage.

⁸¹ N.Y. Pub. Health Law § 2785-a; N.Y. Crim. Proc. Law §§ 210.16; 390.15; N.Y. Fam. Ct. Act § 347.1.

⁸² N.Y. Pub. Health Law § 2781(1).

⁸³ N.Y. C.P.L.R. 3121(a) (McKinney 2011).

⁸⁴ N.Y. Pub. Health Law § 2781(1).

1. INFORMATION PRIOR TO TESTING

The pre-test information usually required by Article 27-F is not required for testing in connection with an application for insurance. Insurance companies need only provide such applicants with "general information about AIDS and the transmission of HIV infection." And, as noted previously (page 5), insurers do not have to offer anonymous testing.

2. CONSENT FORM

Although insurance applicants must give written informed consent to an HIV test, the written authorization (which must be dated and signed) need only contain the following information:

- a general description of the HIV test;
- a statement about the purpose of the test;
- a statement that a positive test result indicates the individual tested may develop AIDS and may wish to consider further independent testing;
- a statement that the individual tested may identify and designate on the consent form a person to whom the test result may be disclosed if the insurer makes an "adverse underwriting decision" (a decision to deny insurance or only offer insurance at a higher rate than usual); and
- the Department of Health's HIV Counseling Hotline number (1-800-872-2777), which provides information about the meaning of the test, referrals for counseling, and other information.⁸⁶

3. POST-TEST COUNSELING

Post-test counseling is not required for HIV tests in connection with insurance applications. Insurers must let applicants (or their designee, e.g., a doctor) receive the test result.⁸⁷ The insurer also must notify the applicant of any "adverse underwriting decision" based on the result and let the applicant elect in writing to learn the test result directly or to designate someone else to learn the result.⁸⁸

If the applicant wants to learn the test result directly, the insurer must give the applicant the Department of Health's HIV Counseling Hotline number (1-800-872-2777) and advise him/her to consult with a doctor about the test's meaning and need for counseling.⁸⁹

C. HOME TESTING KITS

Article 27-F's requirements for informed consent do not prohibit a person from directly ordering an HIV test on a specimen and directly receiving the results of that test.⁹⁰

⁸⁵ N.Y. Ins. Law § 2611(a).

⁸⁶ N.Y. Ins. Law § 2611(b).

⁸⁷ N.Y. Ins. Law § 2611(b)(4).

⁸⁸ N.Y. Pub. Health Law § 2611(c).

⁸⁹ N.Y. Ins. Law § 2611(c).

⁹⁰ 10 N.Y.C.R.R. § 63.3(h).

PART 2

CONFIDENTIALITY AND DISCLOSURE OF HIV-RELATED INFORMATION

INTRODUCTION

Section I of this Part explains the basic rule that prohibits many (but not all) people and agencies in New York State from disclosing HIV-related information about their patients, clients, and others. Section II explains the basic rule requiring that patients or clients provide consent before any disclosure of HIV-related information is made, and Section III explains the major exceptions that allow the disclosure of HIV-related information even without consent. In addition, the law requires most disclosures to be documented and accompanied by a notice prohibiting unauthorized redisclosures. Section IV explains how to keep records about HIV-related information, and Section V explains the penalties for violating the confidentiality law.

I. GENERAL HIV CONFIDENTIALITY RULE: NO DISCLOSURE WITHOUT CONSENT UNLESS EXCEPTION APPLIES

A. THE BASIC RULE

General Rule Against Disclosing HIV-Related Information:

Covered persons may not disclose confidential HIV-related information about a protected individual unless:

- the individual consents to the disclosure in a proper, HIV-specific release form,or
- one of the law's specific exceptions permits the disclosure without consent

B. APPLICABLE LAWS AND REGULATIONS

1. NEW YORK'S LAW: ARTICLE 27-F

Article 27-F of the New York State Public Health Law ⁹¹ — the HIV Testing and Confidentiality Law — establishes the basic rules concerning confidentiality and disclosures of HIV-related information in this state. Section 2782 is the primary section concerning confidentiality and disclosures; § 2785 concerns court-ordered disclosures by health and social service providers. In addition to Article 27-F, the state's HIV Reporting and Partner Notification Law⁹² governs confidentiality and disclosure of HIV-related information in the context of HIV/AIDS case reporting and contact (partner) notification activities. The policy rationale for Article 27-F's confidentiality protections is discussed in Part 1, pages 1-2. The Legislature subsequently enacted the HIV Reporting and Partner Notification Law to

- track the HIV epidemic and monitor the course of HIV disease in individuals, so as to improve its ability to plan and carry out needed prevention and treatment efforts; and
- curb the spread of HIV by promoting early activities to identify and alert the sexual and needle-sharing partners of infected individuals of their exposure and possible infection, so that they can protect themselves and others from acquiring or transmitting the virus.

The State Department of Health's "lead agency" regulations implementing these laws are in 10 N.Y.C.R.R. Part 63. Other state agencies also have issued regulations implementing Article 27-F's confidentiality and disclosure rules, and health and social service providers must comply with the specific Article 27-F regulations issued by the state agency that funds, licenses or regulates them. A note about wording: Since the law defines the sex and needle-sharing partners of infected individuals as "contacts," this manual also uses that term for the sake of clarity.

2. OTHER CONFIDENTIALITY LAWS AND RULES

a. OTHER POTENTIALLY APPLICABLE LAWS AND RULES

Other federal or state confidentiality requirements may also protect the confidentiality of HIV-related information. For example —

- most health care providers (as well as health plans and health care clearinghouses covered by this law) must also comply with the federal Health Insurance Portability and Accountability Act ("HIPAA"). 93 HIPAA establishes minimum privacy protections for medical records and other "protected health information" ("PHI"). The interaction between Article 27-F and HIPAA is explained below in Section I.B.2.b.
- medical care providers must also comply with state laws and regulations protecting the confidentiality of medical records;
- many mental health care providers must comply with the confidentiality requirements of New York Mental Hygiene Law § 33(13);

⁹¹ N.Y. Pub. Health Law §§ 2780-2787.

 $^{^{92}}$ N.Y. Pub. Health Law §§ 2130-2139.

⁹³ 42 U.S.C. § 1320d *et seq.* The U.S. Department of Health and Human Services ("HHS") regulations implementing HIPAA's privacy standards (the HIPAA "Privacy Rule") can be found at 45 C.F.R. Parts 160 and 164.

- drug and alcohol treatment programs must also comply with the federal law and regulations protecting the confidentiality of drug and alcohol patient records (42 U.S.C. §§ 290dd-2; 42 C.F.R. Part 2); and
- licensed health care and social service professionals must also comply with confidentiality requirements imposed by their state licensing agencies.

b. DEALING WITH MULTIPLE OR POTENTIALLY CONFLICTING CONFIDENTIALITY REQUIREMENTS

A good rule of thumb for health or social service providers subject both to Article 27-F and other confidentiality laws or regulations is: comply with all confidentiality requirements when possible; but when in doubt, abide by the stricter confidentiality rule. In general, Article 27-F will "trump" any less restrictive federal, state or local confidentiality law or regulation; but if other laws have more restrictive requirements, the stricter requirements apply.

HIPAA generally preempts, or overrides, any "contrary" state law provision. ⁹⁴ "**Contrary**" means that a covered entity would "find it impossible to comply" with both the state and federal requirements, or that the state law "stands as an obstacle" to achieving HIPAA's purposes and objectives. ⁹⁵ However, HIPAA does *not* preempt state laws that are "**more stringent**," which generally means that they provide greater privacy protection and/ or give the individual more rights. ⁹⁶ Because Article 27-F usually is more protective of privacy than HIPAA, health care providers will need to comply with Article 27-F's "more stringent" requirements.

C. POLICIES AND PROCEDURES AND IN-HOUSE TRAINING

The Department of Health's Article 27-F regulations require health care providers and health facilities to develop and implement policies and procedures to maintain the confidentiality of HIV-related information. These policies and procedures, which must be reviewed at least annually, must include

- provisions for employee in service education and updates when there are changes to relevant laws and regulations;
- protocols to prohibit employees, agents and contractors from discriminating (see Part 3);
- a list of the job titles and functions of employees with access to HIV-related information and a requirement that no one have such access unless they have first received HIV confidentiality education (see "internal communications" discussion on pages 44-45); and
- protocols for ensuring the security of records and procedures to handle requests by other parties for confidential HIV-related information (see "record-keeping issues" discussion at pages 76-81).⁹⁷ Other agency regulations have similar provisions.

^{94 45} C.F.R. § 160.203.

⁹⁵ 45 C.F.R. § 160.202.

 $^{^{96}}$ 45 C.F.R. §§ 164.202 and 164.203.

^{97 10} N.Y.C.R.R. § 63.9.

HIPAA's privacy and security provisions also require covered entities to take measures to ensure compliance with the law (see http://www.hhs.gov/ocr/privacy/). These include workforce training, appointment of a privacy officer, grievance processes, among other requirements.⁹⁸

D. WHO IS PROTECTED

1. WHO IS PROTECTED BY ARTICLE 27-F

Article 27-F protects the confidentiality of HIV-related information about "protected individuals" and their "contacts."

A "**protected individual**" means a person who is the subject of an HIV-related test, or who has been diagnosed as having HIV infection, HIV-related illness, or AIDS.⁹⁹

A "contact" means

- an identified spouse or sexual partner of a protected individual,
- a person identified as having shared needles or syringes with a protected individual, or
- a person who may have been occupationally exposed to HIV by a protected individual under circumstances that present a known risk of transmission.¹⁰⁰

Deceased persons. Article 27-F does not say whether HIV-related information about an individual remains confidential after death. While some courts have suggested it does not, the State Department of Health has taken the position that it remains confidential after death. The law is clear, however, that HIV-related information about decedents may be released in the following circumstances:

- <u>HIV case reporting and partner notification</u>: HIV testing is permitted to determine cause of death. When HIV is diagnosed, the case must be reported to the Department of Health (see page 50); and public health authorities may notify the decedent's spouse or other known contacts of their possible exposure (see pages 54-60), but without revealing the decedent's identity.¹⁰¹
- <u>Death certificates</u>: The law permits HIV-related information to be listed in a death certificate and related documents identifying cause of death, and permits that information to be released to those who ordinarily would have access to the death certificate. These include the spouse, children, parents, or lawful representative of the deceased individual, persons who can document a medical need or who need the document to establish a legal right or claim. Death records are not subject to Freedom of Information Law requests.

 $^{^{98}}$ See, e.g., 45 C.F.R. \S 164.520 and 164.530.

 $^{^{99}}$ N.Y. Pub. Health Law $\S~2780(6).$

¹⁰⁰ N.Y. Pub. Health Law § 2780(10).

¹⁰¹ N.Y. Pub. Health Law § 2132.

¹⁰² N.Y. Pub. Health Law § 2782(8).

¹⁰³ See N.Y. Pub. Health Law § 4174(1) for a full list.

- Occupational exposure: The HIV status but not the identity of a deceased person may be disclosed to an exposed worker if the incident meets the conditions required by the law's occupational exposure rule. (See pages 62-64.)
- Administrator/Executor: See page 75.

2. WHO IS PROTECTED BY HIPAA

Any individual who receives health care from a "covered entity" as defined by HIPAA (see page 35) is protected by HIPAA's privacy and security rules.

E. WHAT INFORMATION IS PROTECTED

1. WHAT INFORMATION IS PROTECTED BY ARTICLE 27-F

Article 27-F protects confidential HIV-related information. "Confidential HIV-related information" includes any information (written or oral), held by a person covered by Article 27-F, that does or reasonably could:

- reveal that an individual **had an HIV-related test**, and any test results;
 - » this includes information that a person has undergone one of the "HIV-related tests" that detect the virus itself — such as an HIV antibody test, RNA or DNA viral load tests, PCR (polymerase chain reaction) tests, and rapid HIV tests; it also includes information about tests that do not detect the virus but indicate HIV disease, such as a CD4 (T-cell) test (when used to diagnose or monitor HIV only), and bronchoscopy (which diagnoses PCP pneumonia, an AIDS-defining illness), even though those tests are not technically considered "HIVrelated tests";
- reveal that an individual has been diagnosed as having **HIV infection or any related illness**, including **AIDS**; or
- identify the "**contacts**" of an individual who has been diagnosed as having HIV infection or any related illness (see page 27). ¹⁰⁴

a. EXAMPLES OF CONFIDENTIAL HIV-RELATED INFORMATION

Some examples of confidential HIV-related information are:

- a notation in a counseling agency client's chart that the client has had an HIV test or been offered a test (even if the results are not known or not recorded);
- a notation that a client's HIV test results were negative, positive or not definitive;
- a statement that a person has had PCP pneumonia, even without mention of HIV or AIDS (this information is protected because this illness

¹⁰⁴ N.Y. Pub. Health Law § 2780(7).

is associated with and triggers a diagnosis of AIDS, and information about this illness "could reasonably identify" that person as having HIV disease; the same is true for other CDC-defined "indicator" illnesses — ones that the federal Centers for Disease Control lists as illnesses indicative of AIDS in its definition of the disease):

- information that a person is taking a well-known HIV medication, such as a protease inhibitor;
- a report showing a low T-cell count or other lab test results confirming immune deficiency (unless the cause is shown not to be HIV-related);
- a notation in a client's chart that s/he is HIV positive, and a note in another part of the chart that he is living with his spouse, whose name and address are also noted. As his spouse and presumably his sexual partner, she is a "contact" of the HIV positive client (as defined in § 2780(10)).

b. EXAMPLES OF WHAT IS NOT CONFIDENTIAL HIV-RELATED INFORMATION

Examples of information that is not confidential HIV-related information are:

- a note in a patient's medical record that she was referred for HIV counseling and testing (however, if the record then notes that the patient was in fact tested for HIV or records her test result, that information is confidential);
- a note in a client's record that he is gay or bisexual or has a history of IV drug use. Without more, this information may suggest that the client has engaged in behavior known to create a risk of HIV infection, but it does not necessarily lead to that conclusion. However, if the client's record explicitly reflects that an HIV risk assessment was done e.g., it notes that "client's history of having unsafe sex with other men suggests he may have HIV infection," or notes that "because of her previous IV drug use, client is at risk for HIV infection" that information is likely protected because it could reasonably identify the client as having an HIV-related condition.

c. RULE OF THUMB

When in doubt, treat as protected by Article 27-F any information that might identify an individual — or his/ her contact — as having been tested for or diagnosed with an HIV-related condition.

2. WHAT INFORMATION IS PROTECTED BY HIPAA

Unlike Article 27-F, which only protects HIV-related information, HIPAA protects all "individually identifiable health information" held or transmitted by a "covered entity" (which includes health care providers, health plans, and health care clearinghouses; see page 35). This information is known as "protected health information" ("PHI").

"Individually identifiable health information" is health information created or received by a covered entity, and which relates to:

- a past, present, or future physical or mental health condition of an individual;
- the provision of health care to the individual; or

• payment for the provision of health care to an individual,

and that identifies or reasonably could be used to identify the individual. ¹⁰⁵ There are no restrictions on the use or disclosure of de-identified health information. ¹⁰⁶

F. WHO MUST COMPLY

1. WHO MUST COMPLY WITH ARTICLE 27-F'S CONFIDENTIALITY REQUIREMENTS

Article 27-F's confidentiality requirements apply to any person or agency who obtains HIV-related information either:

- in the course of providing one or more "health or social services" (as defined below) to individuals, or
- pursuant to a proper, HIV-specific release form authorizing the disclosure of confidential HIV-related information.¹⁰⁷

a. PROVIDERS OF COVERED HEALTH OR SOCIAL SERVICES

"Health or social services" covered by this law include a wide range of health and social services provided by public and private individuals and organizations in New York, including:

- any kind of care or treatment, clinical laboratory tests, counseling services for adults or children, educational services for adults or children, and home care or health care (including acute, chronic, custodial, residential, and outpatient care) services provided pursuant to the Public Health Law or Social Services Law:
- "public assistance or care" as defined in Article I of the Social Services Law, which includes Medicaid, various forms of welfare, institutional care for adults, and publicly funded child care;
- employment-related services, housing and shelter services, foster care, protective services, day care, and preventive services that are provided pursuant to the Social Services Law;
- services for individuals with mental disabilities, which, as defined in Mental Hygiene Law § 1.03(3)), include mental illness, retardation, developmental disabilities, alcoholism and substance dependence; and
- criminal justice services: probation, parole, correctional, and detention services and rehabilitative services for youth provided under laws dealing with aspects of the state's criminal and juvenile justice systems.¹⁰⁸

All agencies providing these health and social services — including ALL staff and volunteers — must comply with Article 27-F's confidentiality requirements. So must health care providers that are associated with or under contract to health maintenance organizations (HMOs) or other medical services plans. ¹⁰⁹

 $^{^{105}}$ 45 C.F.R. \S 160.103.

¹⁰⁶ 45 C.F.R. §§ 164.502(d)(2), 164.514(a) and (b).

¹⁰⁷ N.Y. Pub. Health Law § 2782.

 $^{^{108}}$ N.Y. Pub. Health Law $\S~2780(8)$.

¹⁰⁹ N.Y. Pub. Health Law § 2784.

b. THOSE WHO RECEIVE HIV-RELATED INFORMATION PURSUANT TO RELEASE

People and agencies (whether or not they provide any of the "health or social services" just described) must comply with the law's confidentiality requirements when they get HIV-related information pursuant to a proper HIV-specific release form (see page 36).

c. GOVERNMENTAL AGENCIES AND EMPLOYEES

State and local government. Article 27-F's confidentiality requirements apply to state and local governmental agencies and their employees when they obtain HIV-related information about individuals in the course of providing health or social services under a government program, or in the course of monitoring other providers of such services to individuals, or when they obtain such information pursuant to a proper release form. State and local Health Departments and public health staff must also comply with the confidentiality requirements of the HIV Reporting and Partner Notification Law in handling any information about people with HIV/AIDS and their contacts pursuant to that law (see pages 51-60).

Federal government. State laws, including Article 27-F, cannot directly control federal agencies, such as the Social Security Administration (which administers disability benefits), or the Veterans Administration. However, Article 27-F's confidentiality requirements do apply to most providers who may be asked to disclose HIV-related information about their clients to those federal agencies and their employees.

Also, any individual in New York — including federal employees — who receives HIV-related information in accordance with the requirements of Article 27-F must comply with the law's restrictions on disclosure and re-disclosure. This means that if a case worker at the Social Security Administration (not generally covered by the law) receives HIV-related information about an applicant for disability benefits from a physician (who is covered by the law), that case worker may not re-disclose that information unless authorized by Article 27-F.

Note that Article 27-F does not apply to the military or to federal prisons.

d. AGENCIES WITH CERTAIN STATE CONTRACTS

Agencies that are not "health or social service providers" may nonetheless be required to comply with Article 27-F's mandates through contract with the state or local government.

Many community-based HIV/AIDS service providers are not included in Article 27-F's definition of covered "health or social service" providers. Only information they obtain pursuant to HIV-specific release form would be protected by the law. To make sure that they and their staff protect their clients' confidentiality, organizations funded through the Department of Health AIDS Institute may be required to adhere to the law's mandates as a term of their state contracts. While confidentiality violations might not subject these agencies to the penalties specified in Article 27-F (see pages 82-85), they would place them in breach of contract with the AIDS Institute.

¹¹⁰ N.Y. Pub. Health Law §§ 2782(6); 2786.

¹¹¹ N.Y. Pub. Health Law § 2782(3).

e. RECIPIENTS OF ARTICLE 27-F'S "NOTICE PROHIBITING RE-DISCLOSURE"

Anyone who receives a "notice prohibiting re-disclosure" of HIV-related information (see pages 41-42) must adhere to Article 27-F's mandates.

f. Anyone who received hiv-related information pursuant to article 27-F

Anyone to whom confidential HIV-related information was disclosed pursuant to Article 27-F is prohibited from re-disclosing the information unless authorized by that law, except if the disclosure was to:

- the protected individual (or person authorized by law to consent to the protected individual's health care);
- the protected indvidual's foster parent or other relative or legally responsible person with whom a child is to be placed when the disclosure is for the purpose of providing care, treatment, or supervision of the child (see page 65);
- a prospective adoptive parent with whom the protected individual has been placed for adoption. 112

This means that even if Article 27-F does not require sending a notice prohibiting redisclosure in a given circumstance, the recipient of confidential HIV-related information is nonetheless bound by Article 27-F unless the recipient falls into one of the three categories listed above.

2. WHO DOES NOT NEED TO COMPLY WITH ARTICLE 27-F'S CONFIDENTIALITY REQUIREMENTS

a. PROTECTED INDIVIDUALS THEMSELVES

A "protected individual" — the one who has been tested for or diagnosed with HIV/AIDS — is free to disclose his/her own HIV-related information. 113

PEOPLE AUTHORIZED TO ACT ON THE PROTECTED INDIVIDUAL'S BEHALF

When a protected individual lacks "capacity to consent" to disclosures of HIV-related information (see page 39), a person who is legally authorized to consent to health care for that individual may freely disclose HIV-related information about that individual to anyone else. ¹¹⁴ The only people likely to fit this description are:

- the parent(s) of a minor who lacks capacity to consent,
- the legal guardian of such a minor or of an individual adjudicated as incompetent,
- an individual's health care "agent" named in a health care proxy (see page 11), or
- a surrogate per the Family Healthcare Decisions Act¹¹⁵ (see page 11).

But only "natural persons" are covered under this rule. For example, an agency, such as the local child welfare agency, may be appointed as the legal guardian of a child in

¹¹² N.Y. Pub. Health Law § 2782(3).

¹¹³ N.Y. Pub. Health Law § 2782(3)(a).

¹¹⁴ N.Y. Pub. Health Law § 2782(3)(b).

¹¹⁵ N.Y. Pub. Health Law Art. 29-CC.

foster care, and may be given legal authority to consent to health care for that child. But, because a child welfare agency is not a "natural person," it remains subject to Article 27-F's confidentiality and disclosure requirements. The special rules that apply to foster parents and prospective adoptive parents are explained below (see pages 64-68).

3. OTHERS NOT SUBJECT TO THE LAW

a. FRIENDS, FAMILY AND OTHER NATURAL PERSONS

The law's confidentiality requirements do not apply to natural people — like an individual's parents or friends — who get HIV-related information about a person directly from that person, or from someone else who got the information in a way other than in the course of providing health or social services to the individual or others, or pursuant to an HIV-specific release form. For example:

- An HIV positive man (John) tells his sexual partner his HIV status. The sexual partner tells John's parents. Article 27-F does not apply to the sexual partner or the parents.
- A woman with HIV infection (Mary) tells her sister her diagnosis. Article 27-F does not apply to Mary's sister. If she re-discloses Mary's HIV status to others, she would not be violating Article 27-F.

b. JUDICIARY

Article 27-F's confidentiality requirements do not apply to courts (that is, to judges), and may not apply to court employees (such as court officers and clerks). However, virtually all health or social service providers and other individuals who may be asked to disclose HIV-related information to the courts are subject to the law.

c. POLICE

Article 27-F's confidentiality requirements do not apply to the police, but Constitutional privacy protections do apply to the police and other government agencies.

d. SCHOOLS

Public and private school personnel generally are not covered by Article 27-F, unless HIV-related information comes to particular school staff in the course of providing a covered health or social service or through release. The following school staff are covered:

- Health staff, such as the school nurse or mental health or drug/ alcohol counselor, who get HIV-related information in the course of providing a student "health services" within the law's definition.
 - For example, if a mother informs the school nurse that her daughter needs to take HIV medications during the school day, the nurse is bound by Article 27-F's confidentiality requirements because the nurse received the information while providing health services to the daughter.
- Any school staff who get HIV-related information pursuant to a proper HIV release form (such as a school nurse, health clinic, principal, or teacher).

Note: Constitutional privacy protections apply to public schools and their employees, even if Article 27-F does not apply.

e. EMPLOYERS

Employers are not covered by Article 27-F, except when they obtain HIV-related information about an employee pursuant to an HIV-specific release form. But many employers are bound by the confidentiality provisions of the federal Americans with Disabilities Act (see pages 98-99).

f. LANDLORDS

Except for those who provide housing and shelter services regulated by the Social Services Law — who are defined as covered "social services" providers — landlords are not subject to Article 27-F's confidentiality requirements unless they received HIV-related information about a housing applicant or tenant pursuant to an HIV-specific release form. Landlords who learn about a tenant's HIV status from the tenant or neighbors are not covered by Article 27-F. But Constitutional privacy protections apply to public (governmental) housing providers.

g. NEWSPAPERS AND OTHER MEDIA

h. CHURCHES AND OTHER HOUSES OF WORSHIP

i. SOME HEALTH AND SOCIAL SERVICE PROFESSIONALS

Professionals who do not work in one of the covered health or social services, or who get HIV-related information when off duty (not in connection with their work) are not covered. They are bound by Article 27-F only if they got the information pursuant to an HIV-specific release form. However, they may be covered by HIPAA or another confidentiality law (see page 25).

j. INSURANCE COMPANIES

Just as insurance companies are subject to special, less stringent rules with respect to HIV testing (see pages 5 and 22-23), Article 27-F's general confidentiality and disclosure rules do not apply to insurance companies or "insurance support organizations" (like the Medical Information Bureau, noted at page 5). Managed care organizations and health maintenance organizations (HMOs), however, are considered "insurance institutions" and "health care providers") under Article 27-F, according to the New York State Department of Health. Therefore, they need to comply with Article 27-F's general confidentiality requirements.

¹¹⁶ N.Y. Pub. Health Law §§ 2782(1)(i); 2784.

¹¹⁷ N.Y. Pub. Health Law § 2780(16).

¹¹⁸ N.Y. Pub. Health Law § 2782(13).

4. WHO MUST COMPLY WITH HIPAA'S CONFIDENTIALITY REQUIREMENTS

a. COVERED ENTITIES

All "covered entities" under HIPAA must comply with its Privacy Rule. A covered entity is:

- a health care provider who transmits any health information electronically in connection with specified covered financial and administrative transactions; 119
- a health plan (plan that provides, or pays the cost of, medical care); or
- a health care clearinghouse (entity that processes and/or facilitates the processing of health information from another entity). 120

HIPAA's privacy requirements do not apply to entities that are *not* "health care providers," "health plans" or "health care clearinghouses" as defined by HIPAA. While both "health and social service" providers must comply with Article 27-F, only those who are "health care providers" under HIPAA must comply with HIPAA.

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¹¹⁹ Examples of covered transactions include processing claims, payment and remittance, coordination of benefits, claim status, enrollment and dis-enrollment in a health plan, health plan eligibility, health plan premium payments, referral certification and authorization, first report of injury, and health claims attachments. 45 C.F.R. § 160.103. ¹²⁰ 45 C.F.R. §§ 160.102(a); 160.103; 164.104.

II. DISCLOSURES WITH CONSENT

A. THE RULE: CONSENT (IN AN HIV-SPECIFIC RELEASE FORM) REQUIRED

A person or agency that is subject to Article 27-may disclose HIV-related information about a protected individual who has signed a proper **written** release specifically authorizing that disclosure (or, if the individual lacks capacity to consent, a person authorized to consent to health care for that individual has signed the release form). Oral consent does not authorize disclosures under Article 27-F. All such release forms must be:

- voluntarily signed and revocable at any time; and
- in proper form, with all elements required by Article 27-F. 122

B. HIV-SPECIFIC RELEASE: REQUIRED ELEMENTS

Under Article 27-F, the HIV-specific release form must contain 8 elements to be valid:

- specific authorization to disclose **HIV-related information**;
- **name** of the person whose HIV-related information will be disclosed;
- **name** of the person/agency disclosing the HIV-related information;
- name of the **recipient** of the HIV-related information (see explanation on page 38);
- **reason** for the disclosure;
- **date** the release form is signed;
- **time period** during which the consent will remain in effect:
 - » the consent should not last longer than necessary to fulfill its purpose;
 - » the release can specify that it will remain in effect until a certain date (e.g., May 10, or "10 days after the date of this release"), or until the occurrence of a specified event or condition ("This release will remain in effect until the date I stop receiving case management services from ABC Services.");
 - » the Department of Health recommends that releases be renewed at least annually; and
- **signature** of the person whose HIV-related information will be released or, if that person lacks capacity to consent, signature of the person authorized to consent for that individual (see pages 39-41). 123

¹²¹ N.Y. Pub. Health Law § 2782(1)(a).

 $^{^{122}}$ N.Y. Pub. Health Law §§ 2780(9); 2786; 45 C.F.R § 164.508(b).

¹²³ N.Y. Pub. Health Law § 2780(9).

If an organization is covered by HIPAA, the release (which is called an "authorization" under HIPAA) must have an additional 2 elements:

- an explanation of the patient's **right to revoke** the authorization in writing and either a statement of the exceptions to the right to revoke, or, if the exceptions are included in the program's notice of patient's privacy rights, a reference to that notice; ¹²⁴ and
- a statement of the provider's **ability to condition treatment**, **payment**, **enrollment**, **or eligibility for benefits** on the consent (this must state either that the program may not condition services on the patient signing the consent or the consequences of refusing to sign the consent if the program may condition services on such signature). 125

The State Department of Health has developed two model forms that comply with both Article 27-F and HIPAA. The "Authorization for Release of Health Information and Confidential Related HIV-Related Information" (see Appendix E) can authorize the disclosure of HIV and non-HIV health information. The "Authorization for Release of Health Information (Including Alcohol/Drug Treatment and Mental Health Information) and Confidential HIV/AIDS-related Information" (see Appendix F) also can authorize the release of alcohol/drug treatment and mental health information. These forms also can be found on the website of the Department of Health, AIDS Institute, http://www.health.ny.gov/diseases/aids/forms/. Other state agencies have developed forms for use by providers funded or regulated by those agencies.

Although providers may develop other HIV-specific release forms for use by their staff, all release forms must contain information consistent with the Department of Health's standardized model forms.

C. GENERAL RELEASES NOT SUFFICIENT; SUBPOENAS NOT SUFFICIENT

A general release form authorizing disclosures of medical or other information about a pro-tected individual is not sufficient to authorize a disclosure of HIV-related information — unless that release form specifically indicates its dual purpose as a general authorization and a specific authorization for the release of confidential HIV-related information, and complies with Article 27-F's requirements, set out above. ¹²⁶ The only exception is for certain disclosures to insurers (see page 69).

A subpoena, by itself, neither permits nor compels any person or organization to release confidential HIV-related information.¹²⁷ To permit disclosures, a subpoena must be accompanied by either a proper HIV-specific release form or a special court order issued in compliance with Article 27-F (see pages 70-72).

¹²⁴ 45 C.F.R. § 164.508(c)(2)(i).

¹²⁵ 45 C.F.R § 164.508(c)(2)(ii).

¹²⁶ N.Y. Pub. Health Law § 2780(9).

¹²⁷ N.Y. Pub. Health Law § 2782(1).

D. PRACTICAL POINTERS FOR HIV-SPECIFIC RELEASE FORMS

1. DESCRIBING RECIPIENTS: GENERAL OR SPECIFIC?

Article 27-F requires an HIV-specific release form to "specify to whom disclosure is authorized." Thus, a general designation of a recipient — e.g., to "possible housing providers," or to "anyone who may be assigned to provide me home care" – does not satisfy the law's requirements. On the other hand, it would be permissible to ask a client to authorize disclosures by the agency to "any of the five housing providers listed below."

It is permissible to name an agency or organizational unit, provided that the whole organization (or unit) needs the HIV-related information to carry out the purposes specified in the release. A release form identifying a local Department of Social Services ("DSS") as the recipient, when only one unit or program within the DSS needs the information, is not permissible. Alternatively, the form can list the job title of pertinent staff who need the information, such as "my DSS caseworker" or "those DSS employees working on my case." The form does not have to list such individuals by name.

2. REVOCATION OF CONSENT

Under both Article 27-F and HIPAA, individuals have the right to revoke their consent to disclose HIV information at any time, for any reason. The revocation prevents the provider from making any further disclosure in reliance on that release form.

Under Article 27-F, individuals may revoke their consent orally or in writing. (Though HIPAA requires revocation of an authorization to be in writing, ¹²⁹ Article 27-F's "more stringent" provision applies.) Under Article 27-F, individuals do not have to use special language to revoke an HIV-specific release. For example, if a person who has previously signed a release form tells the provider, "I've changed my mind," or "I take back my release," those statements both operate as revocations of the release.

An individual's decision to revoke his/her consent must be documented in the client's record in a way that will ensure that all staff are aware of it. This can be done by a dated, large notation on the release form itself, or a visible notation elsewhere, such at the front of the client's chart. If HIV-related information has already been released, the person or agency that made the disclosure does not have an obligation to retrieve the information. However, individuals have a right to be informed, upon request, of any disclosures that have been made; and agencies should be prepared to respond to such requests (see page 77).

¹²⁸ N.Y. Pub. Health Law § 2780(9).

¹²⁹ 45 C.F.R § 164.508(c)(2).

¹³⁰ N.Y. Pub. Health Law § 2782(5)(b).

E. CAPACITY TO CONSENT TO DISCLOSURES

1. WHAT IS "CAPACITY TO CONSENT"?

Any individual who has "capacity to consent" generally has the right to decide whether to allow or forbid disclosures of HIV-related information about him/herself. Article 27-F defines "capacity to consent" in the same way for disclosure decisions as for HIV testing decisions¹³¹ (see pages 2, 5-11). Thus, each individual's capacity must be determined, without regard to age, by conducting an individualized assessment that asks:

- 1. Is this person able to understand and appreciate the nature and consequences of the proposed disclosure? That is, does the person understand:
 - "what is going to be disclosed, to whom and why?"
 - "what might happen (good and bad) as a result of this disclosure?"
- 2. Is this person able to make an informed decision about whether to permit it? That is
 - "am I making this decision voluntarily, or is someone forcing me?"

If both answers are yes, the individual's capacity to consent must be recognized, and his/her disclosure decision must be respected. The fact that an individual may have a mental or physical disability does not automatically determine capacity to consent.

If the answer to either question is no or doubtful, then those with responsibility for assessing the individual's capacity should either:

- **determine whether someone else is legally authorized** to consent to health care for that individual, identify that person, and decide whether to contact that person to obtain his/her consent to the disclosure (see Sections 3-6, below);
- **defer the disclosure** until the protected individual (re)gains capacity to consent; or
- determine whether the disclosure can be made without the individual's consent (see exceptions in section III).

Guidelines for assessing capacity in particular situations, including those involving minors and people with impairments, are discussed below.

2. WHO ASSESSES CAPACITY?

As with HIV testing, Article 27-F does not specify who should assess particular individuals' capacity to consent to disclosures. Nor does it require this assessment to be done by medical or mental health specialists. It makes sense for health and social service agencies to presume that most clients — adults and even adolescents — do have the capacity, and therefore the right, to make disclosure decisions about themselves. At the same time, providers should designate the staff responsible for making such assessments when questions arise in a particular case.

 $^{^{131}}$ N.Y. Pub. Health Law $\S~2780(5).$

3. INFANTS AND VERY YOUNG CHILDREN

a. DO THEY HAVE CAPACITY TO CONSENT?

Infants and very young children will not have capacity because they will not be able to satisfy the two-part test above.

b. WHO MAY CONSENT ON THEIR BEHALF?

When a child lacks capacity, it is permissible to seek consent for disclosure from a person legally authorized to consent to health care for the minor. ¹³² These persons are as follows:

Intact families. The birth parents ordinarily have legal authority to consent to health care — and so to HIV-related disclosures — for the child. 133

Foster care. Foster parents themselves may disclose HIV-related information about their own foster child "for the purpose of providing care, treatment or supervision" of the child; they do not need anyone's consent.¹³⁴ However, foster parents do not have the legal authority to give effective consent for others to disclose HIV-related information about their foster child. Consent for these disclosures must be obtained from the person(s) with legal authority to consent to health care for the foster child: either the child's birth parent (in cases of voluntary placement) or the local social services commissioner (when the commissioner has guardianship or protective custody of the child). (See also pages 6-8.)

Adoption. Once an adoption is finalized, the adoptive parents generally assume all parental rights; they thus have legal authority to consent to HIV-related disclosures. In addition, a prospective adoptive parent with whom a child has been placed for adoption is authorized to disclose HIV-related information about that child, without restriction and without obtaining the consent of anyone else. ¹³⁵ However, until adoption becomes final, the rules applicable to children in foster care govern disclosures by persons other than the prospective adoptive parents. (See also page 8.) ¹³⁶

4. OLDER CHILDREN AND ADOLESCENTS (UNDER AGE 18)

Minors (under age 18) may and often do have the capacity to consent to disclosure of HIV-related information about themselves. For older children or adolescents, providers must assess that particular individual's capacity to consent as described on pages 40-41.

If the older minor has capacity to consent to disclosure and declines to give it, no disclosure may be made, unless —

¹³² N.Y. Pub. Health Law § 2781(1).

¹³³ N.Y. Pub. Health Law § 2504(2).

¹³⁴ N.Y. Pub. Health Law § 2782(3)(c).

¹³⁵ N.Y. Pub. Health Law § 2782(3)(d).

¹³⁶ These rules are explained in an administrative directive issued by the former State Department of Social Services (now the State Office of Children and Family Services), entitled Foster Care: Assessment of Foster Children for Capacity to Consent and HIV Risk; Counseling of Adolescents; Legal Consent for HIV Testing; Documentation and Disclosure, 97 ADM-15 (July 24, 1997) ("OCFS 97 ADM-15"). The New York City Administration for Children's Services also has issued a bulletin on the subject, Bulletin 98-2/Procedure 101, HIV Related Assessment, Testing, Counseling and Clinical Trial Enrollment of Children and Youth in Foster Care (December 30, 1998). That agency's Pediatric AIDS Unit handles questions about HIV-related disclosures concerning foster care children (212-341-8943).

- that child is in foster care and the disclosure is required under rules for children in foster care (see pages 64-68); or
- Article 27-F allows the disclosure without consent. (See pages 49-51 regarding notifying parents about a minor's HIV status, and pages 70-72 regarding court- ordered disclosures.)

5. INDIVIDUALS WHO HAVE BEEN ADJUDICATED INCOMPETENT

a. DO THEY HAVE CAPACITY?

As with HIV testing (see page 10), a person who has been judicially declared incompetent to make health care decisions will not have the capacity to consent to disclosures of HIV-related information.

b. WHO MAY CONSENT ON THEIR BEHALF?

The person appointed as the individual's legal guardian may be given the authority to make health care decisions including the right to consent to HIV-related disclosures.

6. INDIVIDUALS WITH TEMPORARY INCAPACITY

a. DO THEY HAVE CAPACITY?

Sometimes, a person will lack capacity to consent to a disclosure of HIV-related information because of conditions that temporarily impair the person's cognitive abilities or judgment, or because of other physical or mental conditions. For example, a client might be intoxicated or under the influence of drugs, experiencing stress or other psychiatric problems, unconscious or comatose. In these circumstances, the provider may wish to defer making the disclosure.

b. WHO MAY CONSENT ON THEIR BEHALF?

In these cases, if the individual has a health care proxy in place, consent may be sought from the health care agent (see page 11). Alternatively, in a hospital or nursing home, a "surrogate" selected pursuant to the Family Health Care Decisions Act can provide consent (see pages 11-12).¹³⁷

F. NOTICE PROHIBITING RE-DISCLOSURE

Article 27-F generally requires that when any disclosure is made pursuant to this law, including disclosures made pursuant to consent, the disclosure shall be accompanied by a "notice prohibiting redisclosure," 138 which informs the recipient that it is now bound by Article 27-F and may not re-disclose HIV-related information without consent or as otherwise permitted by law (see Appendix G). 139 The notice does *not* need to be sent, however, when the disclosure is:

 $^{^{137}}$ N.Y. Pub. Health Law, Art. 29-CC.

¹³⁸ N.Y. Pub. Health Law § 2782(5)(a).

¹³⁹ N.Y. Pub. Health Law § 2780(9).

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- to a health care provider and is necessary for the care or treatment of the individual or the individual's child;
- to a third party for health care reimbursement;
- to the protected individual;
- by a physician conducting contact notification; or
- by a physician to the parents of a minor.

(All of these disclosures are discussed in greater detail in Section III). Therefore, when any provider is disclosing HIV-related information pursuant to consent, the provider should send the notice prohibiting re-disclosure unless one of the five circumstances above, applies. The notice prohibiting re-disclosure must accompany any written disclosures and must follow oral disclosures within 10 days.¹⁴⁰

¹⁴⁰ N.Y. Pub. Health Law § 2782(5)(b).

III. DISCLOSURES WITHOUT CONSENT

Article 27-F and HIPAA permit the disclosure of confidential HIV-related information without consent in a limited number of circumstances. These "exceptions" fall into the following basic categories:

- Protected individuals
- Internal communications among authorized staff
- Health care providers/facilities (when necessary for care)
- Physicians' disclosures about minors and incompetent adults to their parents or guardians
- HIV/AIDS case reporting
- Contact reporting and notification
- Newborn HIV test results
- Occupational exposure
- Foster care or adoption
- Insurers
- Court-ordered disclosures
- Program monitoring, evaluation or review
- Medical education, research or therapy
- Criminal justice-related disclosures
- Child abuse/neglect and elder abuse/neglect
- Administrators and executors of estates

A. PROTECTED INDIVIDUALS

1. DISCLOSURES TO INDIVIDUALS ABOUT THEMSELVES

Health and social service agency staff may disclose HIV-related information to the protected individual him/herself without consent. When the client lacks capacity to consent, disclosures may be made to a person authorized by law to consent to health care for the client. In such cases, providers must confirm that the person to whom they make a disclosure is in fact "authorized by law to consent to health care for that individual." (This problem arises primarily in cases of disclosures about a minor; see pages 6-10.)

Providers should be careful to ascertain whether the client already knows or wants to know his/her HIV status before launching into discussions with that client about his/her diagnosis. As noted previously (see page 16), individuals have the right not to know their HIV-related diagnosis.

¹⁴¹ N.Y. Pub. Health Law § 2782(1)(a); 45 C.F.R. § 164.524; see also 45 C.F.R. § 164.510(a)(3).

2. DISCLOSURES BY INDIVIDUALS ABOUT THEMSELVES

Any individual with HIV may inform any other person about his/her own HIV status. ¹⁴² However, providers should counsel their clients about the possible consequences of such disclosures. For example, because the client's friends and family are not bound by Article 27-F or HIPAA, they could re-disclose this sensitive information to anyone, and the client would have no remedy under the HIV confidentiality law.

B. INTERNAL COMMUNICATIONS

1. THE RULE

Internal Communications

Authorized employees of a health or social service provider may share confidential HIV-related information about their clients within their agency, without consent, *if* they:

- are on agency's written "need to know" list, and
- reasonably need the information to provide services.

2. WHO COMES UNDER THE INTERNAL COMMUNICATIONS RULE

The internal communications rule applies to:

- providers of health or social services who are subject to Article 27-F (listed on page 30), including health care facilities and providers listed on page 46; and
- state and local governmental agencies that become subject to Article 27-F (see page 31).

3. WHICH "INTERNAL COMMUNICATIONS" ARE ALLOWED

The internal communications rule allows employees of an entity that is covered by Article 27-F to have access to and share confidential HIV-related information about clients without their consent **if those employees:**

- are **allowed access to client records** in the ordinary course of business (this means medical records for health care providers and facilities; client records for other health or social services);
- are specifically authorized **in the agency's written "need-to-know" protocol** to have access to HIV-related information about the clients in question (the regulations implementing Article 27-F require all covered health and social service providers to have "need-to-know" protocols); and
- have a reasonable need to know or share the information to carry out their authorized duties in providing, supervising, administering or monitoring the services.¹⁴³

¹⁴² N.Y. Pub. Health Law § 2782(3).

¹⁴³ N.Y. Pub. Health Law §§ 2782(1)(c); 2782(6)(b); and 2786(2).

4. HOW COVERED AGENCIES CAN CREATE A NEED-TO-KNOW PROTOCOL

Although Article 27-F does not specify which employees belong in the need-to-know circle, the law does require providers to establish protocols specifying which employees have access to confidential HIV-related information.

Covered agencies should take the following steps to create and implement their policies:

a. CONDUCT AN AGENCY-SPECIFIC ASSESSMENT

Assess which staff legitimately need to have or share HIV-related information about clients.

Permissible reasons include:

- providing direct care/services to the clients;
- performing administrative, billing or reimbursement functions;
- planning, coordinating or supervising services to clients (for example, when staff work in "teams").

Impermissible reasons include:

- "infection control" as discussed in on page 47, staff are not entitled to learn a client's HIV status solely for the purpose of protecting themselves from potential exposure to HIV;
- belief that employees have a "right to know" (they do not). HIV-related information may not be shared to satisfy employees' curiosity.

b. CREATE A WRITTEN NEED-TO-KNOW PROTOCOL

The protocol should describe who may have or share HIV-related information on a need-to-know basis by:

- listing the job titles of those with authorized access, and
- describing the functions of each job that justify having and sharing HIVrelated information.

c. DISSEMINATE THE PROTOCOL AND TRAIN STAFF

Give the protocol to all staff, not just those on the need-to-know list.

Internal communications of HIV-related information under this exception need not be noted in the client's record. Nor is the notice prohibiting re-disclosure required (see page 41).

HIPAA also requires covered entities to make reasonable efforts to limit the information shared internally to "the minimum necessary to accomplish the intended purpose." ¹⁴⁴

Section IV (pages 76-81) contains more information about how to record and maintain HIV-related information securely.

¹⁴⁴ 45 C.F.R. § 164.502(b)(1).

C. DISCLOSURES TO HEALTH CARE PROVIDERS AND HEALTH FACILITIES

1. THE RULE

Health Care Provider Rule

HIV-related information may be disclosed, without consent, to a health care provider or facility when:

- knowing it is necessary for that provider to give appropriate care or treatment to
 - the protected individual,
 - his/her child, or
 - a contact of the protected individual.

2. HEALTH CARE PROVIDERS AND HEALTH FACILITIES COVERED BY THIS EXCEPTION

Disclosures without HIV-specific consent may be made to "health care providers" and "health facilities" in certain situations, as discussed at pages 47-49, below.¹⁴⁵

"Health facilities" include:

- hospitals,
- blood, sperm, organ and tissue banks,
- laboratories, and
- facilities providing care or treatment to persons with a "mental disability"—including mental illness, mental retardation, developmental disabilities, alcoholism or substance dependence. 146

"Health care providers" include:

- physicians,
- nurses,
- providers of services for persons with "mental disabilities" (as defined above),
- other medical, nursing, counseling, health or mental health care service providers, including those associated with health maintenance organizations and medical service plans, and
- licensed or certified providers of diagnostic medical services, including nurse practitioners, midwives and physician assistants.¹⁴⁷

This exception, therefore, authorizes unconsented-to disclosures to a fairly broad array of health and mental health facilities and providers (hereafter "health care providers"). At the same time, the disclosures can only be made in certain circumstances, discussed below.

This exception does not permit disclosures to institutions or persons who are not included within the above definition of "health care providers" and "health facilities" — such as day care facilities, schools, housing and many other social service providers.

¹⁴⁵ N.Y. Pub. Health Law § 2782(1)(d).

 $^{^{146}}$ N.Y. Pub. Health Law $\$ 2780(12); N.Y. Mental Hyg. Law $\$ 1.03(3).

¹⁴⁷ N.Y. Pub. Health Law § 2780(13); 10 N.Y.C.R.R. § 63.1(j).

3. WHEN KNOWING HIV INFORMATION IS "NECESSARY" FOR CARE

As highlighted in the "rule" box, above, a health care provider may be given HIV-related information about an individual when it is necessary for that health care provider (or one or more of its employees) to know the client's HIV status or related diagnosis in order to provide appropriate care to that client, her child, her contact (or a person authorized to consent to health care for the contact) (see page 27 for definition of "contact), or an occupationally exposed individual (see pages 62-64. HIPAA also permits these disclosures. Here

a. APPLYING THE STANDARD

Article 27-F does not specify when a health care provider/facility must be given HIV-related information about an individual in his/her care. This must be assessed on a case-by-case basis.

i. DISCLOSURES FOR "INFECTION CONTROL" NOT ALLOWED

Under standards developed by the State Department of Health, it is not necessary — and not permissible — to disclose an individual's HIV status to a health care provider solely for "infection control" purposes, i.e., to protect health care workers from possible exposure to HIV.¹⁵⁰

This is because casual contact creates no risk of HIV transmission, and health care workers and others can effectively minimize their risk of occupational exposure through universal infection control precautions that must be in place regardless of whether a particular individual's HIV status is known. Article 27-F regulations require health care providers to develop and implement universal infection control protocols, and to educate their employees about and monitor compliance with them. If health care providers only take precautions when they know a patient is infected, they are putting themselves at unnecessary risk.

ii. NO GENERAL "RIGHT TO KNOW"

Some providers believe that they have a "right to know" the HIV status of their patients, either because they wish to take additional infection control precautions for those known to be infected, or because they assume they always need this information to treat individuals. They have no such legal right, though. Nor do patients (or their providers) have a legal obligation to tell health care providers their HIV status.

iii. EXAMPLES

• **EMS.** Jan, who is HIV-positive, is at her HIV case management office where she falls unconscious, hits her head, and bleeds. The case management office calls emergency medical services (EMS), and EMS asks about Jan's medications. May the case management office tell EMS about Jan's HIV medications or her HIV status?

Yes. The agency may tell EMS about Jan's HIV medications and her HIV status so that EMS can provide the appropriate care to Jan en

¹⁴⁸ N.Y. Pub. Health Law § 2782(1)(d).

¹⁴⁹ 45 C.F.R. § 164.506(c).

¹⁵⁰ 10 N.Y.C.R.R. § 63.6(j).

route to the hospital, and convey the information to the hospital upon arrival. If Jan were conscious, the agency could permit her to make her own disclosure.

• **Referral to Specialist.** Sam has seen a primary care physician since his HIV diagnosis three years ago. His primary care physician now plans to refer him to a specialist. Does the physician's office need an HIV-specific release form to disclose Sam's HIV status to the specialist?

No. The primary care physician may disclose Sam's HIV-related information to the specialist because it is necessary for the specialist to provide appropriate care and treatment to Sam.

4. WHO DECIDES WHETHER A DISCLOSURE IS "NECESSARY" FOR THE PATIENT'S CARE?

The provider or individual in possession of the confidential HIV-related information — not the outside health care provider requesting the confidential HIV-related information — has the discretion to decide whether the requesting provider really needs to know the client's HIV status to appropriately treat or care for that individual (or his child or contact). A health care provider cannot compel any other agency to make such a disclosure if that agency chooses not to do so.

It makes sense for health and social service agencies to designate the specific staff members with responsibility for deciding, on a case-by-case basis, when and to whom unconsented-to disclosures may be made. If the agency does not have medical staff, making such judgments obviously can be difficult. The designated staff person must use his/her best judgment.

5. SHOULD PROVIDERS ASK THE CLIENT TO SIGN AN HIV-SPECIFIC RELEASE ANYWAY?

The Department of Health recommends that when there is no emergency, community-based organizations should always seek consent from the client anyway before disclosing HIV-related information to outside health care providers. This is so even when the outside provider may need that information in order to provide the client appropriate care or treatment.

6. LIMITING DISCLOSURES TO AUTHORIZED STAFF

People making disclosures under this exception must be careful about the person(s) to whom they disclose confidential information. The only employee(s) of a health care provider or facility who may be given HIV-related information under this exception are those who –

- are authorized (under the health care provider's written "need to know" protocol) to have access to medical records, and
- provide health care to the subject of the information, or maintain the provider's medical records for billing or reimbursement purposes.

These criteria are more fully discussed in the Internal Communications section (page 44).

7. DOCUMENTATION

Any disclosure must be documented in the agency's medical records pertaining to the individual whose HIV-related information is disclosed (see page 76). The notice prohibiting re-disclosure (see page 41) does *not* need to be sent to the health care provider/facility receiving the information under this rule.¹⁵¹

D. PHYSICIANS' DISCLOSURES ABOUT MINORS AND INCOMPETENT ADULTS TO PARENTS/LEGAL GUARDIANS

Physicians (but no one else) may sometimes disclose HIV-related information about a minor, even without an HIV-specific release form, to a person who is authorized by law to consent to health care for the minor — usually the parent or legal guardian. This special rule also permits physicians to make unconsented-to disclosures about persons who have been judicially declared incompetent to those who are authorized to consent to health care on the person's behalf — again, usually the parent or legal guardian. The discussion in this section focuses mainly on disclosures about minors because it is more common and often more controversial than disclosures about persons adjudicated incompetent.

1. THE RULE

Physician Disclosures to Parents/Guardians

Physicians may disclose HIV-related information about a minor child or incompetent adult to parents/legal guardians *if* physician reasonably believes:

- disclosure is medically necessary for timely care and treatment, and
- minor/incompetent adult will not inform parent/guardian, even after counseling about need for disclosure.

But *not* if, in physician's judgement:

- disclosure would not be in minor/incompetent's best interest, or
- minor/incompetent has authority to consent to own treatment

2. APPLYING THE RULE

Article 27-F does not impose any parental notification requirement on physicians or anyone else who learns of a minor's HIV status or related condition. Parents may, of course, be notified if their minor child signs an HIV-specific release form. Parents may also be given HIV-related information about an infant or a young child who lacks capacity to consent (see page 65).

For practical purposes, this rule only comes into play with older minors who have capacity to consent. In these cases, physicians who wish to make a disclosure should always first seek the minor's consent. But, except in the two circumstances explained below, a physician may tell parents HIV-related information about their minor child even without the minor's consent, when **the physician reasonably believes that both:**

 $^{^{151}}$ N.Y. Pub. Health Law $\S~2782(5).$

¹⁵² N.Y. Pub. Health Law § 2782(4)(e).

- The minor will not inform, even after being given appropriate counseling (which is required) about the need to inform the parent/guardian; **and**
- <u>Informing the parents is necessary for care.</u> Disclosure is permissible only if the physician makes a reasonable judgment that informing the parent(s) about the minor's HIV status is "medically necessary in order to provide timely care and treatment" to the minor. ¹⁵³

If, for example, the physician does not believe that the minor needs treatment for a particular problem at the time, or believes that parental involvement is not needed to secure the needed treatment, the disclosure would not be warranted. The rule does not permit physicians to tell a minor's parents about his HIV status simply because they feel that parents should know.

On the other hand, if parental consent is required to authorize a particular treatment (and the parent's knowledge of the minor's HIV status has a bearing on this), the law allows the physician's disclosure.

Two circumstances barring any disclosure. Even if both of the above conditions are satisfied, however, the law prohibits doctors from informing parents/guardians when, in the physician's judgment, **either:**

- <u>Disclosure would not be in minor's best interests.</u>¹⁵⁴ While Article 27-F does not explain when a disclosure would run counter to a minor's best interests, possible circumstances include
 - » where there is a risk of domestic violence or adverse actions against the minor by the parent/guardian or others associated with them, or
 - » where the minor is a "street kid" who has no relationship with his parent/guardian, or is otherwise so alienated from them that contacting them would not facilitate appropriate care and treatment; or
- Minor has legal authority to consent to the care or treatment in question. ¹⁵⁵ As explained previously, minors generally do not have the right to consent to their own health care; their parents or legal guardians do. In the following circumstances, however, minors do have the right to consent to their own health care:
 - » when the minor is married, a parent, or pregnant;
 - » in emergencies requiring immediate medical care; and
 - when the minor seeks treatment for certain specific health problems, such as sexually transmitted diseases (see pages 8-9).

In these cases, physicians are forbidden from making any HIV-related disclosure to the minor's parents. (See also the discussion about minors and consent to treatment for HIV/AIDS, on page 9.)

¹⁵³ N.Y. Pub. Health Law § 2782(4)(e).

¹⁵⁴ N.Y. Pub. Health Law § 2782(4)(e)(A).

¹⁵⁵ N.Y. Pub. Health Law § 2782(4)(e)(B).

Similarly, HIPAA permits a health care provider to disclose health related information to the legal guardian or "personal representative" of a minor, but it also defers to State law. ¹⁵⁶ Consequently, such disclosures may only be made within the limits prescribed by Article 27-F.

3. NO LIABILITY FOR NOT DISCLOSING

Article 27-F never obligates a physician to notify the parent/legal guardian. Physicians (and their employers or associated health care providers) may not be held liable for failing to disclose HIV-related information to a parent/guardian. ¹⁵⁷

4. DOCUMENTATION

A physician who makes a decision or takes action under this rule must document the reason(s) in the minor/incompetent person's medical record. However, the physician does not need to provide the notice prohibiting re-disclosure that must accompany most disclosures of HIV-related information (see page 41). ¹⁵⁸

E. HIV/AIDS CASE REPORTING

1. THE RULE

HIV/AIDS Case Reporting

Physicians and other diagnostic providers must report:

- each case of HIV infection, HIV-related illness, and AIDS upon initial diagnosis,
- name of person diagnosed, and
- name of contacts (sexual and needle sharing partners) known by or given to the provider.

2. WHAT MUST BE REPORTED

Under the HIV Reporting and Partner Notification Law, which took effect on June 1, 2000, each case of HIV infection (except those diagnosed through anonymous testing), HIV-related illness, and AIDS must be reported to public health authorities on forms developed by the Department of Health. The reports must include:

- name and address of the individual with HIV disease;
- diagnostic and other information about the case;
- name and address of contacts known to or provided to the reporter (see page 27 for definition of "contacts");
- information about partner notification efforts completed or planned for each identified contact; and
- information concerning the mandated domestic violence screening

¹⁵⁶ 45 C.F.R. § 164.502(g).

¹⁵⁷ N.Y. Pub. Health Law § 2783(3)(a).

¹⁵⁸ N.Y. Pub. Health Law §§ 2782(4)(e); 2782(5)(a).

required to be conducted with respect to each contact for whom notification is being considered. 159

Upon receiving a case report, the Department of Health or local public health officials may follow up with the reporter and request additional information to enable them to monitor the HIV epidemic and facilitate contact notification when they determine that it is merited to protect the public health.¹⁶⁰

3. WHEN THE REPORT MUST BE MADE

The report must be made upon "determination" or "diagnosis" of HIV infection, HIV-related illness, and/or AIDS, and upon periodic monitoring of HIV infection by laboratory tests. ¹⁶¹ The following must be reported:

- any antigen or antibody tests or combination of tests indicative of HIV infection;
- HIV nucleic acid (RNA or DNA) detection test results;
- all CD4 counts (unless the test is performed for non-HIV-related reasons); HIV subtype and antiviral drug resistance testing;
- certain other diagnostic tests that the Department of Health may determine indicate an HIV infection, HIV-related illness or AIDS; ¹⁶² and
- clinical diagnoses of AIDS-defining illnesses.

4. WHO MUST REPORT

Four categories of medical providers and entities are mandated case reporters:

- physicians and other persons authorized to order diagnostic tests or make medical diagnoses — or their agents. Diagnostic providers include physicians, nurse practitioners, physician assistants and midwives who are authorized to order diagnostic tests and make clinical diagnoses;¹⁶³
- **laboratories** performing diagnostic tests for screening, diagnosis or monitoring of HIV infection;
- **medical examiners, pathologists, or coroners** when HIV testing is done to determine cause of death; and
- blood and tissue banks and organ procurement organizations. 164

No one else is required to submit HIV case reports (or may, without the individual's consent). That includes counselors or other mental health providers who learn of the individual's HIV infection, public assistance and child welfare workers, employers, family members, etc. Doctors who are treating a patient with HIV, who are not the "diagnostic provider" making the initial diagnosis of HIV, HIV-related illness or AIDS, are not mandated to make HIV case reports.

 $^{^{159}}$ N.Y. Pub. Health Law §§ 2130, 2132; 10 N.Y.C.R.R. § 63.4.

¹⁶⁰ 10 N.Y.C.R.R. § 63.4(b).

¹⁶¹ N.Y. Pub. Health Law § 2130; 10 N.Y.C.R.R. § 63.4.

¹⁶² 10 N.Y.C.R.R. § 63.4(a)(4).

¹⁶³ 10 N.Y.C.R.R. § 63.1(k).

 $^{^{164}}$ N.Y. Pub. Health Law §§ 2130; 2132; 10 N.Y.C.R.R. § 63.4(a).

Anonymous testing. Results of tests performed at anonymous test sites will not be reported unless the tested person voluntarily decides to convert the test to a confidential one. ¹⁶⁵ If an anonymously tested person decides to seek medical care, however, the physician or other diagnostic provider who confirms the HIV diagnosis must report.

5. WHO RECEIVES THE REPORTS

Cases must be reported to the State Department of Health, which must promptly forward them to designated local public health officials in the county/city where the protected person lives. ¹⁶⁶

6. CONFIDENTIALITY OF CASE REPORTS

State and local public health officials **must keep confidential** all reports and information they obtain in connection with case reporting and contact notification activities. They may only use the information to track the HIV epidemic or facilitate partner notification efforts (where merited to protect the public health); and other than re-disclosure to the protected individual, may only re-disclose this information as follows:

- <u>within New York State</u>: to other public health officials only if, in the public health official's judgment, the disclosure is necessary for monitoring the HIV/ AIDS epidemic or to conduct notification activities (see page 56).
- <u>outside New York State</u>: contact names and locating information may be disclosed to public health officials in other states if necessary to notify the contact or for purposes of de-duplication, but the identity of the protected individual may not be disclosed.¹⁶⁷

7. PENALTY FOR NOT REPORTING

A mandated reporter who fails to adhere to the HIV/AIDS case reporting law can be subject to civil fines and be required to comply with the law. Prior to April 1, 2014, the civil fine can be up to \$2,000 per violation, and after April 1, 2014, can go up to \$10,000 if the violation causes serious physical harm. ¹⁶⁸ If the violation is "wilful," the mandated reporter could be criminally prosecuted for committing a misdemeanor and be subject to fines. ¹⁶⁹

¹⁶⁵ N.Y. Pub. Health Law § 2138; 10 N.Y.C.R.R. § 63.4(b).

¹⁶⁶ N.Y. Pub. Health Law § 2130; 10 N.Y.C.R.R. §§ 63.4(a), 63.8(a)(2).

¹⁶⁷ N.Y. Pub. Health Law §§ 2134; 2135; 10 N.Y.C.R.R. § 63.4(c).

 $^{^{168}}$ N.Y. Pub. Health Law $\S~12.$

 $^{^{169}}$ N.Y. Pub. Health Law \S 12-b.

F. CONTACT (PARTNER) REPORTING AND NOTIFICATION

1. THE RULE

Contact Reporting and Notification

Reporting: Mandated HIV/SIDS case reporters (physicians and other diagnostic providers) must report to public health officials

- names/other information about known contacts, and
- information about their own contact notification efforts.

Notification:

- Public health officials must notify contacts about possible exposure to HIV if they determine that notification is merited to protect public health.
- Physicians may notify contacts in certain circumstances, but are not obligated to.

Confidentiality: Name of infected individual may *not* be revealed during notification.

With the passage of the HIV Reporting and Partner Notification Law in 2000, the reporting of an infected patient's contacts by physicians and diagnosing providers became a mandatory part of HIV/AIDS case reporting, and partner notification efforts are required in certain cases. At the same time, the law safeguards the identity of the HIV positive person during the notification process, and is designed to ensure that notification not occur where it could result in domestic violence to the protected individual or contact. HIPAA permits health care providers to comply with all state partner notification laws.¹⁷⁰

2. REPORTING OF CONTACTS

a. WHAT IS A "CONTACT"?

"Contacts" (or "partners") are a protected individual's identified:

- spouse (present or past, dating back 10 years);
- sexual partners (dating back 10 years); and
- needle sharing partners. 171

Occupationally exposed persons are not included in this definition for notification purposes, but see pages 62-64 regarding disclosure when there has been an occupational exposure.

b. WHO MUST (AND MAY) REPORT CONTACTS

i. MANDATORY REPORTING OF CONTACTS.

Physicians and other diagnostic providers who also are mandated HIV/AIDS case reporters have a legal duty to report the known contacts of an individual whose case of HIV infection, HIV-related illness or AIDS they initially diagnose

¹⁷⁰ 45 C.F.R. § 164.512(b)(1)(iv).

¹⁷¹ N.Y. Pub. Health Law § 2780(10); 10 N.Y.C.R.R. § 63.1(m).

and report. This duty applies only to those who are mandated to report the case, and requires only the reporting of those contacts known to or provided to the reporter at the time the mandated case report is made (see page 52, on who must make case reports, and when).

ii. PHYSICIANS' DISCRETIONARY REPORTING OF CONTACTS.

Except for reporting known contacts when making mandated HIV/AIDS case reports, physicians have no obligation to locate or identify any contact.¹⁷² But physicians may, without obtaining an HIV-specific release form, report the names of contacts (as well as information about the HIV-infected patient involved) to public health authorities for the purpose of initiating notification efforts, if:

- the physician believes that notification is **medically appropriate** and there is a significant risk of infection to the contact;¹⁷³ and
- the physician or his agent has given the protected individual the counseling and information about notification described below and the required domestic violence screening has been applied (see page 58).¹⁷⁴

iii. OTHERS.

No one else has a duty to report any contact, or may (except as page 59 notes).

c. WHAT MUST BE REPORTED

When making a mandated HIV/AIDS case report, the physician or other diagnostic provider must report the following contact information:

- information identifying the protected individual, including his/her name and address, contact and locating information, and other information including demographic information;
- the names and addresses, if available, of contacts known to the reporter or provided to the reporter by the protected individual; this includes contacts that the reporter
 - » learns about while providing medical care to the individual,
 - » learns from the individual in post-test counseling, and
 - » already knows about even through other sources;
- information concerning the required domestic violence screening for each reported contact (see page 58);
- whether the reporter conducted post-test counseling;
- whether the notification has been done or, if not, whether the reporter intends to notify the contact(s) personally or make a referral to public health authorities for notification; and
- if the reporter conducted the notification, the results, including the date each contact was notified. 1775

 $^{^{172}}$ N.Y. Pub. Health Law §§ 2782(4)(c); 2783(3); 10 N.Y.C.R.R. 63.8(i).

¹⁷³ N.Y. Pub. Health Law § 2782(4)(a)(2).

¹⁷⁴ N.Y. Pub. Health Law §§ 2782(4)(a); 2137; 10 N.Y.C.R.R.§§ 63.4(b); 63.8(l).

 $^{^{175}}$ N.Y. Pub. Health Law $\$ 2130(3); 10 N.Y.C.R.R. $\$ 63.4; 63.8(a)(1).

d. WHO RECEIVES THE REPORTS

Information about known contacts must be included in mandated HIV/AIDS case reports to the State Department of Health, which must promptly forward it to designated local public health officials in the county/city where the protected person lives. ¹⁷⁶ Physicians who exercise their discretion to report contacts at other times (see page 56) may call the partner notification assistance programs listed on page 57.

e. TIME LIMIT ON MAINTAINING CONTACT INFORMATION

Local public health officials must forward information about their contact notification activities to the State Department of Health. Neither state nor local public health officials may maintain contact names (obtained from the reporter or from their own contact notification activities) for more than three years following completion of notification activities.¹⁷⁷

3. CONTACT NOTIFICATION

a. WHEN NOTIFICATION MUST AND MAY BE DONE

i. BY PUBLIC HEALTH AUTHORITIES

Public health officials have the primary responsibility for conducting or verifying that contact notification has been done. They must take "reasonable measures" to follow up contact reports and undertake notification efforts when they determine that it is **merited in order to protect the public health.**¹⁷⁸ In deciding when notification is "merited," they must give priority to those cases where:

- <u>contacts were reported</u>: contacts are identified in HIV/AIDS case reports, including spouses and individuals whom the HIV positive person wants to have notified, unless the reporter certifies that they have already been notified; and
- <u>new diagnosis:</u> the report concerns a person newly diagnosed with HIV infection.¹⁷⁹

Public health staff also must respond to all requests from individuals with HIV/AIDS and their health care providers for assistance in notifying contacts. 180

ii. BY PHYSICIANS

Physicians are **never obligated** to — and cannot be held liable if they do not — notify contacts personally. ¹⁸¹ (They must, however, report known contacts to the public health authorities, when making mandated case reports. See above.)

At any time, a physician may directly notify the patient's contact(s), or may ask public health officials to do so, if the patient signs an HIV-specific release form. If

¹⁷⁶ N.Y. Pub. Health Law § 2130; 10 N.Y.C.R.R. §§ 63.4(b); 63.8(a)(2).

¹⁷⁷ 10 N.Y.C.R.R. § 63.8(j).

¹⁷⁸ N.Y. Pub. Health Law §§ 2133(1) and 2782(4)(a)(6).

¹⁷⁹ 10 N.Y.C.R.R. § 63.8(b).

¹⁸⁰ 10 N.Y.C.R.R. § 63.8(e).

¹⁸¹ N.Y. Pub. Health Law § 2783(3)(a); 10 N.Y.C.R.R. §63.8(i).

the patient does not sign an HIV-specific release form, then in circumstances other than mandated HIV/AIDS case reporting, a physician may initiate notification — by disclosing the patient's and contacts' names to public health officials and asking them to do the notification, or by notifying contacts directly — but **only** if the physician:

- concludes that notification is **medically appropriate** and that the contact may face a **significant risk of infection**;
- counsels (or tries to counsel) the HIV-positive individual about the need to notify the contact;
- conducts the required domestic violence screening with respect to each contact, in accordance with the Department of Health protocol (see below); and
- informs the patient of:
 - » the physician's intent to notify the contact(s),
 - » the physician's responsibility to report the case and contact(s) to the public health authorities,
 - » the patient's option to express a preference for the physician or public health staff to do the notification (the physician must honor a patient's preference for public health authorities to do the notification but, even when a patient prefers that the physician do it, can decline and have it done by public health staff instead), and
 - » the fact that the protected individual's name may not be disclosed during notification. 182

Physicians and patients may prefer to have public health staff notify contacts since they always perform notifications in person and are specially trained. These contact notification programs are:

- New York State Department of Health "Partner Services": 800-541-AIDS, and
- New York City Contact Notification Assistance Program (C-NAP): 212-693-1419 or 311.

iii. BLOOD, ORGAN AND TISSUE DONATIONS

Blood banks, organ procurement organizations, and tissue banks that ascertain that their donors are HIV positive may disclose that information to the donor's physician so that known contacts can be notified. 183

b. COMMUNICATING WITH THE PROTECTED INDIVIDUAL

When public health officials conduct notification activities, they must confirm that the protected individual has received post-test counseling, which must include counseling about HIV-positive individuals' need to notify their contacts and their notification options (see page 15).

¹⁸² N.Y. Pub. Health Law § 2782(4)(a); 10 N.Y.C.R.R. § 63.8(a)(l).

¹⁸³ 10 N.Y.C.R.R. § 63.8(k).

Public health staff may communicate with the protected person, when needed, to seek cooperation in notification efforts, verify information about the identity or location of known contacts, and conduct or confirm the domestic violence screening and make necessary referrals. But any communications with the individual must be in a confidential, private and safe manner.

If the individual cannot be located for post-test counseling or declines to be assessed for domestic violence risk, the public health official must determine, in consultation with the reporting physician, whether to proceed with contact notification.¹⁸⁴

c. DOMESTIC VIOLENCE SCREENING

Neither public health authorities nor physicians may notify any contact without first assessing the risk of domestic violence to the protected individual and contact in accordance with a protocol developed by the Department of Health, and addressing any such risk. 185

Therefore, local public health authorities may not conduct notification without first confirming (or obtaining) and considering information from the domestic violence screening protocol. (The Department of Health has published various materials regarding the domestic violence screening protocol, which can be obtained through the AIDS Institute's website, www.health.ny.gov/diseases/aids.) In so doing, they may consult with the provider who made the case or contact report and consider information that the protected individual gave, and if necessary, they may communicate directly with the protected individual in a confidential, safe manner.

Notification may not occur unless the official is satisfied, in his/her professional judgment, that "reasonable arrangements, efforts or referrals to address the safety of affected persons have been made." Department of Health guidelines advise that notification should be deferred if the domestic violence screening indicates a risk of severe negative effect on the health and safety of the protected individual, his/her children or person(s) close to them, or a contact.

d. NOTIFYING THE CONTACT

Public health officials must make a "good faith effort" to notify known contacts where merited to protect the public health and, where the contacts live outside of the protected individual's jurisdiction, to notify public health officials in the contact's jurisdiction. ¹⁸⁷ In doing this, they (as well as physicians who conduct notification activities) must adhere to the following rules.

i. COUNSELING THE CONTACT

The person notifying the contact must provide counseling or make an appropriate referral for counseling and testing. This counseling must be in person unless reasonable circumstances prevent it (for instance, the contact prefers it to occur by phone). The counseling must address:

¹⁸⁴ 10 N.Y.C.R.R. § 63.8(f).

 $^{^{185}}$ N.Y. Pub. Health Law §§ 2133, 2137; 10 N.Y.C.R.R. § 63.8(c).

¹⁸⁶ 10 N.Y.C.R.R. § 63.8(c).

¹⁸⁷ 10 N.Y.C.R.R. §63.8(a)(3).

- coping emotionally with potential exposure to HIV;
- domestic violence issues;
- the nature of HIV infection and HIV-related illness, including, where appropriate, the risk of prenatal and perinatal transmission;
- the availability of anonymous and confidential testing;
- preventing exposure or transmission of HIV infection;
- discrimination that might occur from HIV-related disclosures; and
- legal protections against such disclosures. 188

ii. CONFIDENTIALITY

The person notifying the contact **may not disclose** to the contact:

- the **identity of the protected individual** (even if the contact is a spouse); or
- the identity of any other contact. 189

This protection applies even if the protected person is deceased.¹⁹⁰ Of course, not revealing the protected individual's name does not always guarantee confidentiality. A contact who has been monogamous and has not shared drug injection equipment may still be able to ascertain the infected person's identity. This is one reason the risk of domestic violence must be assessed and addressed before notification may proceed.

iii. DEALING WITH "VULNERABLE" POPULATIONS, INCLUDING ADOLESCENTS

When public health officials conduct notification involving "vulnerable" populations (e.g., adolescents and individuals in residential and institutional settings), they must follow Department of Health guidelines (available on the Department of Health AIDS Institute website at www.health.ny.gov/diseases/aids). 191

4. HOW TO "WARN" CONTACTS IF YOU ARE NOT A PHYSICIAN OR PUBLIC HEALTH OFFICIAL

Providers and individuals other than physicians and diagnostic providers who are mandated HIV/AIDS case reporters have **no legal duty to notify (or ask public health authorities to notify) any contact,** including spouses. Nevertheless, they may believe they have a professional, therapeutic or ethical obligation to warn those at risk of infection through unsafe sex or sharing needles with an HIV-positive person. They may only do so as follows:

a. EDUCATE THE CLIENT

Educate the client about special confidential programs that help with partner services, including making anonymous and on-line notifications. These are New York State Department of Health Partner Services at 800-541-AIDS and, in New York City, the Contact Notification Assistance Program (CNAP) at (212) 693-1419 or 311 (see page 57).

¹⁸⁸ N.Y. Pub. Health Law §§ 2133(2), (4); 10 N.Y.C.R.R. § 63.8(g).

¹⁸⁹ N.Y. Pub. Health Law § 2133(3); 10 N.Y.C.R.R. § 63.8(a).

¹⁹⁰ 10 N.Y.C.R.R. §63.8(h).

¹⁹¹ 10 N.Y.C.R.R. § 63.8(d).

b. WITH AN HIV-SPECIFIC RELEASE FORM

Obtain an HIV-specific release form from the protected individual (see page 36) authorizing the provider to either tell the contact or help the client tell the contact, or call Partner Services or CNAP;

c. IN SOME CASES, THROUGH A PHYSICIAN

Providers with physicians on staff may be authorized (under the internal communications rule, explained at pages 44-45) to give those physicians the relevant information and ask them to initiate any needed notification;

d. ANONYMOUS CALL TO DEPARTMENT OF HEALTH

The provider and client could call Partner Services or CNAP together, and the client can choose to either not disclose his/her status at all or self-disclose during the call. The provider should document the client's oral consent for this call; or

e. COURT ORDER

Seek a court order under Article 27-F that will authorize the disclosures needed to ensure the contact is notified, on the ground that the court-ordered disclosure is necessary to prevent "a clear and imminent danger to someone whose life or health may unknowingly be at significant risk as a result of contact" with the individual (see pages 70-71).

G. ACCESS TO NEWBORN HIV TESTING INFORMATION

1. THE RULE

Newborn Testing

Results of a newborn's HIV test must be disclosed to the:

- mother (unless she lacks capacity to consent to the newborn's health care),
- newborn's physician, and
- State Department of Health.

New York's newborn HIV testing requirement was discussed in Part 1, page 18. This section discusses who has access to the newborn's test results. Because a newborn HIV test is in reality a test of the mother (a positive test reveals that the mother has HIV, but not necessarily that the newborn is infected), the confidentiality law protects the information with respect to both the newborn and mother. ¹⁹² The following are required to receive newborn test results, whether or not the mother signs an HIV-specific release.

¹⁹² 10 N.Y.C.R.R. §§ 69-1.3(1)(3), 69-1.5(g)(3).

a. MOTHER

If positive, a newborn's HIV test results must be disclosed to the mother, unless she lacks capacity to consent to health care for the newborn. In such cases, the results must be given to the individual with authority to consent to such care (which, depending on the circumstances, might be the father or other person authorized by law). This means that the father does not have the legal right to obtain the newborn's test result unless the mother lacks capacity to consent, and the father is the individual with authority to consent to health care for the newborn. If there is no record that the mother had an HIV test during the pregnancy, the results must be given "as soon as practicable," but no later than twelve hours after birth. 194

b. PHYSICIAN

The newborn's HIV test results (positive or negative) must be given to the newborn's physician/primary health care provider. As the child ages, the records may be disclosed to other health care providers on the same basis as any other individual's HIV-related information: when necessary for care of treatment of the child (see pages 46-47). The newborn's test results also must be given to the mother's physician. ¹⁹⁵

c. SPECIALIZED CARE CENTERS

When the newborn's physician requests, the newborn's HIV test results must be disclosed to an HIV specialized care center — a publicly funded facility to which HIV-positive newborns and their mothers must be referred. 196

d. STATE DEPARTMENT OF HEALTH

The delivering hospital must provide the Department of Health with the names of newborns who test positive, as well as other data required by the Department of Health. ¹⁹⁷ These disclosures are all permitted under HIPAA, as well, because HIPAA allows disclosures to parents and guardians of minors and to health care providers for purposes of treatment, and disclosures required under state public health reporting laws.

2. DOCUMENTING THE TEST RESULTS

Newborn HIV test results, like all other HIV test results (see page 76), must be documented in the newborn's medical record. 198

¹⁹³ Department of Health memorandum, Series 97-2, 1/24/97.

¹⁹⁴ 10 N.Y.C.R.R. § 69-1.3(1)(2).

¹⁹⁵ 10 N.Y.C.R.R. § 69-1.5(g)(4).

¹⁹⁶ 10 N.Y.C.R.R. § 69-1.5.

¹⁹⁷ 10 N.Y.C.R.R. §§ 69-1.3(6); 69-1.4(2); 69-1.5(6).

¹⁹⁸ N.Y. Pub. Health Law § 2782(8); 10 N.Y.C.R.R. §§ 69-1.3(1)(3); 69-1.5(g)(3).

H. OCCUPATIONAL EXPOSURES

Article 27-F allows the physicians of individuals who may have experienced an on-the-job exposure to HIV in specified occupational settings to be told the HIV status of the "source" of the exposure in limited circumstances, without the source's consent. ¹⁹⁹ In limited circumstances, Article 27-F also allows for HIV testing of the "source" (see page 20). ²⁰⁰

Such disclosures are also permitted under HIPAA, which allows disclosures of protected health information to a health care provider for the purpose of treatment, and also allows disclosure of protected health information to an individual when it is necessary to prevent or lessen a serious and imminent threat to the health of the individual.²⁰¹

1. THE RULE

Occupational Exposure

"Source" person's HIV status may be disclosed to occupationally exposed worker if:

- the exposure occurred in job setting covered by the law,
- there is risk of transmission of HIV as determined by medical experts, and
- procedural and other requirements have been met.

2. OCCUPATIONAL SETTINGS WHERE RULE APPLIES

Disclosures of the source patient's status are only allowed in cases where staff, employees, or volunteers are exposed while performing their professional duties in the following occupational settings:

- Medical or dental offices (public or private);
- Facilities regulated, authorized or supervised by specified state agencies:
 - » Department of Health (e.g., hospitals, laboratories, home health care providers);
 - » Office of Alcoholism and Substance Abuse Services (e.g., alcohol and drug treatment facilities);
 - » Office of Mental Health (e.g., halfway houses);
 - » Office for People with Developmental Disabilities²⁰² (e.g., community residences, group homes);
 - » Office of Children and Family Services (e.g., foster care agencies)
 - » Department of Correctional Services (state prisons); and

¹⁹⁹ 10 N.Y.C.R.R. §63.8(m).

²⁰⁰ N.Y. Pub. Health Law § 2781(6)(e).

²⁰¹ 45 C.F.R. § 164.512(j).

²⁰² Note that the regulations still refer to this agency by its previous name, the Office of Mental Retardation and Developmental Disabilities.

• Settings where emergency response personnel (paid or volunteer) — Including emergency medical technicians, firefighters, law enforcement officers (police, probation, parole), or local correctional officers or medical staff — are performing an emergency response function.²⁰³ However, if the emergency response employee is governed by federal law, federal law will govern, not Article 27-F.²⁰⁴

Disclosures of the source patient's status are not allowed for occupational exposure in facilities not on this list, such as schools, day care centers, churches, and community-based organizations.

3. WHEN DISCLOSURES CAN BE MADE

Disclosures are permitted only when all of these conditions are met:

a. ON-THE-JOB EXPOSURE

When exposure occurs during performance of the employee's job, in one of the occupational settings discussed above;

b. RISK OF HIV TRANSMISSION

The incident must present a risk of HIV transmission, as determined by medical experts in accordance with Department of Health standards. This means:

- exposure is to one of these potentially infectious body substances: blood, semen, vaginal secretions, breast milk, tissue or certain other fluids (exposure to other substances including urine, feces, saliva, sweat, tears, nasal secretions, vomit not containing visible blood does not present a risk); and
- there is direct contact between the potentially infectious substance and the employee's non-intact skin (e.g., open wound), mucous membranes (e.g., eyes, nose, mouth), or vascular system (examples include needle sticks, puncture wounds and direct saturation/permeation of non-intact skin; but not human bites without direct blood-to-blood or blood-to-mucous membrane contact, contact with intact skin, contacts in settings where scientifically accepted barrier techniques are not breached).²⁰⁵

c. INCIDENT REPORT

A report detailing the exposure, including witnesses, must be filed with supervisory staff;²⁰⁶

d. REQUEST BY EXPOSED WORKER

The exposed worker or his/her medical provider must request the information about the source's HIV status as soon as possible after the incident, and must need the information to decide whether to begin or continue post-exposure prophylaxis;²⁰⁷ and

²⁰³ 10 N.Y.C.R.R. § 63.8(m)(3).

²⁰⁴ 10 N.Y.C.R.R. § 63.8(m).

²⁰⁵ 10 N.Y.C.R.R. §§ 63.8(m)(1)-(2); 63.10(d).

²⁰⁶ 10 N.Y.C.R.R. § 63.8(m)(4).

²⁰⁷ 10 N.Y.C.R.R. § 63.8(m)(5).

e. DOCUMENTATION

The request must be documented in the exposed employee's medical record, although the rule does not require the employee's test result to be put in his/her personnel records. 208

When all of the above conditions are met, and the appropriate health care provider or medical officer determines, in his/her professional judgment, that there is a risk of transmission, the provider or officer may disclose the HIV status of the source, if known, to the exposed person's physician and, without identifying the name of source patient, to the exposed person.²⁰⁹

4. CONFIDENTIALITY

The **source's name may not be provided** to the exposed employee. If the employee already knows the source's identity, s/he may not disclose the source's HIV status to anyone, except as authorized by the law. The provider or officer who released the source's HIV status to the exposed employee is also prohibiting from re-disclosing the source's HIV status, except as permitted by law.²¹⁰

5. TESTING THE SOURCE

Providers may, in certain circumstances, test the source of an occupational exposure to determine his/her HIV status, and reveal the results of the test (but not the source's identity) to the exposed employee. For a detailed discussion of testing the source of an occupational exposure, see page 20.

6. OCCUPATIONAL EXPOSURES IN SETTINGS NOT COVERED BY THIS EXCEPTION

If an occupational exposure occurs in a setting not covered by this exception (e.g., school, church, or community based organization), the source's HIV status may be disclosed only with the source's consent, with a court order issued under Article 27-F (see pages 70-72), or as otherwise authorized by Article 27-F.

I. FOSTER CARE AND ADOPTION

Many parties involved in foster care and adoption want — and may legitimately need — HIV-related information about foster and adoptive children, as well as their foster, adoptive and birth parents. This section discusses the circumstances under which this information may and, in some cases, must be shared among the interested parties without consent.

(See also page 40, explaining who has authority to consent to HIV-related disclosures about children, including foster children, and pages 6-9, dealing with HIV testing of children in foster care.) Two publications by the New York State Office of Children and Family Services (OCFS) provide useful guidance on these issues: Working Together: Health Services for Children in Foster Care ("Working Together") (3/1/09) and Foster Care: Assessment of Foster Children for Capacity to Consent and HIV Risk; Counseling of Adolescents; Legal Consent for HIV Testing; Documentation and

²⁰⁸ 10 N.Y.C.R.R. § 63.8(m)(6).

²⁰⁹ 10 N.Y.C.R.R. § 63.8(m)(7).

 $^{^{210}}$ Id.

Disclosure, 97 ADM-15, July 24, 1997 ("OCFS 97 ADM-15"). Both are available on the OCFS website at www.ocfs.state.ny.us.

1. DISCLOSURES ABOUT FOSTER CARE AND ADOPTIVE CHILDREN'S HIV STATUS

a. DISCLOSURES TO "AUTHORIZED AGENCIES"

Health and social service providers (and others covered by the law) may disclose HIV-related information about foster care or pre- or post-adoptive children, without consent, to "an authorized agency in connection with foster care or adoption of a child." An "authorized agency" includes –

- licensed foster care and adoption agencies that are authorized by the State Office of Children and Family Services or local social services district to care for, place out or board out children;
- government social service officials who are authorized by law to place out or board out children; and
- any court.²¹²

Disclosures are justifiable only when the HIV-related information is directly relevant to a particular foster care or adoption proceeding. And, though consent is not required, obtaining an HIV-specific release form where practicable is consistent with the general philosophy of Article 27-F favoring consensual disclosures.

b. DISCLOSURES BY "AUTHORIZED AGENCIES"

The authorized agencies referred to in this section are foster care and adoption agencies, and the governmental social service agencies and officials responsible for foster care and adoption matters.

i. TO FOSTER/ADOPTIVE PARENTS

"Authorized agencies" **must** disclose the "medical history" of a child in foster care or adoption proceedings — including HIV-related information — to the child's prospective and current foster/adoptive parents 213 as described below. These disclosures are permitted by Article 27-F. 214

<u>Upon placement into foster care</u>, to the extent the information is available. Prospective adoptive parents of a child legally freed for adoption should be given it once they have been determined to meet the criteria for adoption, have indicated an interest in adopting a particular child, and the agency has begun the placement agreement process.

<u>After placement, upon request.</u> Once a child is in foster care or has been adopted, medical history (including HIV) information about the child must be disclosed "upon request" by the adoptive/foster parent.²¹⁵ Medical history information

²¹¹ N.Y. Pub. Health Law § 2782(1)(h).

²¹² N.Y. Soc. Svc. Law § 371(10).

N.Y. Soc. Svc. Law § 373-a. The regulations refer to the medical history as a "comprehensive health history." 18 N.Y.C.R.R. §§ 357.3(b); 421.2(d).

²¹⁴ N.Y. Pub. Health Law § 2781(1)(h).

²¹⁵ N.Y. Soc. Svc. Law § 373-a.

about the child's birth parents also must be given to foster/adoptive parents (see page 68).

These disclosures are required whether or not the child has capacity to consent, or signs an HIV-specific release form. This means, for example, that if an adolescent in foster care chooses to have a confidential (as opposed to anonymous) HIV test, the results will be given to the foster parents even if the adolescent does not consent to the disclosure. In contrast, the birth parents of a foster child with capacity to consent generally may not be told their child's test results or any other HIV-related information without the child's consent (see pages 49-51).

ii. TO LAW GUARDIANS

"Authorized agencies" **must** disclose HIV-related information "relating to" a foster/adoptive child to the child's law guardian (the lawyer who represents the child's interests in foster care, adoption, or child abuse and neglect proceedings) without consent (even if the child has capacity to consent), **but only** for the purpose of representing the child in that proceeding or certain other family law matters.²¹⁶

Since this rule permits disclosure of any HIV-related information "relating to the minor," a law guardian also may be given HIV-related information about a foster/adoptive child's siblings, assuming it is necessary for representing the minor.

Re-disclosure by the law guardian. If the child has capacity to consent, the law guardian may not re-disclose the information (e.g., to the court, birth parent or anyone else) without an HIV-specific release form signed by the child or as authorized by a court order issued in accordance with Article 27-F (see pages 70-72). If the child lacks capacity to consent, the law guardian may re-disclose the information, but only for the purpose of representing the child.²¹⁷ The law guardian may sometimes re-disclose the information to the birth parent(s) of a child who lacks capacity to consent, but only when necessary and relevant to the legal proceeding.

iii. TO OTHER FOSTER CARE/ADOPTION AGENCIES

"Authorized agencies" **must** disclose the "medical history" – including HIV-related information – to other authorized foster care/adoption agencies when the child is transferred there, regardless of the child's capacity to consent.²¹⁸

iv. TO THE FOSTER CHILD

"Authorized agencies" **must** disclose the "medical history" – including HIV-related information – to the foster child who is discharged to his own care or is adopted and requests the information, regardless of the child's capacity to consent.²¹⁹

²¹⁶ N.Y. Pub. Health Law § 2782(1)(p); Working Together, p. 7-7; OCFS 97 ADM-15, p. 31.

²¹⁷ N.Y. Pub. Health Law § 2782(1)(p).

 $^{^{218}}$ 18 N.Y.C.R.R. \S 357.3(b)(1); Working Together, p. 7-7; OCFS 97 ADM-15, p. 31.

²¹⁹ 18 N.Y.C.R.R. § 357.3(b)(6); Working Together, p. 7-7; OCFS 97 ADM-15, p. 31.

v. TO THE BIRTH PARENTS

"Authorized agencies" **must** disclose HIV-related information to the birth parents without consent *if* the child lacks capacity to consent, but only with the child's consent, if the child has capacity.²²⁰

vi. TO SERVICE PROVIDERS

"Authorized agencies" **must** disclose HIV-related information to community service providers (e.g., psychologist, home aide, day care or school staff) when necessary to obtain essential health or social services for the child, *but only* if the local social services commissioner or designee has signed an HIV-specific release form authorizing the disclosure (see page 36 regarding who has authority to give consent).

Note that disclosures to day care and school staff may be made only when necessary for administration of medication or another medical need. ²²¹

vii. TO THE COURT; IN COURT

Since courts are "authorized agencies," Article 27-F allows foster/adoptive agencies to give them HIV-related information, without consent, "in connection with foster care or adoption of [the] child."²²²

Foster/adoptive agencies may also make in-court disclosures about such children, if authorized by consent from the appropriate person. They must disclose HIV-related information in a court hearing related to the foster child if ordered by a judge in accordance with the court order provisions of Article 27-F.²²³

c. DISCLOSURES BY FOSTER/ADOPTIVE PARENTS

Foster parents may disclose HIV-related information about their own foster child without consent, but only for the "purpose of providing care, treatment or supervision" of the child.²²⁴ In other instances, the foster parents must obtain consent from the appropriate person (e.g., birth parent or social service officials, depending on the case).

Prospective adoptive parents with whom a child has been placed and adoptive parents may freely disclose HIV-related information about their child.²²⁵

d. DISCLOSURES BY BIRTH PARENTS

Birth parents who retain the legal authority to make health care decisions for their child in foster care may freely disclose HIV-related information about their own child who lacks capacity to consent (§ 2782(1)(a)). Birth parents who learn from their own child his/her HIV status may legally re-disclose it.

²²⁰ Working Together, p. 7-7; OCFS 97 ADM-15, p. 31. See also 18 N.Y.C.R.R. § 357.3(b)(5), requiring the disclosure of HIV-related information to parent/guardian when child is released to their care, but only with consent of the child if the child has capacity to consent.

²²¹ Working Together, p. 7-7; OCFS 97 ADM-15, p. 32.

²²² N.Y. Pub. Health Law § 2782(1)(h).

²²³ Working Together, p. 7-7; OCFS 97 ADM-15, pp. 31-32.

²²⁴ N.Y. Pub. Health Law §2782(3)(c), (e)

²²⁵ N.Y. Pub. Health Law § 2782(3)(d); Working Together, p. 7-7; OCFS 97 ADM-15, p. 32.

e. DISCLOSURES BY THE FAMILY COURT

The court may disclose HIV-related information about a child in connection with foster care or adoption proceedings²²⁶ and may issue an order authorizing others to disclose such information, but only in accordance with the special court order requirements explained at pages 70-72.

2. DISCLOSURES ABOUT FOSTER AND PRE-ADOPTIVE PARENTS' HIV STATUS

a. DISCLOSURES BY AUTHORIZED AGENCIES

"Authorized agencies" must maintain the confidentiality of HIV-related information about foster and pre-adoptive parents.²²⁷ They may not re-disclose it to their foster/adoptive child's birth parent or others without an HIV-specific release form or an authorizing court order.

Nor should they generally re-disclose it to the court without the foster/adoptive parent's consent. Though the law allows HIV-related disclosures to courts "in connection with foster care or adoption of a child",²²⁸ this type of a non-consensual disclosure would be justifiable only if directly relevant to the case. The mere fact that a foster/adoptive parent has HIV/AIDS does not supply that justification.

3. DISCLOSURES ABOUT BIRTH PARENTS' HIV STATUS

a. TO FOSTER/ADOPTIVE PARENTS

The Social Services Law requires "authorized agencies" to give prospective and current foster/adoptive parents the "medical histories" (including available HIV-related information) of the birth parents of a child legally freed for adoption or placed in foster care, just as it does with the child's medical history, and in the same time frames (see page 65).²²⁹ However, the identity of the birth parent may not be disclosed to the foster/adoptive parents, unless either:

- the birth parent signs an HIV-specific release form; or
- the court issues an order authorizing disclosure of the parent's identity along with the HIV-related information, in accordance with Article 27-F's court order requirements (explained at pages 70-72).²³⁰

b. TO LAW GUARDIANS

"Authorized agencies" **must** disclose HIV-related information "relating to" a foster/ adoptive child — which sometimes might include HIV-related information about the child's birth parents, if directly relevant to the issues in the case — to the child's law guardian, but only if necessary to represent the child (see page 66).²³¹ Law guardians

 $^{^{226}}$ N.Y. Pub. Health Law $\$ 2782(1)(h).

²²⁷ N.Y. Pub. Health Law § 2782(3).

²²⁸ N.Y. Pub. Health Law § 2782(1)(h).

²²⁹ N.Y. Soc. Svc. Law § 373-a; 10 N.Y.C.R.R. § 357.3(b).

 $^{^{230}}$ N.Y. Soc. Svc. Law \S 373-a.

²³¹ N.Y. Pub. Health Law §2782(1)(p).

must comply with Article 27-F in re-disclosing any information about the birth parents' HIV status.

c. TO FOSTER/ADOPTIVE CHILD

"Authorized agencies" **must** disclose the birth parent's "medical history" – including HIV-related information – to the foster child who is discharged to his own care or is adopted and requests the information. However, information identifying the birth parents must be eliminated.²³²

J. DISCLOSURES TO THIRD-PARTY PAYERS AND INSURERS

As noted previously, Article 27-F has limited application to insurers (see pages 22 and 34). But health and social service providers and others who are covered by Article 27-F must comply with the law in disclosing HIV-related information about individuals to insurance companies and other third-party payers. This section explains how providers may disclose HIV-related information to insurers. In short, they generally do not need the HIV-specific release form required in other contexts.

Although HIPAA permits providers to disclosure health information for purposes of payment and health care operations without a release, Article 27-F is "more stringent" regarding release of HIV-related information to insurers and other third-party payers (as described below), and therefore providers must comply with Article 27-F. However, insurers and other third party payers, while subject to HIPAA as "health plans," are generally not subject to Article 27-F's confidentiality requirements (see page 34).

1. HEALTH CARE REIMBURSEMENT CLAIMS

When health care providers contact insurers to obtain reimbursement for health care services, they generally are not required to get consent on an HIV-specific release form. Instead, they may use an "otherwise appropriate authorization," which means an authorization for the release of medical records.²³³ This provision, however, has several important limitations:

- For health care reimbursement only. It only applies when the disclosure to the insurance company is for the purpose of getting reimbursed for health care.
- **General release still needed.** The provider must obtain "appropriate authorization" as required by other applicable laws or regulations. General release forms authorizing the release of medical information will satisfy legal requirements for most health care providers. However, most alcohol and drug treatment programs must use the special release forms required by federal law.²³⁴
- **Disclose only "to the extent necessary"** to obtain reimbursement for the health services. For example, if a provider seeks reimbursement for HIV-specific health care, the provider may need to release HIV-specific information so the third-party payer can verify the nature of the services provided. But if the provider seeks reimbursement for treating a broken ankle, then there may be no need to disclose HIV-specific information.²³⁵

²³² N.Y. Soc. Svc. Law § 373-a; 18 N.Y.C.R.R. § 357.3(b)(6).

²³³ N.Y. Pub. Health Law §§ 2782(1)(i); 2784.

 $^{^{234}}$ See 42 U.S.C §§ 290dd-2; 42 C.F.R. Pt. 2, § 2.31.

 $^{^{235}}$ N.Y. Pub. Health Law $\S~2782(1)(i)$.

2. DISCLOSURES TO INSURERS FOR OTHER PURPOSES

Article 27-F states that health and social service providers that disclose information to insurance institutions (including HMOs and MCOs) for purposes other than reimbursement for health care services — for example, in connection with a disability, life or health insurance application, or for quality assurance or utilization review — do not need to use the special HIV-specific release form. However, the law then describes the type of written authorization that these insurers must use, and it is virtually identical to the HIV-specific release form. ²³⁶ Providers also must give the insurer the notice prohibiting re-disclosure (see page 41). ²³⁷

K. COURT-ORDERED DISCLOSURES

Article 27-F establishes four permissible grounds for issuing a special court order authorizing the disclosure of confidential HIV-related information about an individual.²³⁸ Although HIPAA has less restrictive rules governing subpoenas and court orders, Article 27-F is "more stringent" and therefore providers must follow it when dealing with subpoenas and court orders.

1. THE RULE

Court Orders

Courts may order disclosure of HIV-related information if special procedures are followed and the court finds:

- compelling need for disclosure for adjudication of a criminal or civil case, or
- clear and imminent danger to life or health of person unknowingly at significant risk, or
- clear and imminent danger to public health, or
- applicant is lawfully entitled to the information, and disclosure is consistent with Article 27-F.

a. COMPELLING NEED FOR ADJUDICATION OF A CRIMINAL OR CIVIL CASE

A court might find a "compelling need" for a disclosure in a civil case²³⁹ where, for example, Jane sued John for infecting her with HIV by having unprotected sex without disclosing his HIV status. Some courts have found a "compelling need" to disclose John's HIV status because Jane's claim is dependent on his being HIV positive. Such a "compelling need" might be found in a criminal case if, for example, Joe were being prosecuted for the crime of reckless endangerment for having unprotected sex without divulging he had HIV. At least one court has ordered the defendant's HIV status disclosed, as necessary to prove such a case.

b. CLEAR AND IMMINENT DANGER TO AN INDIVIDUAL'S LIFE OR HEALTH

A court may order a disclosure where it finds "a clear and imminent danger to an individual whose life or health may unknowingly be at significant risk as a result of contact" with the individual about whom the HIV-related information pertains. ²⁴⁰ This could justify an

 $^{^{236}}$ See N.Y. Pub. Health Law $\S~2782(1)(j).$

 $^{^{237}}$ N.Y. Pub. Health Law $\S~2782(5).$

²³⁸ N.Y. Pub. Health Law § 2785.

²³⁹ N.Y. Pub. Health Law § 2785(2)(a).

²⁴⁰ N.Y. Pub. Health Law § 2785(2)(b).

order permitting a wife to be told that her husband is infected, where she is unaware of his diagnosis, and identifying him is the only effective way to warn her of her risk.

c. CLEAR AND IMMINENT DANGER TO THE PUBLIC HEALTH

Only public health authorities may seek an authorizing order on this ground.²⁴¹ At the time this manual was published, the authors knew of only one time when such an order was granted by a New York court: in a highly publicized case about a man with HIV who, without revealing his status, had unprotected sex with many teenage girls. The court authorized his name and picture to be published to help criminal justice authorities locate him, and to alert his sexual contacts about his HIV status.

d. APPLICANT LAWFULLY ENTITLED TO THE DISCLOSURE

One example of when an applicant is lawfully entitled to the disclosure is where someone is seeking HIV-related information from a party who refuses to give it even though the disclosure is legal under Article 27-F.²⁴²

e. ADDITIONAL FINDING REQUIRED BY COURT

In assessing whether there is a "compelling need" or a "clear and imminent danger" under the first three grounds for issuing orders authorizing disclosures, the court must:

- make written findings of fact, including scientific or medical findings, and must cite specific evidence in the record to support each finding; and
- weigh the need for the disclosure against the harm it would cause to the individual's privacy, as well as to the public's interest in encouraging testing and preventing discrimination.²⁴³

2. COURTS ONLY; SUBPOENAS NOT SUFFICIENT

Only a court of competent jurisdiction may issue an order authorizing a disclosure of confidential HIV-related information,²⁴⁴ and only an order issued in compliance with Article 27-F's special requirements can validly permit or compel disclosure. Thus, while a federal or state court may order disclosure, administrative bodies (such as arbitrators in union grievance proceedings, or hearing officers in welfare or unemployment insurance agencies) may not.

A subpoena, by itself, may not authorize or compel the disclosure of any confidential HIV-related information (even if the subpoena is issued by a court or signed by a judge). While a subpoena is an "order," in that it commands someone to do something, it does not constitute the special kind of court order required under Article 27-F. (See page 79), discussing how to respond to a subpoena seeking HIV-related information.)

3. PROCEDURES FOR SEEKING A COURT ORDER AUTHORIZING DISCLOSURE

The following special procedures must be followed whenever an order is sought under § 2785, so that the persons affected have an opportunity to participate in the proceeding and to ensure the proceeding's confidentiality:

²⁴¹ N.Y. Pub. Health Law § 2785(2)(c).

²⁴² N.Y. Pub. Health Law § 2785(2)(d).

 $^{^{243}}$ N.Y. Pub. Health Law $\S~2785(5).$

 $^{^{244}}$ N.Y. Pub. Health Law $\S~2785(1)$.

a. NOTICE

The person to whom the confidential HIV-related information pertains, as well as any person or agency that is holding the records or information being sought, must be given "adequate notice" of an application for an order, and be notified in a manner that will not reveal to others the identity of the person to whom the confidential information pertains.

b. OPPORTUNITY TO RESPOND

Both the person to whom the confidential information pertains and the person or agency from whom the information is sought must have an opportunity to file a written response to the application, or appear in person, for the limited purpose of giving evidence on whether the statutory criteria for issuing an order have been met.

The only time a court may issue an order without providing the required notice and opportunity to be heard is when a public health official applies for a disclosure order under the third ground described above, and shows that the circumstances require an immediate order.

c. CONFIDENTIALITY OF PROCEEDINGS

When a court receives an application for any order authorizing disclosure, it must take these steps to ensure that the proceedings are confidential:

- order all papers that are part of the application or decision to be sealed and not made available to anyone except those directly involved in the application (or appeal, if there is one);
- conduct the proceeding to determine whether to grant the application "in camera" (i.e., not open to the public); and
- take any necessary steps to prevent the name of the individual to whom the HIV-related information pertains from being revealed in any of the application or decision papers).²⁴⁵

4. THE COURT ORDER

Finally, if the court decides that an order authorizing the disclosure should be issued, it must:

- limit disclosure to the information necessary to fulfill the purpose of the order;
- limit disclosure to the persons whose need for the information is the basis for the order, and specifically prohibit re-disclosure by those persons;
- conform to Article 27-F's provisions and policy to the extent possible; and
- include any other measure the court deems necessary in order to limit any disclosures not authorized by the order.²⁴⁶

 $^{^{245}}$ N.Y. Pub. Health Law § 2785 (1)-(4).

²⁴⁶ N.Y. Pub. Health Law § 2785(6).

L. PROGRAM MONITORING, EVALUATION OR REVIEW

Under both Article 27-F and HIPAA, certain private and government oversight authorities may obtain HIV-related and other health-related information from the agencies they oversee, without an HIV-specific release form from the individuals whose HIV-related information is being disclosed. Because Article 27-F is "more stringent" in this regard than HIPAA, providers must follow Article 27-F's restrictions.

1. THE RULE

Program Monitoring, Evaluation or Review

Certain oversight authorities may obtain HIV-related information from entities they oversee, without an HIV-specific release form from the client, if they:

- use it for program monitoring, evaluation and review only; and
- do not re-disclose HIV-related information to anyone, except
 - · back to the program being monitored
 - if a government agency oversees or administers the program, to the government oversight agency.

2. WHAT IS AN OVERSIGHT AUTHORITY?

Oversight authorities include a "health facility staff committee or an accreditation or oversight review organization" that is "authorized to access medical records" of a health or social service provider.²⁴⁷

3. GOVERNMENT OVERSIGHT AUTHORITIES

When a federal, state or local government agency supervises or monitors a provider of health or social services or administers the program under which those services are provided, the service provider may disclose HIV-related information about the individual recipients of those services:

- to authorized employees of the federal, state or local government agency that supervises or monitors the provider or administers that program of services,
- when it is "reasonably necessary" for that governmental agency to have the HIV-related information in order to supervise, monitor or administer the program in question.²⁴⁸

This rule also works in reverse: the governmental agency may also disclose HIV-related information about recipients of the program's services to authorized employees of the provider when it is "reasonably necessary" for the oversight function. The individual recipients of the services do not need to consent.

²⁴⁷ N.Y. Pub. Health Law § 2782(1)(f).

 $^{^{248}}$ N.Y. Pub. Health Law §§ 2782(1)(f), § 2782(6).

²⁴⁹ N.Y. Pub. Health Law §§ 2782(1)(f), 2782(6), 2786.

The Article 27-F regulations issued by the various state agencies with this type of oversight authority establish specific rules defining

- when communications between providers and government agencies are "reasonably necessary"; and
- which employees of the provider and governmental agency may be authorized to have access to HIV-related information for these purposes.

M. DISCLOSURES FOR MEDICAL EDUCATION, RESEARCH, THERAPY OR TRANSPLANTATION

No consent (in an HIV-specific release form) is required for disclosures of HIV-related information to health care providers or facilities

- in connection with the procurement, processing, distribution or use of human bodies or body parts (including organs, tissues, eyes, bones, arteries or fluids);
- for use in medical education, research, or therapy; or
- for transplants.²⁵⁰

N. CRIMINAL JUSTICE-RELATED DISCLOSURES

1. TO CRIMINAL JUSTICE STAFF

Authorized employees or agents of the State Division of Parole, Department of Correctional Services, Division of Probation and Correctional Alternatives and Commission of Correction are permitted to have access to HIV-related information about individuals under their agencies' jurisdiction, without consent from those individuals, in accordance with the specific agency's Article 27-F regulations. Such information may be shared only if the employee is **on the agency's need-to-know list** and has a **reasonable need** for that information to carry out his/her duties.²⁵¹

Article 27-F also authorizes the medical directors of local correctional facilities (jails) to have access to confidential HIV-related information about inmates to the extent the medical director is authorized to obtain access to inmates' records in order to carry out his powers, functions and duties. ²⁵² Jails' policies regarding access to HIV-related information may differ from locality to locality.

2. PEOPLE CONVICTED OF OR INDICTED FOR SEX OFFENSES

As discussed on page 21, a court may order someone who has been convicted of a sex offense or indicted for certain sex offenses to undergo an HIV test at the victim's request. The results must be communicated to the victim and the tested person, unless the tested person does not want to learn them. The victim may re-disclose the results to his/her immediate family, guardian, physicians, attorneys, medical or mental health providers, and past and future contacts to

²⁵⁰ N.Y. Pub. Health Law § 2782(1)(e).

 $^{^{251}}$ N.Y. Pub. Health Law §§ $2782(1)(m),\,2782(1)(1)),\,2782(1)(o).$

²⁵² N.Y. Pub. Health Law §§ 2782(1)(n), 2786(2)(a).

whom there was or is a reasonable risk of HIV transmission. The results may not be given to the court.²⁵³ HIPAA also permits this disclosure.²⁵⁴

O. CHILD ABUSE/NEGLECT AND ELDER ABUSE/NEGLECT

Neither Article 27-F nor HIPAA prevents people and agencies from carrying out their duties and authority to report, investigate, or re-disclose child protective or adult protective information as required or permitted by the laws addressing child abuse and neglect and elder abuse and neglect. ²⁵⁵ If a person's HIV status is relevant to a report of suspected child or elder abuse, for example, then it may be disclosed without the individual's consent. It should not be assumed, however, that the HIV status of the individuals involved — either those responsible for or the victims of suspected abuse or neglect — is relevant in every case. If that information has no bearing on the specific abuse or neglect at issue, no HIV-related disclosure would be warranted.

P. ADMINISTRATORS AND EXECUTORS OF ESTATES

Article 27-F permits the disclosure of confidential HIV-related information about a deceased person to the executor or administrator of an estate to fulfill his/her responsibilities as executor/administrator.²⁵⁶ HIPAA also permits this disclosure.²⁵⁷

 $^{^{253}}$ N.Y. Pub. Health Law \S 2785-a.

²⁵⁴ 45 C.F.R. §§ 164.512(a); 164.512 (e)(1)(i).

²⁵⁵ N.Y. Pub. Health Law §2782(7); 45 C.F.R. § 164.512(c).

 $^{^{256}}$ N.Y. Pub. Health Law $\ 2782(1)(q)$

²⁵⁷ 45 C.F.R § 164.502(g)(4).

IV. RECORD-KEEPING ISSUES

A. DOCUMENTING HIV-RELATED INFORMATION IN CLIENT RECORDS

Article 27-F allows covered providers to find a workable balance between their legal duty (under professional licensure requirements or regulations establishing standards of care) to maintain accurate records about individuals in their care on the one hand, and their obligation to minimize the risk that HIV-related information might be -

- put in client records even when not directly relevant to care, and
- made accessible to people who might misuse the information, on the other.

The law requires that "confidential HIV-related information **shall be recorded in the medical record of the protected individual**" but does not specify whether it must be documented in other kinds of client records. The State Department of Health regulations implementing Article 27-F require health care providers regulated by the Department to develop and implement written policies and protocols to ensure the confidentiality of any records containing HIV-related information and protect such information from unauthorized access and disclosure. These regulations state that "HIV-related information shall be recorded in the medical record such that it is readily accessible to provide proper care and treatment." ²⁵⁹ At the same time, they require any records containing HIV-related information to be maintained so as to ensure that such information is accessible only to those authorized to have access to it and is disclosed only as authorized by Article 27-F. ²⁶⁰

Within these general guidelines, providers have the discretion to set up record-keeping systems that are responsive to their own needs. They have discretion to decide where and how to record HIV information in parts of the record other than the medical record.

Choices include recording the information in a separate part of the record or integrating it throughout. The advantage of keeping HIV-related information in a separate part of the record is that it makes is less likely that the information will be inadvertently and impermissibly disclosed – both internally and externally. The disadvantage, however, is that it may be impractical and impede the continuity and coordination of care. Some providers may also choose to use euphemisms when referring to HIV status, such as "medical condition" or "health concerns." Whichever method a provider chooses should be documented in the agency's record-keeping protocols.

Each agency should also check the Article 27-F regulations applicable to it for guidance on this issue, although these decisions are generally left up to the provider.

²⁵⁸ N.Y. Pub. Health Law § 2782(8).

 $^{^{259}}$ 10 N.Y.C.R.R. \S 63.7.

²⁶⁰ 10 N.Y.C.R.R. §§ 63.6, 63.8.

B. DOCUMENTING DISCLOSURES

1. THE GENERAL RULE

Except as described in the next section, whenever a person or agency subject to Article 27-F discloses any HIV-related information about any protected individual, "a notation of [that disclosure] shall be placed in the medical record of the protected individual." The documentation should include who requested the information (if there was a request), the date of the disclosure, who the recipient was, and authorization under Article 27-F. This requirement applies to oral and written disclosures, even if the client signed an HIV-specific release.

2. EXCEPTIONS

The only circumstances in which a disclosure need not be documented in the client's record are:

- **internal communications** among employees of a health care provider or facility who have access to HIV-related information about a particular client under the agency's "need-to-know" policy and protocol (see pages 44-45);
- **program evaluations** (see page 73);
- governmental payors who need the information to process payments; and
- other than first disclosure to insurers: the first disclosure to insurers
 — for reimbursement or any other purposes must be documented in that individual's medical record. However, subsequent disclosures to the same insurer need not be noted.²⁶²

3. A PRACTICAL APPROACH

One sensible way of complying with these documentation requirements is to keep a running list (which could be in a separate part of a client's record) of all disclosures of HIV-related information about the individual. This will make it easier to verify all disclosures, upon client request (see next section).

C. CLIENTS' RIGHTS TO BE INFORMED OF DISCLOSURES MADE ABOUT THEM

Every individual has the right to be informed, upon his/her request, of any disclosure of confidential HIV-related information made by any covered health or social service provider, or by anyone who has received such information pursuant to individual's HIV-specific release (including insurance institutions). HIPAA also requires covered health care providers to provide individuals, upon request, with an accounting of certain disclosures made regarding a patient's health care. Health care.

²⁶¹ N.Y. Pub. Health Law § 2782(5)(b).

²⁶² N.Y. Pub. Health Law § 2782(5)(b).

 $^{^{263}}$ N.Y. Pub. Health Law $\$ 2782(5)(b).

²⁶⁴ 45 C.F.R. § 164.528 (c).

D. RESPONDING TO REQUESTS FOR HIV-RELATED INFORMATION ABOUT CLIENTS

1. DEVELOP AND FOLLOW A POLICY

The regulations implementing Article 27-F generally mandate covered providers to develop written protocols for responding to requests for HIV-related information. To fulfill these mandates and prevent any unauthorized disclosures, health and social service agencies should establish a policy like the following to deal with all requests for HIV-related information (including requests for oral disclosures as well as for records):

- The agency should designate specific staff to handle all such requests and train all employees to refer any requests to the designated staff.
- When any request for client records or information is received, the designated staff members should determine if disclosing HIV-related information in response to the request is authorized because (1) the client has signed a valid HIV-specific release form authorizing that disclosure, or (2) the requesting party is authorized to obtain the information under one of the exceptions to the general rule requiring the client's consent to the disclosure. Remember that a subpoena, even one signed by a judge, does not authorize the disclosure of HIV-related information (see page 71).
- If the agency is authorized to disclose the HIV-related information, it may make the disclosure, but must also document it and, when required, send the notice prohibiting re-disclosure to the recipient within ten days, when required (see page 41), as discussed above.
- If the disclosure is not authorized, the designated agency staff should contact the client. If the client chooses to sign an HIV-specific release form, the agency may make the disclosure. If the client does not wish to sign a release and no basis exists for making an unconsented-to disclosure, the agency staff should inform whoever is seeking the disclosure that, to the extent the information is confidential under state law, it will not be disclosed without appropriate authorization (see the next section, in this regard).

2. WHAT TO DO WHEN THERE IS NO AUTHORIZATION TO RELEASE THE INFORMATION: SUBPOENAS AND GENERAL RELEASES

How should an agency respond when it receives a release or other document that authorizes or compels disclosure of some information or records about a client, but does not provide proper authorization under Article 27-F? For example, the requesting party may give the agency a —

- general release form for a client's "medical records," or other records; or
- subpoena (or even court order, but not the type required under Article 27-F)

a. THERE ARE TWO OPTIONS

i. OPTION #1

Ask the client if he or she wishes to sign an HIV-specific release form for the disclosure. If so, have the client sign a release that complies with Article 27-F;

make the disclosure; and send the recipient the notice prohibiting re-disclosure (Appendix G).

ii. OPTION #2

Send the requesting party the information or records without the HIV-related information. This means either withholding those parts of the client's record that contain HIV-related information or redacting (blotting out) HIV-related information in the records that are sent.

If an agency chooses the second option, does it then have a legal obligation to inform the requesting party that not all of the information or records sought are being disclosed? In many cases, the agency probably does not have such an obligation. But even if it believes it does, there are ways to inform recipients that some of the records have been withheld or redacted without revealing that such information is HIV-related. For example, an agency could give all recipients of any records it discloses — whether or not those records contain HIV-related information — a general notice that says:

"This agency maintains a policy of redacting/removing from all client records any information whose confidentiality is protected under state law. No such information will be disclosed in the absence of appropriate authorization that meets the requirements of state law."

b. SUBPOENAS

The only time there may be a clear legal obligation to inform a recipient that information has been withheld or redacted is when the request is made by way of a subpoena or court order compelling disclosure. (*Remember*: a subpoena does not authorize disclosure of HIV-related information; even a court order does not authorize such a disclosure unless the court order was sought and obtained in accordance with § 2785. See pages 70-72.) While the agency cannot ignore the subpoena or court order, it may respond by —

- disclosing the records called for in the subpoena or court order except to the extent they contain HIV-related information (i.e., withhold or redact such information); and
- simultaneously sending the recipient a notice, such as the following:
 "Any information whose confidentiality is protected by Article 27-F of the Public Health Law is withheld/redacted from any records maintained by this agency before such records are disclosed in response to any subpoena or to a court order. State law prohibits the disclosure of such information in the absence of appropriate authorization. Appropriate authorization means either
 - » a written release that complies with the requirements of Article 27-F of the Public Health Law, or
 - » a special court order issued in accordance with Public Health Law § 2785.

This notice is not intended to imply that these records contain any information protected by Article 27-F."

This informs those receiving the notice about the legal requirements for obtaining

confidential information, without revealing whether there is any such information in the records being sought. While some may read it to imply that the records they seek do contain HIV-related information, the notice itself confirms nothing.

E. SAFEGUARDING CLIENT RECORDS AND INFORMATION

1. ARTICLE 27-F

a. SAFEGUARDING PAPER AND ELECTRONIC RECORDS WITHIN THE AGENCY

All entities covered by Article 27-F should have written policies about how to safeguard the confidentiality of paper and electronic records. The policies should specify –

- where HIV-related information is maintained in paper and electronic records, who has access, and that only authorized persons can see or access the files' confidential HIV-related information, including after working hours;
- that paper files not be left on desks or otherwise viewable to unauthorized persons, that computer screens containing HIV-related information not be viewable by unauthorized persons, and paper files and flash drives be returned to their proper confidential location when they are not in use;
- whether any files paper, flash drives, e-mailed files may ever be removed from the premises and, if so, under what conditions;
- that documents containing confidential HIV-related information should be shredded when they are no longer needed or obsolete, or specify another method of disposing of such records.

b. FAXING AND E-MAILING CONFIDENTIAL HIV-RELATED INFORMATION

Article 27-F does not prohibit electronic transmission of HIV-related information (e.g., through fax or email), but anyone who does transmit HIV-related information electronically should take reasonable steps to ensure that it goes only to the person(s) authorized to receive it. Entities covered by Article 27-F should have written policies and procedures governing electronic transmission of HIV-related information. Where possible, people should avoid directly or indirectly revealing the identity of the individual who is the subject of HIV-related information (e.g., by using first names, initials, or non-identifying terms such as "client X"). In situations where client-identifying information must be sent electronically, some suggestions are:

- confirm the fax number or email address before sending;
- check that the fax number or email address was properly entered before clicking "send";
- when faxing, find out where the fax machine is and who has access to it
 at the receiving end. Do not fax anything without knowing that the
 person authorized to receive the information will be there to collect it;
- include the Notice Prohibiting Re-disclosure (Appendix G);
- send a "trial" fax or email (without confidential information) and confirm

that it arrived at its intended recipient. Only send the real one after receiving confirmation.

2. HIPAA

HIPAA also requires covered entities to put in place appropriate administrative, technical, and physical safeguards to protect the privacy of protected health information from any intentional or unintentional use or disclosure which would violate HIPAA, including any incidental use or disclosure made in the course of an otherwise permitted or required use or disclosure. ²⁶⁵ HIPAA also sets forth specific security and electronic standards which require covered entities to have security controls and measures in place to protect confidential patient information when it is electronically stored, maintained, or transmitted. ²⁶⁶

²⁶⁵ 45 C.F.R. § 164.530(c).

 $^{^{266}}$ See 45 C.F.R. Parts 142 & 162.

V. REMEDIES FOR HIV TESTING AND CONFIDENTIALITY VIOLATIONS

A. ARTICLE 27-F

Article 27-F provides several types of redress for individuals whose rights have been violated by illegal HIV testing or disclosure of HIV-related information.

1. PENALTIES IMPOSED BY THE STATE

Individuals or agencies who —

- "perform, or permit or procure the performance of an HIV-related test" in violation of § 2781 of the law (governing HIV testing; see Part 1), or
- "disclose, or compel another person to disclose, or procure the disclosure of confidential HIV-related information" in violation of § 2782 of the law (the confidentiality and disclosure rules; see Part 2) —

face the possibility of:

- a civil penalty (fine) of up to \$5,000 for each occurrence, paid to the State Department of Health, ²⁶⁷ and
- criminal prosecution, if the person "wilfully" commits any of the acts outlined above. This is a misdemeanor, punishable by up to one year in prison, a fine of up to \$10,000 (until April 1, 2014) or \$2,000 (after April 1, 2014), or both imprisonment and fine. ²⁶⁸An act may constitute a "wilful" violation of the Public Health Law or its regulations if it is done deliberately and voluntarily; "bad" intention is not a prerequisite.

2. REMEDIES THAT INDIVIDUALS CAN TAKE THEMSELVES

People whose rights have been violated under Article 27-F's testing or confidentiality requirements or the HIV Reporting and Partner Notification Law may file a complaint with the Department of Health and/or bring their own lawsuit.

a. ADMINISTRATIVE REMEDIES: DEPARTMENT OF HEALTH COMPLAINTS

The State Department of Health is authorized to investigate and remedy violations of Article 27-F.²⁶⁹ The Special Investigation Unit (SIU) of the Health Department's AIDS Institute takes complaints of HIV law violations. People do not need lawyers to make complaints. They can call the Department's toll-free HIV Confidentiality Hotline (1-800-962-5065), or write to the New York State Department of Health, AIDS Institute, Special Investigation Unit, 90 Church Street, New York, NY 10007. Though not required to, they can use a complaint form that the SIU and Hotline will give them upon request or download it from the Department of Health website at http://www.health.ny.gov/diseases/aids/forms/informedconsent.htm.

²⁶⁷ N.Y. Pub. Health Law §§ 12 and 2783(1).

 $^{^{268}}$ N.Y. Pub. Health Law §§ 12-b and 2783(2).

 $^{^{269}}$ N.Y. Pub. Health Law §§ 12; 12-b; 2783.

The Department of Health investigates complaints, or refers them for investigation by the agency that funds or regulates the provider involved. The SIU or other government agency conducting the investigation can require providers and/or their employees to take corrective actions, like developing needed policies or conducting training, to prevent future problems.

The Department of Health can conduct hearings to decide whether a person or agency has violated Article 27-F and, if so, what penalties or corrective actions are appropriate. It also may bring a lawsuit to recover civil penalties (e.g., get an order requiring the violator to pay a fine, which, as noted above, is awarded to the Department of Health, not to the person injured by the violation). It may ask the State's Attorney General to go to court to get an injunction (an order telling the violator to do or refrain from doing something) to prevent or remedy violations of the law.²⁷⁰

b. LAWSUITS

Individuals claiming violations of Article 27-F's HIV testing or confidentiality requirements may also bring their own lawsuits seeking injunctive relief (orders requiring those found to have violated the law to take remedial action or refrain from acting illegally) and/or monetary damages to prevent or remedy harm caused to them by unlawful testing or disclosures. The amount of damages recoverable depends on the actual damages caused by the violation (e.g., emotional distress; lost wages due to job discrimination resulting from an illegal disclosure).

People can go directly to court; they do not have to file a complaint with the SIU or exhaust any other remedies before suing. Though individuals can represent themselves, having a lawyer is extremely helpful (the Legal Action Center specializes in this area; and other legal service providers are listed in Appendix H). The time limit for filing these lawsuits is generally three years from the date of the act(s) complained of (except as noted next).

i. LAWSUITS AGAINST MUNICIPALITIES

Under New York State's General Municipal Law § 50-e, there is a shortened statute of limitations (one year and 90 days) for personal injury and many other types of lawsuits against cities, as well as a requirement to file a "notice of claim" within 90 days of the action complained of. There is a strong argument (and case law) that these requirements do not apply to lawsuits brought under Article 27-F. Nevertheless, when possible, it may be prudent to comply with these requirements in order to avoid the time and expense litigating that issue in court.

ii. RULES ON LAWSUITS BASED ON LACK OF INFORMED CONSENT TO HIV TESTING

In a lawsuit challenging a physician's (or other medical professional's) failure to obtain informed consent before ordering or performing an HIV-related test, or failing to provide the necessary pre-test information, the remedy will be governed by the rules for medical malpractice lawsuits based on the lack of informed consent to medical treatment.²⁷¹ Among other things, these suits must be filed within two and a half years after the HIV test in question was done.

²⁷⁰ N.Y. Pub. Health Law §§ 2783(1)-(2); 12; 12-b.

²⁷¹ N.Y. Pub. Health Law § 2783(4). Informed consent standards are in N.Y. Pub. Health Law § 2805-d.

iii. LAWSUITS FOR VIOLATIONS OF INDIVIDUALS' CONSTITUTIONAL PRIVACY RIGHTS

Some governmental agencies and their employees — such as state or local police departments, public schools, and federal agencies like the Social Security Administration or federal prisons — are not covered by Article 27-F, and may not be sued for violating the state law (see pages 33-34). But these agencies may be sued for violating individuals' federal Constitutional privacy rights, and federal agencies may be sued under the Privacy Act.²⁷² Constitutional claims must be filed within three years of the privacy violation alleged, and claims under the Privacy Act must be filed within two years.

B. HIPAA

HIPAA does not give individuals a federal right to sue for violations of its privacy or other provisions, but violations may be grounds for state tort actions.

Individuals may file a complaint with the covered entity they allege has violated their rights under HIPAA's Privacy Rule. HIPAA requires covered entities to have procedures and policies in place for accepting, investigating and handling the disposition of HIPAA privacy violations. Each covered entity is responsible for establishing its own procedure for processing patient complaints.

Individuals may also file a complaint charging health care providers covered by HIPAA with violating HIPPA's Privacy Rule with the Office of Civil Rights ("OCR") of the U.S. Department of Health and Human Services (HHS).²⁷³ HHS is the federal agency responsible for enforcing HIPAA. HHS may investigate complaints of HIPAA privacy violations by reviewing the covered entity's policies, procedures, and practices, and the circumstances regarding the alleged act or omission. HHS can impose fines or other sanctions on the covered entity for each violation.²⁷⁴ Information about filing a complaint with OCR is available on its website http://www.hhs.gov/ocr/privacy/. Complaints must be filed within 180 days of discovery of the act or omission.²⁷⁵

HHS may also conduct compliance reviews to determine whether covered entities are complying with the regulations.²⁷⁶ Covered entities must maintain and provide records and compliance reports, cooperate with investigations and compliance reviews, and permit access to necessary information.²⁷⁷

C. LIMITS ON PHYSICIANS' AND PUBLIC HEALTH OFFICIALS' LIABILITY

1. PHYSICIANS' IMMUNITY FOR MAKING OR NOT MAKING DISCLOSURES

Article 27-F specifically grants physicians (and their employers or health care providers with whom they are associated) immunity from liability for —

• failing to disclose HIV-related information to a protected individual's contact;

 $^{^{272}}$ 5 U.S.C.A. \S 552a.

²⁷³ 45 C.F.R. § 160.306(a).

 $^{^{274}}$ 42 U.S.C. \S 1320d-5 et seq.

²⁷⁵ 45 C.F.R. § 160.306(b).

²⁷⁶ 45 C.F.R. § 160.308.

²⁷⁷ 45 C.F.R. § 160.310.

- failing to disclose HIV-related information to a "person authorized pursuant to law to consent to health care" for a protected individual (usually a parent or guardian of a minor);
- disclosing HIV-related information to a "contact or a person authorized pursuant to law to consent to health care for a protected individual," when the disclosure is "carried out in good faith and without malice, and in compliance with [Article 27-F]"; and
- disclosing HIV-related information to "any person, agency, or officer authorized to receive such information, when carried out in good faith and without malice, and in compliance with [Article 27-F]". ²⁷⁸

This provision explicitly recognizes that physicians have a good deal of discretion to disclose, or not to disclose, HIV-related information in a variety of circumstances. And it protects those physicians who exercise that discretion in good faith, in compliance with the law.

2. LIMITATIONS ON LIABILITY: HIV CASE REPORTING AND PARTNER NOTIFICATION

The HIV Reporting and Partner Notification Law also explicitly protects persons who, in good faith, conduct HIV/AIDS case reporting and contact notification activities authorized by the law, from any civil or criminal liability, including claims for libel, slander, or violation of the doctor-patient privilege. This protection extends to physicians and other diagnostic providers mandated to report HIV/AIDS cases, as well as physicians and public health officials carrying out partner notification efforts.

²⁷⁸ N.Y. Pub. Health Law § 2783(3)(a)-(c).

²⁷⁹ N.Y. Pub. Health Law § 2136.

PART 3

PROTECTIONS AGAINST HIV-RELATED DISCRIMINATION

INTRODUCTION

Federal, New York State and New York City laws that prohibit discrimination based on an individual's "disability" forbid virtually all health and social service providers, as well as government agencies, from refusing to serve or discriminating in the provision of *services* to, and from discriminating in *employment* against, people because they have or are believed to have HIV disease, including HIV infection, any related illness or AIDS.

I. APPLICABLE LAWS AND BASIC RULES

A. NONDISCRIMINATION LAWS AND REGULATIONS

The laws that protect both clients and job applicants and employees from HIV-based discrimination include:

1. THE REHABILITATION ACT OF 1973

This federal law (sections 501, 503 and 504 of the Act, contained in 29 U.S.C. (United States Code) $\S\S$ 791 through 794) —

applies to:

• federal government agencies;²⁸⁰

²⁸⁰ Section 501, codified at 29 U.S.C. § 791.

- any agency with federal contracts or subcontracts of \$10,000 or more;²⁸¹ and
- any agency that receives federal grants or funding, 282 directly or indirectly. 283

protects:

• individuals with a past, current or perceived "disability" who are qualified to receive the service or benefit, participate in the program or perform the job in question. Courts have ruled that individuals who are known or believed (even erroneously) to have HIV disease, including conditions from asymptomatic infection to AIDS, are persons with "disabilities" (defined in the same way as in the ADA, below).

2. THE AMERICANS WITH DISABILITIES ACT OF 1990 & THE ADA AMENDMENT ACT OF 2008

The Americans with Disabilities Act of 1990 (the "ADA"), 42 U.S.C. § 12101 et seq., is another federal anti-discrimination law. The ADA was amended by the ADA Amendment Act of 2008 (the "ADAAA"), which became effective January 1, 2009. When this manual uses the term "ADA," it refers to the ADA, as amended.

The nondiscrimination requirements of the ADA ---

apply to:

- public and private employers with 15 or more employees, employment agencies, and labor organizations; ²⁸⁴
- all state and local governments and agencies of such governments (including government employers of any size); ²⁸⁵
- places of "public accommodation" and other services operated by private entities, including hospitals, professional offices of health care providers (e.g., doctors, dentists, nurses), private schools, day care and other social service centers, hotels, restaurants, stores, etc.; ²⁸⁶ and
- public transportation²⁸⁷ and telecommunications systems.²⁸⁸

protect:

- individuals with a past, present or perceived "disability," which is defined as:
 - » "a physical or mental impairment that substantially limits one or more major life activities of such individual";
 - » "a record of such an impairment"; or
 - » "being regarded as having such an impairment." 289

²⁸¹ Section 503, codified at 29 U.S.C. § 793(a).

²⁸² Section 504, codified at 29 U.S.C. § 794(a).

²⁸³ Herman v. United Bhd. of Carpenters & Farmers of Am., 60 F.3d 1375, 1381 (9th Cir. 1995).

 $^{^{284}}$ Title I, 42 U.S.C. §§ 12101-12117.

²⁸⁵ Title II, Part A, §§ 12131 -12134.

²⁸⁶ Title III, 42 U.S.C. §§ 12181-12189.

²⁸⁷ Title II, Part B.

 $^{^{288}}$ Title IV.

²⁸⁹ 42 U.S.C. § 12102(1).

While the ADAAA did not change the three-category definition of "disability" under the ADA, it did add provisions to ensure that the law is applied expansively in order to protect individuals with disabilities.²⁹⁰

For example, "major life activities" contained within the first category now include (without limitation): "caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working." ²⁹¹ Importantly, "major life activity" also includes the operation of a major bodily function, including but not limited to, functions of the immune system . . . "²⁹²

According to the ADAAA, "[t]he determination of whether an impairment substantially limits a major life activity" is to be made "without regard to the ameliorative effects of mitigating measures," such as medication or a reasonable accommodation. Moreover, "[a]n impairment that is episodic or in remission is a disability if it would substantially limit a major life activity when active." 294

Another example is that an individual may now meet the definition of "being regarded as having an impairment" – the third category – by establishing that s/he was subjected to an action prohibited by the ADA "because of an actual or perceived physical or mental impairment whether or not the impairment limits or is perceived to limit a major life activity." ²⁹⁵

Therefore, now that the ADAAA is in effect, it should prove easier to establish that an individual with HIV (or an individual who is perceived to have HIV) is an "individual with a disability."²⁹⁶ In fact, the EEOC's regulations implementing the ADAAA state "the individualized assessment of some types of impairments will, in virtually all cases, result in a determination of coverage" under the "actual disability" category or the "record of" category of disability.²⁹⁷ As an example, the EEOC regulations provide that HIV infection, at a minimum, substantially limits the immune function (a major life activity).²⁹⁸

In the context of employment, Title I protects "qualified" individual with disabilities, which means individuals who, with or without reasonable accommodations, can perform the essential functions of the job.²⁹⁹ With respect to state or local governmental services, programs, and activities, Title II, also protects "qualified" individuals with a disability, which means individuals

Prior to the passage of the ADAAA, many people with disabilities had difficulty asserting claims under the ADA because of the restrictive manner in which federal courts had defined "disability." To remedy this, Congress passed the ADAAA. Congress noted that the ADAAA was specifically intended to reject the holdings in several Supreme Court decisions and portions of the United States Equal Employment Opportunities Commission's ("EEOC") ADA regulations that had an overly restrictive definition of "disability." Thus, the ADAAA emphasizes that the definition of "disability" should be "construed in favor of broad coverage of individuals . . . to the maximum extent permitted by the terms of [the ADA]" and that the determination of "whether an individual's impairment is a disability under the ADA should not demand extensive analysis." 42 U.S.C. § 12102(4)(A); 42 U.S.C. §12101(5) (ADAAA Findings and Purposes).

²⁹¹ 42 U.S.C. § 12102(2)(A).

²⁹² 42. U.S.C. § 12102(2)(B).

²⁹³ 42 U.S.C. § 12102(4)(E)(i)(I).

²⁹⁴ 42 U.S.C. § 12102(4)(D).

²⁹⁵ 42 U.S.C. § 12102(3)(A) (emphasis added).

²⁹⁶ Even prior to the enactment of the ADAAA, courts, including the U.S. Supreme Court, have concluded that HIV is a covered disability even in cases of asymptomatic HIV infection.

²⁹⁷ 29 C.F.R. § 1630.2(j)(3)(ii).

²⁹⁸ 29 C.F.R. § 1630.2(j)(3)(iii).

²⁹⁹ 42 U.S.C. §§ 12112(a), 12111(8).

who, with or without reasonable modifications to rules, policies or practices, meet the essential eligibility requirements for the receipt of services or participation in the program in question.³⁰⁰ With respect to public accommodations such as private health or social service providers, Title III protects individuals with disabilities from being discriminated against on the basis of disability in the "full and equal enjoyment" of the services or public accommodation in question.³⁰¹ As in other titles of the ADA (as amended), a public accommodation is required to make reasonable modifications in its policies, practices or procedures when necessary to provide the particular services.

The ADA (as amended) also protects individuals who are subjected to discrimination in employment, in receipt of public services and by public accommodations because of their association with an individual with a disability.³⁰²

3. THE NEW YORK STATE HUMAN RIGHTS LAW

This state law (N.Y. Exec. Law §§ 290 et seq.) —

applies to:

- public and private employers (with 4 or more employees);³⁰³
- places of public accommodation³⁰⁴ (including hospitals, clinics and most other health care providers that offer their services to the public); and
- most housing providers and social service providers. 305

protects:

• individuals with a past, present or perceived "disability," which is generally defined as "a physical, mental or medical impairment" and, in the context of employment, means a condition that does not interfere with the person's ability (with or without reasonable accommodations) to perform the job requirements in a "reasonable manner." Many cases brought under this law, including those decided by the state's highest court (the Court of Appeals), have confirmed the law's protection of individuals who are known or believed (even erroneously) to have HIV infection or any related illness.

4. THE NEW YORK CITY HUMAN RIGHTS LAW

This New York City law (N.Y.C. Admin. Code, Article 8, §§ 8-102, 8-107) —

applies to:

- public and private employers (with 4 or more employees); 307
- public accommodations³⁰⁸ (including virtually all health care and human service providers); and

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300 42 U.S.C. §§ 12132, 12131(2).
301 42 U.S.C. § 12182(a).
302 42 U.S.C. § 12112(b)(4).
303 N.Y. Exec. Law § 292(5).
304 N.Y. Exec. Law § 296(2).
305 See, e.g., N.Y. Exec. Law § 296(2-a), 3-b), (5), (18).
306 N.Y. Exec. Law § 292(21).
307 N.Y.C. Admin. Code § 8-102(5).
308 N.Y.C. Admin. Code § 8-107(4).
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most public and private housing providers in New York City.³⁰⁹

protects:

• individuals with an actual or perceived "disability" – defined generally as any "physical, medical, mental or psychological impairment, or a history or record of such impairment" ³¹⁰— which, courts have repeatedly ruled, includes those known or believed (even erroneously) to have HIV/AIDS.

5. ARTICLE 27-F OF THE NEW YORK STATE PUBLIC HEALTH LAW (HIV TESTING AND CONFIDENTIALITY LAW)

While Article 27-F primarily deals with HIV-related testing and confidentiality, it also requires state agencies that serve or monitor the provision of services to individuals with HIV/AIDS to issue regulations to "provide safeguards to prevent discrimination, abuse or other adverse actions" against such clients.³¹¹ The nondiscrimination requirements of this law and state agencies' regulations implementing it —

apply to:

• all state agencies that obtain HIV-related information in accordance with Article 27-F, and all health care and social service providers that are funded, regulated or monitored by those state agencies.

protect:

• individuals who have been tested for or diagnosed with HIV/AIDS.

6. THE FAIR HOUSING AMENDMENTS ACT OF 1988

The federal Fair Housing Act (42 U.S.C. §§ 3601-3619) makes discrimination in housing and real estate transactions illegal when it is based on "handicap" (as well as when it is based on race, religion, national origin or sex). The law —

applies to:

 most public and private housing providers and other entities involved in the sale or rental of housing, and other housing practices.

protects:

• individuals with a "handicap" ³¹² (defined the same way as "disability" in the Rehabilitation Act and ADA), entities that provide housing for people with disabilities, and individuals subjected to discrimination in housing practices because of their association with people with disabilities.

B. BASIC NONDISCRIMINATION REQUIREMENTS

The nondiscrimination laws outlined above establish two basic rules:

• Do not discriminate against any individual on the basis of his or her suspected or known HIV status; and

³⁰⁹ See, e.g., N.Y. Admin. Code 8-107(5).

³¹⁰ N.Y.C. Admin. Code § 8-102(16)(a).

 $^{^{311}}$ N.Y. Public Health Law $\S~2786(2)(a).$

^{312 42} U.S.C. § 3602(h).

PART THREE: PROTECTIONS AGAINST HIV-RELATED DISCRIMINATION

• Be prepared to offer "reasonable accommodations" to those with HIV-related conditions who may need such accommodations in order to participate in the program, benefits or services in question or to perform the duties of their job.

Each of these concepts is discussed below, as they apply to client services (Section II) and to job applicants and employees (Section III).

II. CLIENT ISSUES

A. NONDISCRIMINATION

1. GENERAL RULE: NO DISCRIMINATION

Under the federal, state and city nondiscrimination laws, health and human service agencies may not deny admission or services or discriminate in the provision of care or services to any individual because of that person's known or suspected HIV status. Under the state and city Human Rights Laws, it is also illegal to discriminate against individuals because of their membership in a group that is believed to be at risk for HIV, or because of their association with persons known to have HIV disease. Under the ADA, providers that serve people with HIV/AIDS cannot be subjected to discrimination because of their association with these people.

2. PARTICULAR APPLICATIONS

a. ADMISSION/ELIGIBILITY CRITERIA

People with known or suspected HIV disease must be considered for admission/receipt of services, on a case-by-case basis, in accordance with the provider's usual stated criteria for admission/receipt of services. Individuals who meet the essential eligibility requirements for the agency's services, and who are currently able to participate in and benefit from the agency's services, are entitled to receive them. Any reasonable accommodations (discussed below) needed to enable a person to participate in a program of services must be made.

It is generally not permissible for health or social service agencies to refuse, limit or provide different, lesser services to individuals known or believed to have HIV disease because of the possibility that in the future their illness may make them unable to participate in or benefit from the agency's program of services.

b. HIV TESTING/DISCLOSURE OF HIV STATUS

Asking or requiring a person to undergo HIV testing or to disclose his or her HIV status as a condition of receiving services is likely to violate federal, New York State and New York City nondiscrimination laws, if the purpose of eliciting information about a person's HIV status is to use that information to deny or give that person different services than others. (A testing requirement also violates Article 27-F of the Public Health Law; see Part 1.)

Therefore, in general, no applicant for or recipient of services may be asked or required to undergo HIV testing, to state whether he has undergone HIV testing, or to disclose his HIV status, as a condition of admission or continued receipt of services. The exception is when having HIV/AIDS is itself a condition of eligibility, as with programs of services that are available only to those with HIV disease; it is legal for these programs to require confirmation of an individual's HIV status.

c. SEGREGATION/DIFFERENTIAL TREATMENT OF CLIENTS WITH HIV

Because HIV is not transmitted through casual contact, in the vast majority of settings (including residential settings) there is no medical or legal justification for segregating or treating differently clients with HIV/AIDS or those believed to be infected. Even in health care settings, where the performance of certain duties by health care workers may create some risk of exposure to HIV (e.g., invasive procedures with the potential for blood-to-blood contact), health authorities require the use of universal precautions — rather than identification and segregation of patients — as the most effective way of reducing the risk of occupational exposure to HIV and other bloodborne diseases.

Segregation or differential treatment for the purpose of protecting others — clients or staff —from possible HIV transmission is therefore generally illegal discrimination. There are other, effective, nondiscriminatory means of protecting staff and clients from potential exposure to HIV. These include —

- educating both clients and staff (without regard to whether any
 individual's HIV status is known) about the nature of HIV and AIDS, the
 ways in which the virus is transmitted, the behaviors that create a risk
 of transmission, and the preventive practices that eliminate or effectively
 reduce that risk; and
- implementing and requiring clients and staff to comply on site with basic hygienic measures and appropriate universal infection control precautions, without regard to whether any client's or employee's HIV status is known.

Health and social service providers that are covered under regulations implementing the state's HIV Testing and Confidentiality Law (Article 27-F) must implement and enforce plans for preventing and managing potential exposures to HIV ("infection control plans"). Thus, a health or social service agency that responded to HIV/AIDS by segregating or selectively discriminating against clients identified as having or being at risk for HIV — rather than by implementing appropriate, across-the-board precautions for preventing transmission — could face potential liability on two counts: for violating the mandate of applicable state regulations and applicable nondiscrimination laws.

B. REASONABLE ACCOMMODATIONS

1. RULE: REASONABLE ACCOMMODATIONS MUST BE MADE

The federal, New York State and New York City nondiscrimination laws require health and human service agencies to make reasonable accommodations to the known disabilities of clients and applicants for services, when necessary to afford the individual access to the service. However, accommodations that would cause the agency undue financial hardship or require it to change the basic, fundamental nature of its services are not required.

a. WHAT ARE REASONABLE ACCOMMODATIONS?

Reasonable accommodations are adjustments in the agency's program of services, or its policies and procedures, that are necessary so an individual can participate fully and equally in those services. For example —

- a counseling agency could schedule a client's appointments in a way that enables the client to make other necessary medical care appointments.
- agencies that ordinarily require face-to-face meetings with their clients could make exceptions for homebound or hospitalized clients, or those whose health makes it difficult to make regular appointments at the agency.

b. WHAT IS NOT REQUIRED

Accommodations that would cause the agency undue financial hardship or require it to change the fundamental nature of its services are not required. For example —

- an agency that never makes home visits to clients, and does not have the human or financial resources to do so, need not develop a home-visit program to continue serving clients with HIV-related illnesses.
- a residential housing or treatment program that has never provided onsite medical services to residents need not develop on-site medical care for people with HIV-related illnesses.

2. HOW TO ASSESS REASONABLE ACCOMMODATIONS

The need for and nature of the reasonable accommodations to be arranged for any client should be assessed and decided on a case-by-case basis, and should be a decision resulting from an interactive process between the client and provider. The provider should —

- designate appropriate agency personnel to be responsible for assessing a client's need for and arranging appropriate reasonable accommodations;
- tell all clients (not only those known or believed to have HIV disease) that the agency will make reasonable accommodations when clients' medical conditions require them;
- encourage (but not require) clients who believe they need accommodations to come forward and talk to designated agency personnel about their needs;
- refrain from requiring clients to disclose their specific diagnoses as a condition of considering whether, and what, reasonable accommodations may be necessary. Instead, focus on identifying the specific limitations imposed by the individual's condition, including those caused by medications or other side effects from treatment. (Verification that a client has a disability requiring accommodations, and details about the limitations it creates, may be sought, for example, from the client's primary health care provider, without requiring disclosure of the specific diagnosis.);
- decide on appropriate accommodations through an interactive process with the client, and give each client the opportunity to identify the accommodations that will work best for her, rather than imposing the agency's own view of what is needed (though the agency, not the client, makes the final decision);
- document the request, needs assessment, and specific accommodation(s) offered and/or arranged; and
- strictly protect the confidentiality of any HIV-related information that is disclosed by or obtained about any client (in this connection, see Part 2).

III. EMPLOYMENT ISSUES

A. NONDISCRIMINATION

In the context of employment (as with client services), the nondiscrimination laws cited above establish the same two cardinal rules:

- do not discriminate against any job applicant or employee on the basis of his or her known or suspected HIV status; and
- be prepared to provide reasonable accommodations to such individuals, when needed.

1. GENERAL RULE: NO DISCRIMINATION

Under federal, New York State and New York City nondiscrimination laws, it is illegal for an employer to refuse to hire, fire or discriminate in the terms or conditions of employment against any job applicant or employee because that person has or is perceived as having any HIV-related condition, if that person is qualified and can (with or without reasonable accommodations, as discussed below) perform the essential functions of the job in question.

These laws are all designed to ensure that employment decisions are made on the basis of jobrelated criteria — ones that measure an individual's actual ability to perform the duties of a particular job — not on the basis of their known or suspected HIV status.

Employers covered by the federal nondiscrimination laws may require that individuals not pose a "direct threat" to "the health or safety of other individuals in the workplace."³¹³ A direct threat means "a significant risk to the health or safety of others that cannot be eliminated by reasonable accommodation."³¹⁴ (The New York State and New York City Human Rights Laws establish similar standards.) Because HIV is not transmissible through casual contact or through any of the activities involved in the performance of the vast majority of jobs, courts have found that the fact that an applicant or employee has HIV disease poses no risk that would justify an employer's exclusion or differential treatment of such a person in most workplaces.³¹⁵

The agencies that enforce the New York State and New York City Human Rights Laws have taken the position that those laws also protect individuals from being subjected to job discrimination because they are members of a group perceived to be at risk for HIV, or because of their relationship or association with others known or believed to have HIV/AIDS. Similarly, the federal ADA explicitly prohibits job discrimination against a person because of her association with someone with a disability, including HIV disease, known to the employer.

³¹³ 42 U.S.C. § 12113(b).

³¹⁴ 42 U.S.C. § 12111(3).

³¹⁵ A small number of positions do involve the performance of duties where a potential risk of HIV transmission may exist (e.g., certain health care workers perform invasive procedures with a potential for blood-to-blood contact). But if such a risk could be eliminated by reasonable accommodation, an employer may not deny an individual employment on the basis of disability. This assessment must be made on an individualized basis; a blanket policy of excluding HIV-positive persons from all jobs as nurses or physicians, for example, is likely illegal.

2. PARTICULAR APPLICATIONS

a. EXAMPLES OF DISCRIMINATORY POLICIES AND PRACTICES

The following employment policies or practices constitute illegal discrimination under one or more of the nondiscrimination laws outlined here:

- a policy of excluding applicants or employees from employment, or from particular jobs, because they are known or believed to have HIV/AIDS.
- using qualification standards that screen out or tend to screen out individuals with HIV/AIDS, unless those standards are job-related.
- not making reasonable accommodations to the known physical or mental limitations of an applicant or employee with HIV/AIDS who is otherwise qualified for and would be capable of performing the job if provided the accommodation, unless the employer shows that the accommodation would impose an undue hardship (see below, at pages 97-98).
- limiting, segregating, or treating an employee with HIV/AIDS in a way that adversely affects his status or opportunities on the job because of his disability.
- refusing to hire or retain an individual with HIV disease because of concerns that her illness may in the future impair her capacity to perform the job.
- refusing employment opportunities to an individual with HIV/AIDS on the basis of the employer's (or co-workers' or clients') fears of "contagiousness."

b. PRE-EMPLOYMENT INQUIRIES AND MEDICAL EXAMINATIONS; HIV TESTING

Requiring a job applicant to disclose his or her HIV status or to undergo an HIV test (or other medical examination) as a condition of employment is generally illegal under the nondiscrimination laws cited above. Employers may ask job applicants questions relating to their ability to perform job-related functions. They generally may not, however, make pre-employment inquiries about whether an applicant has a particular disability (including HIV/AIDS) or about the nature or severity of such a disability.

Under New York State Human Rights Law, employers may not require a job applicant to undergo a medical examination, including an HIV test, as a condition of employment, unless based upon a bona fide occupational qualification — a qualification standard that is job-related and material to job performance. (HIV testing by employers could also be challenged as a violation of Article 27-F of the Public Health Law; see Part 1.)

The federal nondiscrimination laws also prohibit covered employers from requiring applicants to undergo a medical examination before an offer of employment is made. After making a job offer to an individual, though, these employers may make medical inquiries and/or require the individual to undergo a medical examination before beginning the job; and the employer may condition the job offer on the satisfactory results of such medical exams or inquiries, but only if —

• all entering employees (or all employees in a particular job category) are subjected to the examination/inquiry;

- the information obtained as a result of the medical examination is kept strictly confidential (see "Confidentiality in the employment context," at page 98; and
- the information is not used to deny employment to or otherwise discriminate against an individual who is qualified to perform the job (or would be, if reasonable accommodations were made).

c. EMPLOYEE MEDICAL EXAMINATIONS OR INQUIRIES

Under the federal nondiscrimination laws, an employer may not require employees to undergo medical examinations (including HIV tests), or to disclose whether they have a disability or the nature or severity of a disability, unless such a medical examination or inquiry is shown to be job-related and consistent with business necessity. (The New York State and New York City Human Rights Laws have been interpreted to have comparable restrictions.)

Employers may inquire into the ability of an employee to perform job-related functions. They may also conduct voluntary medical examinations as part of a health program available at the worksite. But information obtained through these activities must be kept strictly confidential and may not be used to discriminate (see page 98).

B. REASONABLE ACCOMMODATIONS

1. GENERAL RULE: REASONABLE ACCOMMODATIONS MUST BE MADE

The federal and New York State and New York City laws require employers to make reasonable accommodations to the known physical or mental limitations of job applicants and employees with disabilities (including HIV/AIDS) —

- if the individual is otherwise qualified and the accommodation would enable the individual to perform the essential duties of the job,
- unless the accommodation would impose an "undue hardship" on the operations of the employer.

Under these laws, it is illegal for an employer to fail or refuse to make reasonable accommodations, or to deny an individual employment opportunities when the denial is based on the need to make reasonable accommodations.

a. WHAT ARE REASONABLE ACCOMMODATIONS?

Reasonable accommodations are adjustments or modifications in an employment setting that are necessary to enable an applicant or employee who is otherwise qualified for a job (i.e., who would be able to perform the job if the accommodation were made) to perform the essential duties and functions of the job. Possible reasonable accommodations include —

- job restructuring, part-time or modified work schedules; for example
 - » granting the request of an employee with HIV disease to work a constant shift, to accommodate his need for regular rest,

even though most employees work rotating shifts.

- » allowing an employee to work flexible hours or modify her work schedule to accommodate her need to make medical appointments or receive other treatment or counseling during regular working hours.
- » granting an employee's request for additional unpaid leave days;
- appropriate modifications of examinations, training material, or policies;
- making existing worksites readily accessible to and usable by individuals with disabilities;
- modification of equipment or provision of qualified readers or interpreters; or
- reassigning an employee to a vacant position for which he is qualified.

b. WHAT IS NOT REQUIRED

An employer need not make accommodations that would impose an "undue hardship" on its operations. An undue hardship means significant difficulty or expense for the employer.

Whether a particular accommodation would result in undue hardship must be determined on a case-by-case basis, taking into account such factors as the nature and cost of the needed accommodation, the overall financial resources and size of the employer, the nature and type of the employer's operations, and the impact of the needed accommodation on the employer's operations. For example —

- a small day care center with three staff members would not necessarily
 be required to provide an indefinite unpaid leave to an ill employee,
 if that would seriously impair its ability to provide adequate services to
 clients.
- if an employee holds a position that must be performed on a full-time basis, and she develops an illness that prevents her from continuing to work a forty-hour week, the employer would not be required to retain her on a part-time basis and hire an extra employee to ensure that the position is performed full-time.

2. HOW TO ASSESS REASONABLE ACCOMMODATIONS

The need for and nature of the reasonable accommodations for any individual with HIV must be assessed and decided on a case-by-case basis, through an interactive process between the employer and the employee. The employer should establish the same kinds of reasonable accommodation policies and procedures with respect to employees as are outlined above for clients (see page 97).

3. CONFIDENTIALITY IN THE EMPLOYMENT CONTEXT

Employers must maintain the confidentiality of any medical information (including HIV-related information) that is obtained about the job applicant or employee.

PART THREE: PROTECTIONS AGAINST HIV-RELATED DISCRIMINATION

Under the federal nondiscrimination laws cited above, any information obtained by an employer subject to those laws about the medical history or condition of job applicants and employees must be kept strictly confidential, and must be maintained on separate forms and in separate medical files. The ADA specifies that the only individuals who may have access to the information are:

- supervisors and managers who need to be informed about necessary work restrictions and necessary accommodations;
- first aid and safety personnel who may be informed when appropriate if the disability might require emergency treatment; and
- government officials investigating compliance with those discrimination laws. 316

Note, though, that if an employee tells co-workers about his HIV status, or co-workers learn about it from someone other than from the employer, no confidentiality law prohibits those co-workers from telling others. But if discrimination in the workplace results from these disclosures, including where the employer takes action against the employee because of the worker's HIV status, the employee suffering from these adverse actions can claim the protection of the laws forbidding discrimination.

³¹⁶ 42 U.S.C. § 12112(d)(3)(B).

IV. REMEDIES FOR DISCRIMINATION

The federal, New York State and New York City nondiscrimination laws generally offer both administrative and judicial remedies.

A. REHABILITATION ACT OF 1973

1. REMEDIES

Remedies for violations of the federal Rehabilitation Act include equitable relief (orders making defendants do or refrain from doing something) and (as of the date this manual is published) compensatory damages (money to compensate a person for actual harms caused by the discrimination). In employment cases, equitable relief may include hiring or reinstatement and back pay, and orders to provide reasonable accommodations to an employee. In cases involving discrimination in the provision of benefits or services to clients, equitable relief may include orders not to discriminate, to modify policies or practices, or to provide reasonable accommodations.

2. ADMINISTRATIVE COMPLAINT/LAWSUIT PROCESS

<u>Claims against recipients (public or private) of federal grants or aid.</u> Individuals claiming discrimination in employment or services by an agency that receives federal grants or aid other than federal contracts have the right to file an administrative complaint or a lawsuit — or both — under section 504 of the Rehabilitation Act (29 U.S.C. § 794).

- Administrative complaints may be filed with the federal agency that funds the discriminating agency or with the U.S. Department of Justice in Washington, D.C., which will refer the complaint to the proper federal agency. People do not need a lawyer to do this. To learn how and where to file administrative complaints, under the Rehabilitation Act as well as the ADA, call the Department of Justice's ADA Information Line (800-514-0301). The time limit for filing such complaints is 180 days from the date of the discrimination.
- <u>Lawsuits</u> may also be filed in federal or state court and, in New York, must be filed within three years after the discriminatory act. Individuals need not go through the administrative complaint process before going to court.

<u>Job discrimination by federal contractors or federal employers</u> may be challenged in an administrative complaint filed with (1.) the U.S. Department of Labor's Office of Federal Contract Compliance Programs (OFCCP), if the discriminating agency is a federal contractor;

³¹⁷ Rehabilitation Act § 505, 29 U.S.C. § 794a.

the time limit is 180 days³¹⁸; or (2.)the equal opportunity office of the discriminating employer, if a federal employer is the discriminating agency;³¹⁹ the time limit for beginning the complaint process is 45 days after the discriminatory act.³²⁰

- Persons challenging discrimination by federal employers under Section 501 of the Rehabilitation Act may also file lawsuits in court, but must first go through the administrative complaint process with the employer's equal opportunity office.
- Discrimination by federal contractors in violation of Section 503 of the Act may only be redressed through the administrative process in the OFCCP.

B. AMERICANS WITH DISABILITIES ACT

Individuals claiming violations of the ADA also have a choice of filing administrative complaints or lawsuits (in federal or state court), although the available remedies may differ depending on the nature of the discrimination involved.

1. REMEDIES

Job discrimination. Remedies for employment discrimination in violation of Title I of the ADA include equitable relief (hiring, reinstatement and back pay, or orders to provide reasonable accommodations to an employee) and monetary relief.³²¹ Money damages are not available to those suing state agencies for job discrimination under Title I (and, most likely, Title II), but are available against private employers, and (as of the time this manual is published) when the employer is a county or city governmental agency.

<u>State/local government programs, benefits, or services.</u> State and local governmental agencies' discriminatory actions and policies that violate Title II of the ADA can be remedied through equitable relief and monetary damages.³²²

<u>Public accommodations (private agencies' services or programs).</u> Remedies for discrimination against clients by public accommodations under Title III — including private health or social service providers — can include equitable relief (including orders to prevent discrimination, to modify a policy or practices, to provide auxiliary aids or services, or to make a facility accessible to those with disabilities), and civil penalties (fines) under certain circumstances. Money damages are not available to individuals who file lawsuits, but may be obtained if the U.S. Attorney General decides to bring a lawsuit challenging discrimination by a public accommodation and requests such damages.³²³

³¹⁸ Section 503 of the Rehabilitation Act, 29 U.S.C. § 793.

³¹⁹ Section 501 of the Act, 29 U.S.C. § 791.

³²⁰ 29 C.F.R. § 1614.105(a)(1).

³²¹ Title I, 42 U.S.C. § 12117.

³²² Title II. 42 U.S.C. § 12133.

³²³ Title III. 42 U.S.C. § 12188.

2. ADMINISTRATIVE COMPLAINT/LAWSUIT PROCESS

<u>Private employment</u>. Individuals claiming discrimination by private employers under Title I must file an administrative complaint with the federal Equal Opportunity Employment Commission (EEOC). (Call the EEOC at 1-800-669-4000 for information about EEOC offices and procedures.) The ADA complaint can be filed directly with the EEOC or with the State Division of Human Rights or New York City Commission on Human Rights.

- The deadline for filing these <u>administrative complaints</u> in New York is 300 days after the discriminatory act if the complaint is filed first in the state or city human rights agency which can process complaints alleging violations of the ADA as well as of New York's nondiscrimination laws (see page 103). If the state or city agency decides to stop processing an ADA complaint that was initially filed with it, it will notify the complainant, who must then file the complaint with the EEOC within 30 days after the state or city agency has stopped processing it. The deadline for individuals who do not initially file their ADA complaint with the state or city human rights agency, however, is only 180 days from the date of the discrimination.
- <u>Lawsuit</u>. If the claim is not resolved in the EEOC or the EEOC determines that discrimination did not occur, the complainant will receive a notice of the right to file a lawsuit in court. That suit must be filed within 90 days of receiving the notice.

State/local government employment. Discrimination complaints against public (government) employers under Title II, however, can be filed in court without first filing an administrative complaint.³²⁴ Because Title II does not have a statute of limitations for private lawsuits against public employers, courts typically adopt the most analogous statute of limitations under state law. Under New York state law, such a lawsuit against a public employer that is filed directly in court (bypassing the EEOC process) must be filed within three years of the discrimination.

Government programs, services or activities. Discrimination complaints against a state or local government, under Title II, may be filed directly in court or as an administrative action. Administrative complaints may be filed with either the federal agency that has authority over the government function at issue in the case or with the Civil Rights Division of the U.S. Department of Justice, which will transfer the complaint to the correct federal agency. The ADA Information Line can provide assistance on filing a complaint (call 800-514-0301). The deadline for filing an administrative complaint is within 180 days of the discriminatory act. Under New York state law, complaints may also be filed directly in court (without going through the administrative process) within three years of the discrimination.

<u>Public accommodations.</u> People claiming discrimination by public accommodations including private health or social service providers, under Title III, may also file either an administrative complaint with the Civil Rights Division of the U.S. Department of Justice or file a lawsuit in court (within three years from the date of discrimination under New York state law). They need not go through the administrative complaint process first.

³²⁴ 28 C.F.R. § 35.172(d).

C. NEW YORK STATE HUMAN RIGHTS LAW

Remedies for State Human Rights Law violations include equitable relief and money damages to compensate individuals for harms caused by the discrimination.³²⁵ People may file administrative complaints with the State Division of Human Rights (SDHR), the state agency charged with enforcing this law, or file a lawsuit in state court — not both.

1. ADMINISTRATIVE COMPLAINTS.

The SDHR has offices around the state and has a toll free number to deal with discrimination complaints (1-888-392-3644). The process is easy and individuals do not need lawyers. The time limit for filing complaints with the SDHR is one year from the date of the discriminatory act^{326}

• Lawsuits may be filed within three years of the discriminatory act. People need not file a complaint first with the SDHR.

D. NEW YORK CITY HUMAN RIGHTS LAW

Remedies for violations of the New York City Human Rights Law include equitable relief and compensatory or punitive damages (for acts of discrimination occurring in New York City). ³²⁷ The city's law, like the state's, gives individuals the choice of either filing a lawsuit in state court or filing an administrative complaint with the New York City Commission on Human Rights (but not both).

1. ADMINISTRATIVE COMPLAINTS

The Commission has a telephone number for discrimination complaints (212-306-7450) and currently accepts walk-ins from 9:00 to 3:30 (NYC Human Rights Commission, 40 Rector Street (10th floor), 10006; web site - http://www.nyc.gov/html/cchr/html/howto.html). The deadline for filing complaints with the Commission is one year after the discriminatory act occurred.³²⁸

Lawsuits must be filed within three years from the date of discrimination.³²⁹
 People do not need to file complaints with the Commission before going
 to court, but must notify authorized representatives of the Commission and
 the New York City Corporation Counsel within ten days after commencing
 the lawsuit.³³⁰

E. ARTICLE 27-F OF THE NEW YORK STATE PUBLIC HEALTH LAW

As noted previously (on page 90), the state's HIV Testing and Confidentiality Law does not itself establish remedies for discrimination. But if HIV testing or a disclosure of confidential HIV-related information results in discrimination in violation of the federal, state or New York City

 $^{^{325}}$ N.Y. Exec. Law \S 297.

³²⁶ N.Y. Exec. Law § 297(5).

³²⁷ N.Y.C. Admin. Code §§ 8-109, 8-502.

³²⁸ N.Y.C. Admin. Code § 8-109(e).

³²⁹ N.Y.C. Admin. Code § 8-502(d).

³³⁰ N.Y.C. Admin. Code § 8-502(c).

nondiscrimination laws, that individual may seek administrative and/or judicial remedies for discrimination.

In addition, the state agency regulations implementing Article 27-F prohibit health and social service providers subject to that law, and their staff, from discriminating or otherwise taking adverse action against clients or staff with HIV/AIDS.³³¹ Agency staff who violate the nondiscrimination requirements of these regulations are subject to disciplinary action, up to and including termination. Clients or staff of such providers who believe they are being mistreated or discriminated against for this reason may, therefore, notify the agency's administrators so that appropriate disciplinary action may be taken. They may also file complaints with the Special Investigation Unit of the Department of Health's AIDS Institute (see page 82).

F. FAIR HOUSING AMENDMENTS ACT OF 1988

Remedies for violations of the federal Fair Housing Act include equitable relief, monetary damages and/or civil penalties (42 U.S.C. §§ 3612, 3613(c)).

- <u>Administrative complaints</u> may be filed with the U.S. Department of Housing and Urban Development (HUD), within one year after the discrimination occurred.³³² The Attorney General of the United States also has the authority to monitor and redress housing discrimination under this law.³³³
- Lawsuits may be filed in federal or state court within two years of the discriminatory act.³³⁴ Persons may pursue both administrative and judicial remedies for such discrimination and need not go through the administrative process before going to court.

A FINAL NOTE: SEE APPENDIX H FOR A LIST OF LEGAL RESOURCES FOR PEOPLE WITH HIV-RELATED QUESTIONS OR PROBLEMS.

³³¹ N.Y. Pub. Health Law § 2786(2)(a).

³³² 42 U.S.C. §§ 3610, 3613.

³³³ 42 U.S.C. § 3614.

³³⁴ 42 U.S.C. §§ 3610, 3613.

HIV-Specific Model Consent Form

Informed Consent to Perform HIV Testing

My health care provider has answered any questions I have about HIV/AIDS. I have been provided information with the following details about HIV testing:

- HIV is the virus that causes AIDS and can be transmitted through unprotected sex (vaginal, anal, or oral sex) with
 someone who has HIV; contact with blood as in sharing needles (piercing, tattooing, drug equipment including needles),
 by HIV-infected pregnant women to their infants during pregnancy or delivery, or while breast feeding.
- · There are treatments for HIV/AIDS that can help an individual stay healthy.
- Individuals with HIV/AIDS can adopt safe practices to protect uninfected and infected people in their lives from becoming
 infected or being infected themselves with different strains of HIV.
- Testing is voluntary and can be done anonymously at a public testing center.
- The law protects the confidentiality of HIV test results and other related information.
- The law prohibits discrimination based on an individual's HIV status and services are available to help with such consequences.
- The law allows an individual's informed consent for HIV related testing to be valid for such testing until such consent is revoked by the subject of the HIV test or expires by its terms.

I agree to be tested for HIV infection. If the results show I 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. If I test positive for HIV infection, I understand that my health care provider will talk with me about telling my sex or needle-sharing partners of possible exposure.

I may revoke my consent orally or in writing at any time. As long as this consent is in force, my provider may conduct additional tests without asking me to sign another consent form. In those cases, my provider will tell me if other HIV tests will be performed and will note this in my medical record.

Patient Name:	Date:
Signature:Patient or person authorized to consent	
Medical Record #:	

NEW YORK STATE DEPARTMENT OF HEALTH **AIDS Institute**

Model for General Medical Consent that Includes Written Consent for HIV Testing

Use Sample A OR Sample B

Use

Use

Sample A – Consent for Medical Treatment	
se your facility's general medical consent but amend to include the following:	
I have been given information regarding HIV testing, how HIV can be transmit myself and others safe from HIV infection, that testing is voluntary and can be will be kept confidential and what laws protect people with HIV/AIDS from dis documented in my medical chart.	done anonymously, how my HIV-related information
Consent for HIV-related testing remains in effect until I revoke it, or until the fo	ollowing date
I may revoke my consent orally or in writing at any time. As long as this conse may conduct additional tests on me without asking me to sign another consent HIV tests will be performed and will make a note in my medical record.	nt is in force, <u>(provider name or facility)</u> t form. In those cases, my provider will tell me if other
Patient Name:	Date:
☐ I do not want an HIV test	
Signature: Patient or person authorized to consent	
Sample B — Consent for Medical Treatment	
e your facility's general medical consent but amend to include the following:	
I have been provided information about HIV and I accept testing,	
☐ No, I don't want an HIV test at this time.	
Signature: Patient or person authorized to consent	
Patient or person authorized to consent	

NEW YORK STATE DEPARTMENT OF HEALTH AIDS Institute

Model Form for Documenting Offer of HIV Testing

Sample - Offer of HIV Testing

Your health care provider is required to make an offer of HIV testing to all persons between the ages of 13 and 64 regardless of apparent risk. You are strongly encouraged to accept testing since, as with other medical screenings, it may provide you with important informatin about your health and give you what you need to make good decisions for staying healthy.			
☐ Yes, I accept the offer of HIV testing.			
☐ No, I don't want an HIV test today			
Patient Name:	Date:		
Signature: Patient or person authorized to consent			

NEW YORK STATE DEPARTMENT OF HEALTH AIDS Institute

Informed Consent to Perform HIV Testing and Authorization for Release of HIV-related Information for Purposes of Providing Post-exposure Care to a Health Care Worker Exposed to a Patient's Blood or Body Fluids

An employee has been exposed to your blood or a body fluid in a manner which may pose a risk for transmission of a blood-borne infection. Many individuals may not know whether they have a bloodborne infection because people can carry these viruses without having any symptoms. We therefore are asking for consent to test you for the presence of human immunodeficiency virus (HIV), the virus that causes AIDS. You will also be tested for hepatitis B virus (HBV) and hepatitis C virus (HCV).

Under New York State law, HIV testing is voluntary and requires consent in writing (consent can be withdrawn for testing at any time.) There are a number of tests that can be done to show if you are infected with HIV. Your provider or counselor can provide specific information on these tests. Anonymous testing is available at selected sites. These tests involve collecting and testing blood, urine or oral fluid. Additional testing also will tell whether you are carrying HBV or HCV.

HIV Testing is Important for Your Health

- If your test result is negative, you can learn how to protect yourself from being infected in the future.
- · If your test result is positive:
 - · You can take steps to prevent passing the virus to others.
 - You can receive treatment for HIV and learn about other ways to stay healthy. As part of treatment, additional tests will be done
 to determine the best treatment for you. These tests may include viral load and viral resistance tests.
- An infected mother can pass HIV to her child during pregnancy or birth or through breastfeeding.
- If you are pregnant and have HIV, treatment is available for your own health and to prevent passing HIV to your baby. If you have
 HIV and do not get treatment, the chance of passing HIV to your baby is one in four. If you get treatment, your chance of passing
 HIV to your baby is much lower.

If You Test Positive:

State law protects the confidentiality of your test results and also protects you from discrimination based on your HIV status.

- In almost all cases, you will be asked to give written approval before your HIV test can be shared.
- Your HIV information can be released to health providers caring for you or your exposed child; to health officials when required
 by law; to insurers to permit payment; to persons involved in foster care or adoption; to official correctional, probation and parole
 staff; to emergency or health care staff who are accidentally exposed to your blood; or by special court order.
- The names of persons with HIV are reported to the State Health Department for tracking the epidemic and for planning services.
- The HIV Confidentiality Hotline at 1-800-962-5065 can answer your questions and help with confidentiality problems.
- The New York State Division of Human Rights at 1-800-523-2437 can help if you think you've been discriminated against based on your HIV status.

If you are positive, your counselor/doctor will talk with you about notifying your sex or needle-sharing partners of possible exposure to HIV.

- Your partners need to know that they may have been exposed to HIV so they can be tested and get treated if they have HIV.
- If your health care provider knows the name of your spouse or other partner, he or she must report the name to the health department unless it would result in harm to you.
- Health department counselors can help notify your partner(s) without ever telling them your name.
- To ensure your safety, your counselor or doctor will ask you questions about the risk of domestic violence for each partner to be notified.
- If there is any risk, the Health Department will not notify partners right away and will assist you in getting help.

APPENDIX D

You are also being asked to authorize the release of confidential HIV-related information related to this consent for testing to the health professional, named below, who is treating the health care worker that has been exposed to your blood or body fluid. This is

necessary to provide appropriate care and to counsel the worker about his or her risk of becoming infected and possibly infecting others. Under New York State law HIV-related information can only be given to people you allow to have it by signing a written release, except in the instances outlined above. These individuals are prohibited by law from re-disclosing testing results in a way that could reveal your identity. Name and address of facility/provider disclosing HIV-related information: Name and address of facility/provider to be given HIV-related information: Describe information to be released: HIV, HBV and HCV Test Results Time period during which release of information is authorized From: _______ To: _____ You may revoke this release, but disclosures cannot be revoked, once made. Additional exceptions to the right to revoke this release, if any: __ Describe consequences, if any, of failing to consent to disclosure upon treatment, payment, enrollment or eligibility for benefits. (Note: Federal privacy regulation may restrict some consequences):_____ I understand that I am being asked to submit a specimen for HIV testing for occupational exposure. I agree to testing for the determination of HIV infection. If I am found to have HIV, I agree to additional testing that may occur on the sample I provide today to determine the best treatment for me and to help quide 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. I also authorize release of this information to the health care professional, named above, who is treating the health care worker that has been exposed to my blood or body fluid. Signature: (Test subject or legally authorized representative) Printed Name: Date: Patient ID#: DOB: Address: If legal representative, indicate relationship to subject:

New York State Department of Health AIDS Institute

Authorization for Release of Health Information and Confidential HIV-Related Information*

This form authorizes release of health information including HIV-related information. You may choose to release only your non-HIV health information, only your HIV-related information, or both. Your information may be protected from disclosure by federal privacy law and state law. Confidential HIV-related information is any information indicating that a person has had an HIV-related test, or has HIV infection, HIV-related illness or AIDS, or any information that could indicate a person has been potentially exposed to HIV.

Under New York State Law HIV-related information can only be given to people you allow to have it by signing a written release. This information may also be released to the following: health providers caring for you or your exposed child; health officials when required by law; insurers to permit payment; persons involved in foster care or adoption; official correctional, probation and parole staff; emergency or health care staff who are accidentally exposed to your blood; or by special court order. Under New York State law, anyone who illegally discloses HIV-related information may be punished by a fine of up to \$5,000 and a jail term of up to one year. However, some re-disclosures of health and/or HIV-related information are not protected under federal law. For more information about HIV confidentiality, call the New York State Department of Health HIV Confidentiality Hotline at 1-800-962-5065; for more information regarding federal privacy protection, call the Office for Civil Rights at 1-800-368-1019. You may also contact the NYS Division of Human Rights at 1-888-392-3644.

By checking the boxes below and signing this form, health information and/or HIV-related information can be given to the people listed on page two (and on additional sheets if necessary) of the form, for the reason(s) listed. Upon your request, the facility or person disclosing your health information must provide you with a copy of this form.

consent to disclosure of (please check all that apply):	 My HIV-related information My non-HIV health information Both (non-HIV health and HIV-related information)
Name and address of facility/person disclosing HIV-r	related information:
Name of person whose information will be released: Name and address of person signing this form (if oth	er than above):
	leased:
	Authorized: From: To:
Exceptions to the right to revoke consent, if any:	
(Note: Federal privacy regulations may restrict some	consent to disclosure upon treatment, payment, enrollment, or eligibility for benefits consequences):
Please sign below only if you wish to authorize all ta themselves for the purpose of providing health care a	cilities/persons listed on pages 1,2 (and 3 if used) of this form to share information among and between and services.
Signature	Date

* This Authorization for Release of Health Information and Confidential HIV-Related Information form is HIPAA compliant. If releasing only non-HIV related health information, you may use this form or another HIPAA-compliant general health release form.

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Authorization for Release of Health Information and Confidential HIV-Related Information*

Complete information for each facility/person to be given general information and/or HIV-related information. Attach additional sheets as necessary. It is recommended that blank lines be crossed out prior to signing.			
Name and address of facility/person to be given general health and/or HIV-related information:			
Reason for release, if other than stated on page 1:			
If information to be disclosed to this facility/person is limited, please specify:			
Name and address of facility/person to be given general health and/or HIV-related information:			
Reason for release, if other than stated on page 1:			
If information to be disclosed to this facility/person is limited, please specify:			
The law protects you from HIV-related discrimination in housing, employment, health care and other services. For more information, call the New York City Commission on Human Rights at (212) 306-7500 or the NYS Division of Human Rights at 1-888-392-3644.			
My questions about this form have been answered. I know that I do not have to allow release of my health and/or HIV-related information, and that I can change my mind at any time and revoke my authorization by writing the facility/person obtaining this release. I authorize the facility/person noted on page one to release health and/or HIV-related information of the person named on page one to the organizations/persons listed.			
Signature Date			
If legal representative, indicate relationship to subject:			
Print Name			
Client/Patient Number			

^{*} This Authorization for Release of Health Information and Confidential HIV-Related Information form is HIPAA compliant. If releasing only non-HIV related health information, you may use this form or another HIPAA-compliant general health release form.

Authorization for Release of Health Information and Confidential HIV-Related Information*

Complete information for each facility/person to be given general information and/or HIV-related information. Attach additional sheets as necessary. It is recommended that blank lines be crossed out prior to signing.		
Name and address of facility/person to be given general health and/or HIV-related information:		
Reason for release, if other than stated on page 1:		
If information to be disclosed to this facility/person is limited, please specify:		
Name and address of facility/person to be given general health and/or HIV-related information:		
Reason for release, if other than stated on page 1:		
If information to be disclosed to this facility/person is limited, please specify:		
Name and address of facility/person to be given general health and/or HIV-related information:		
Reason for release, if other than stated on page 1:		
If information to be disclosed to this facility/person is limited, please specify:		
If any/all of this page is completed, please sign below: Signature		
(SUB)ECT OF INFORMATION OR LEGALLY AUTHORIZED REPRESENTATIVE) Client/Patient Number		

^{*} This Authorization for Release of Health Information and Confidential HIV-Related Information form is HIPAA compliant. If releasing only non-HIV related health information, you may use this form or another HIPAA-compliant general health release form.

NEW YORK STATE DEPARTMENT OF HEALTH

Authorization for Release of Health Information (Including Alcohol/Drug Treatment and Mental Health Information) and Confidential HIV/AIDS-related Information

Patient Name		Date of Birth	Patient Identification Number	
Patient Address			<u> </u>	
I, or my authorized representative, request that health infor I. This authorization may include disclosure of information HIV/AIDS-RELATED INFORMATION only if I place my init of these types of information, and I initial the line on the	relating to ALCOH tials on the approp	OL and DRUG TREATMENT, ME riate line in item 8. In the even	NTAL HEALTH TREATMENT, and C t the health information described	ONFIDENTIAL I below includes any
2. With some exceptions, health information once disclosed drug treatment, or mental health treatment information, to other purpose without my authorization unless permitted HIV/AIDS-related information, I may contact the New Yor	may be re-disclose the recipient is pro I to do so under fec	ed by the recipient. If I am auth hibited from re-disclosing such deral or state law. If I experienc	orizing the release of HIV/AIDS-re information or using the disclosed e discrimination because of the re	elated, alcohol or I information for any lease or disclosure c
3. I have the right to revoke this authorization at any time b to the extent that action has already been taken based or			understand that I may revoke this	authorization excep
 Signing this authorization is voluntary. I understand that conditional upon my authorization of this disclosure. How 				
5. Name and Address of Provider or Entity to Release this I	information:			
6. Name and Address of Person(s) to Whom this Information	on Will Be Disclose	ed:		
7. Purpose for Release of Information:				
8. Unless previously revoked by me, the specific information All health information (written and oral), except:	on below may be di	isclosed from: INSERT START DATE	until INSERT EXPIRAT	ION DATE OR EVENT
For the following to be included, indicate the specific information to be disclosed and initial below.		Information to be Di	sclosed	Initials
☐ Records from alcohol/drug treatment programs				
☐ Clinical records from mental health programs*				
HIV/AIDS-related Information				
9. If not the patient, name of person signing form:		10. Authority to sign on be	chalf of patient:	
All items on this form have been completed, my questi	ions about this fo	orm have been answered and	I have been provided a copy o	f the form.
SIGNATURE OF PATIENT OR REPRESENTATIVE AUTHORIZED BY LAW				DATE
Witness Statement/Signature: I have witnessed the executi and/or the patient's authoriz		ation and state that a copy of th	e signed authorization was provid	ed to the patient

However, this form does not require health care providers to release health information. Alcohol/drug treatment-related information or confidential HIV-related information released through this form must be accompanied by the required statements regarding prohibition of re-disclosure.

*Note: Information from mental health clinical records may be released pursuant to this authorization to the parties identified herein who have a demonstrable need for the information, provided that the disclosure will not reasonably be expected to be detrimental to the patient or another person.

DOH-5032 (4/11)

APPENDIX G

NOTICE PROHIBITING REDISCLOSURE OF CONFIDENTIAL INFORMATION

This information has been disclosed to you from confidential records which are protected by state law. State law prohibits you from making any further disclosure of this information without the specific written consent of the person to whom it pertains, or as otherwise permitted by law. Any unauthorized further disclosure in violation of state law may result in a fine or jail sentence or both. A general authorization for the release of medical or other information is NOT sufficient authorization for further disclosure. Disclosure of confidential HIV information that occurs as the result of a general authorization for the release of medical or other information will be in violation of state law and may result in a fine or jail sentence or both.

(Source: Public Health Law § 2782(5); 10 N.Y.C.R.R. § 63.5)



Prepared by the Legal Action Center

LEGAL RESOURCES FOR PEOPLE WITH HIV-RELATED PROBLEMS

African Services Committee

429 W. 127th St New York, NY 10027 (212) 222-3882

AIDS Center of Queens County (ACQC)

161 Jamaica Avenue Jamaica, NY 11432 (718) 896-2500

Albany Law School, Health Law Clinic

80 New Scotland Avenue Albany, NY 12208 (518) 445-2328 Ext. 3369

Bronx AIDS Services, Inc.

540 East Fordham Road Bronx, NY 10458 (718) 295-5605

953 Southern Blvd. Bronx, NY 10459 (718) 295-5690

Empire Justice Center

One West Main Street, Ste. 200 Rochester, NY 14614 (585) 454-4060 Note that Empire Justice Center provides legal services in Rochester, Geneva, Elmira, and Bath.

Erie County Bar Association Volunteer Lawyers Project

237 Main Street # 1000 Buffalo, NY 14203 (716) 847-0662

Gay Men's Health Crisis

446 W. 33rd Street New York, NY 10001 (212) 367-1000

HIV Law Project

15 Maiden Lane (18th Floor) New York, NY 10038 (212) 577-3001

Legal Services of the Hudson Valley

90 Maple Avenue White Plains, NY 10601 (877) 574-8529

30 S. Broadway Yonkers, NY 10701 (914) 376-3751

Legal Action Center

225 Varick Street, 4th Floor New York, NY 10014 (212) 243-1313

Legal Aid Society

Brooklyn Neighborhood Office 111 Livingston Street, 7th floor Brooklyn, NY 11201 (718) 625-1803

Community Law Office 230 East 106th Street New York, NY 10029 (212) 426-3000

Legal Services of Central New York

472 South Salina Street, 3rd Floor Syracuse, NY 13202 (315) 703-6500

Manhattan Legal Services

1 W. 125th Street, 2nd Floor New York, NY 10027 (646) 442-3100

Project Hospitality, Inc. Legal Services Office

14 Slosson Terrace Staten Island, NY 10301 (718) 720-8172

South Brooklyn Legal Services

105 Court Street, 3rd Floor Brooklyn, NY 11201 (718) 237-5500

The Family Center

315 West 36th Street, 4th Floor New York, NY 10018 (212) 766-4522

The Legal Action Center is the only non-profit law and policy organization in the United States whose sole mission is to fight discrimination against people with histories of addiction, HIV/AIDS, or criminal records, and to advocate for sound public policies in these areas.

Since 1973, LAC has worked to combat the stigma and prejudice that keep these individuals out of the mainstream of society. The Legal Action Center is committed to helping people reclaim their lives, maintain their dignity, and participate fully in society as productive, responsible citize



225 Varick Street New York, NY 10014 (212) 243-1313 www.lac.org