

HIV Confidentiality Law 101

New Hire/Annual Update Training

Participant Manual

This training is designed for agency staff to fulfill the New Hire Training or the Annual HIV Confidentiality Law Update. This training provides a basic overview of the law and can be modified to fit with your own agency's policies. Every agency has specific HIV/AIDS Confidentiality Law policies and procedures in place and agency-wide policies and procedures should be explained during this training.

Under Public Health Law, Article 27-F every state agency authorized to receive HIV-related information about an individual is required to have regulations that provide guidance on how the law will be implemented in:

- The agency's setting,
- Local government units involved in providing or administering the agency's programs and services,
- Providers that the agency regulates or monitors.

New York State Department of Health Regulations outlined in this training set important standards which other state agency regulations generally follow. It is important to understand which regulations apply to you and your agency.

Acknowledgements

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- **One-on-one technical assistance** to help individual organizations and collaborative groups address specific needs.
- **Leadership development programs and workshop series** which provide opportunities for administrators, managers, and volunteers to learn more about potential solutions to common needs.
- **Resource products** which provide reference materials and management tools recipients can share with others.

CNYHSA has provided planning and program development assistance to the community since 1976. Issues addressed include health care access, need, utilization, finance, and program design; information system development; program evaluation; case management; strategic planning; and grant writing. **CNYHSA** also sponsors the Ryan White Central New York HIV Care Network and operates two HIV rental assistance programs.

This curriculum was developed and designed by Jeanette Shanley and Steve Wood of REACH CNY. REACH CNY's mission is to ensure access and support for the full range of quality, culturally-sensitive health and human services, reduce teen pregnancies and promote the health and well-being of individuals and families through education and advocacy.

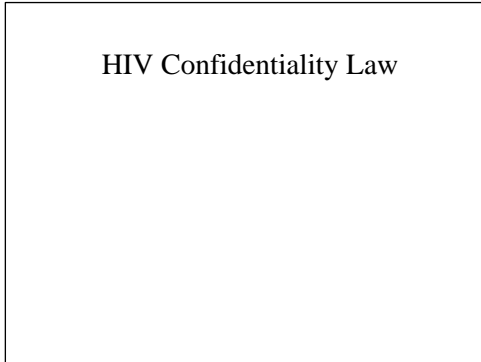
Materials herein have been adapted from the NYS Department of Health, AIDS Institute curriculum "HIV/AIDS Confidentiality Law".

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Introductions:

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HIV Confidentiality Law Activity:

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Questions?

- General Questions
 - NYS HIV Confidentiality Hot Line
 - 1-800-962-5065

- Complex Questions
 - Legal Action Center
 - 212-243-1313

A New Hire Training and/or annual update on HIV Confidentiality Law cannot provide all the information needed within your agency practice. It is helpful to keep, or have easy access to the following phone numbers for when situations or questions arise: General questions can be made to the New York State Confidentiality Hotline at 1-800-962-5065.

More complex questions should be directed to the Legal Action Center at 1-212-243-1313. It is usually best to call the NYS Confidentiality Hotline first, as they are always available, and what may seem complex to us, may be a routine questions to them.

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- What if?

What if?

Notes:

HIV Confidentiality Law applies differently depending on the type of work someone does. For example, probation officers can make different types of disclosures than human service workers, while physicians have blanket rules regarding disclosures.

Definitions and Rationale of the Law

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Definitions

- **Article 27-F** – HIV Confidentiality Law
- **Protected Individual** – Person with HIV, HIV-related illness, or AIDS
- **Disclose** – share or tell information, records, etc.

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NYS HIV Confidentiality Law

- **Governs**
 - Confidentiality & disclosure of information about people tested for, and diagnosed...
 - HIV Testing
- **HIV Reporting & Partner Notification Law**
 - Reporting cases of HIV Infection, HIV related illness & AIDS to State & Public Health Authorities
 - Contact or Partner Notification
 - Disclosures of HIV Information & Occupational Exposure

Definitions:

“**Article 27-F**” is simply what the HIV/AIDS Confidentiality Law is called.

“**HIV-Related Illness**” is the time when the immune system is struggling, where T-Cells counts have dropped between 500 and 201. Individuals with HIV-related illness usually develop common infections that do not respond to standard treatments. An example is a vaginal yeast infection that does not resolve with over-the-counter medications.

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Rationale of the HIV Confidentiality Law

- Public Health Need
- Need to protect people from HIV-based discrimination & stigma
- Regulations Include:
 - Requirements for each state health and human service provider who deals with HIV related information

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Regulations (con't)

- New York State Department of Health Part 63
 - Regulates health care facilities in NY
 - How they comply with the law
 - Setting important general standards

Rationale

The basic idea behind the HIV Confidentiality Law is to maintain an individual’s privacy while providing a continuity of care between disciplines, i.e., health care to human services, to housing services, back to health care and health care specialties. Individuals with HIV and AIDS may

have multiple needs beyond just what a physician can provide to them. It is important that everyone involved in that individual's service knows what is going on with other providers. This law allows that to happen while keeping HIV status private.

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Other State Agencies

- Application for other state agencies that are authorized to obtain HIV information, issue their own regulations
 - The agency's own staff
 - Local government units that provide or administer agency programs or services
 - Programs and Providers that an agency regulates

Providers must be aware of how this law affects their practice, but also how other organizations apply the HIV Confidentiality Law. Since most agencies follow the NYSDOH's policy, the basic rules for handling HIV-related information are essentially the same across the state. Slide 9 outlines those DOH policies.

Regulations:

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**Department of Health
Regulations**

- Five Basic Mandates
 1. Have policies & procedures
 2. Establish rules when there is a reasonable need to know
 3. Establish an internal "need to know"
 4. Safeguards to prevent discrimination
 5. Protocols to deal with Occupational Exposure (when there is risk of HIV transmission)

The five basic mandates of NYS HIV Confidentiality Law are:

1. Have policies and procedures in place to protect confidentiality and prohibit unauthorized disclosures.
2. Establish rules when there is a reasonable need for the agency to get or use confidential HIV-related information to carry out their duties.
3. Establish an internal need to know policy that specifies which employees are authorized to have access to and share confidential HIV-related information.
4. Have safeguards to prevent discrimination or abuse of clients
5. Have protocols to prevent and deal with occupational exposure when there is a significant risk of HIV transmission.

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Basic Confidentiality Rule

- You may not disclose any confidential HIV related information about a protected individual unless:
 1. You have a written HIV specific consent
 2. You are permitted to disclose under specific exceptions
- Depends on who you are, your profession, and how that info impacts the client's care.

Notes:

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What is Confidential HIV-Related Information?

- Any information concerning whether a person has been tested for or diagnosed with HIV infection, HIV-related illness or AIDS
- Any information that identifies or could identify a person as having HIV infection
- Information pertaining to such person's contacts or partners

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Protected Individuals

- Person who had an HIV test
- Person who is treated for HIV/AIDS
 - Prescriptions, medical procedures, etc.
- Person who has an HIV-related test
 - CD4 T-cell count, viral load, etc.
- Person with an HIV-related diagnoses
 - Opportunistic infection, etc.

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Protected Individuals

- The fact that someone has been tested for HIV makes them a protected individual
 - It doesn't matter if the test is Positive or Negative

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What does "Confidential HIV-related Information" mean in practice?

- How to tell if information is confidential
 - Is it HIV related information?
 - Is it information about a specific person? Does it directly or indirectly identify them?
 - Does it reveal that a person has been tested for, or diagnosed with HIV/AIDS?
 - Are you someone covered by the law?
 - Nurse, doctor, case manager, etc., etc., etc.

Disclosures and Who Complies

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Disclosure

- Disclosure is communication of any confidential HIV-related information to someone else
 - Oral
 - Written
 - Computerized
 - Direct/indirect
 - Passive/active
 - Unintentional/inadvertent
 - Intentional/willful

Oral – in person or via telephone

Written – in records and/or on paper

Computerized – records kept online or through email.

It does not matter if an inappropriate disclosure was intentional or not. It is still considered a violation. Liabilities and sanctions will be discussed later in the workshop.

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Disclosure

- Indirect disclosure
 - Reveals a person’s identity without naming them
 - Reveals a person’s HIV status without naming them
- Passive disclosure
 - Letting others see or have access to confidential information

Disclosure:

Example of **indirect disclosure:**

“I saw that guy who works at the convenience store, he has a long ponytail and a tattoo on his forearm, in the waiting room at the agency who serves people with AIDS.”

Example of **passive disclosure:**

Leaving a computer screen on with confidential records visible to anyone who passes by, or leaving files open on your desk when you are not sitting there.

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Who?

- Who is a covered health or human service provider?
 - All individuals who get HIV-related information in providing health or social services
- What does “covered” mean?
 - Any person who obtains HIV-related information must comply with the law.

“What does covered mean?”

It does not matter if information was obtained with or without consent.

Having the information, as a health or human service provider is what triggers the law’s confidentiality requirements.

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Definition of Health or Social Services

- Any public or private care, treatment, lab test, counseling or educational services
- Public assistance (including disability payments)
- Employment related services under the social services law – JobsPlus, JobCore
- Housing services, including shelters
- Foster care, protective services
- Services for the mentally disabled, including alcohol & substance abuse services

Definition of Health or Social Services

- Any public or private care, treatment, lab test, counseling or educational services for adults or children. This includes acute, chronic, custodial, residential, outpatient or other health care.
- Public assistance (including disability payments)
- Employment related services under the social services law – JobsPlus, etc.
- Housing services, including shelters
- Foster care, protective services, day care or preventive services.
- Services for the mentally disabled, including alcohol & substance abuse services

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Definition of Health or Social Services

- Criminal justice services, including probation, parole, criminal & juvenile justice
- Activities of the health care worker includes clinical trials
- Who is covered by consent?
 - Any person who gets HIV related information through a proper HIV consent form

Criminal justice services, including probation, parole, correctional, detention and rehabilitative services under the criminal & juvenile justice systems.

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How to handle requests for records & charts

- Confidentiality law requires providers to have written protocols for requests for confidential info
- Providers must follow a clear policy
 - Designate staff responsible for handling requests
 - Set up policy and step-by-step procedure
 - Review all records/information being sought

How to handle requests for records/charts containing HIV-related information and why every provider and person needs to know how to handle requests for confidential information

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Policy (con't)

- Determine if disclosing HIV information is authorized
 - Client has signed a valid HIV consent, or
 - Requesting party is authorized
- When disclosing:
 - Send the notice prohibiting re-disclosure
 - Document the request (date, time, contents, recipients)

The HIV Confidentiality Law and regulations require providers covered by the law to have written protocols for responding to requests for HIV-related information. NYSDOH AIDS Institute-funded agencies are required to have written protocols.

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Policies (con't)

- Documentation is not required when made to:
 - Health care provider or facility
 - Program review or monitoring
 - Insurance institutions after first disclosure is noted
 - Government agencies for reimbursement
- A consent form can be used as documentation
- Information should be documented in client record
- Do not have clients sign blank forms

Providers must consistently follow a clear policy on responding to requests. Without one, there is no way to prevent inadvertent and unauthorized disclosures of HIV-related confidential information – no way to prevent violations of the law.

Step-by-Step Guide: How to Handle Client Record Requests

Step 1

When any request for client records or information is received, review all the records/information being sought to see if they contain any HIV-related information.

Step 2

If the records do contain any confidential information, determine if disclosing HIV-related information in response to the request is authorized because –

1. the client has signed a valid HIV “Release of Information” form authorizing that disclosure, or
2. the requesting party is authorized to obtain the information under one of the exceptions permitting the disclosure without consent.

Step 3

If you are authorized to make the disclosure, you may do so. You must also:

1. send the Notice Prohibiting Redisclosure when required; and
2. document the request. If the client’s consent authorizes the disclosure, the “Release of Information” form will contain this information and can be the documentation. Otherwise, the disclosure must be documented in the client’s record/chart.

Note: Disclosures (oral or written) do not need to be documented when made to –

- a health care provider or facility (only under the exception allowing for disclosure in order to provide needed services to protected individuals)
- a health care facility or other program review or monitoring organization (under the exception just discussed)
- insurance institutions, after the first disclosure is noted.
- government agencies conducting reimbursement or related activities concerning payment for services to a client.

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If requestor is not authorized...

- Get consent from client
- Withhold HIV-related information from the record
 - Omit the HIV info
 - Black marks
 - Do not have to tell requestor some info has been omitted
- Do not disclose records and/or information

Step 4

If you are NOT authorized to make the disclosure, you have three possible options:

Option #1: consider obtaining consent/authorization. You can contact the client whose information is being requested and, if he or she authorizes the release of information, the information can be released.

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Don't worry!

- When omitting or blacking out information don't worry that it will be identifiable as HIV/AIDS information
- Many things can be omitted
 - ANY medical info
 - Substance use/history
 - Prescribed medications
 - Mental health diagnoses
 - STD history/treatment
 - Any personal info the client doesn't want to share
- Is it ethical to share????

Option #2: withhold or redact the HIV-related information from the records/information you disclose. If the client does not authorize and there is no basis for making a disclosure, you may send the requesting party the records or information without the HIV-related information. This means either withholding the parts that contain the

HIV-related information or redacting (blotting out) the information from the records being sent. Except where the records are being sought by way of a subpoena or court order, agencies probably do not have a legal obligation to tell the requesting party that some of the records sought are being withheld.

Option #3: do not disclose any records/information, and tell the requesting party why. You can inform the requesting party that the information requested is confidential under New York State law and may not be disclosed without appropriate authorization. This can be done with a notice or letter that says:

Providing HIV-Related Information to Promote Appropriate Health Care

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Providing HIV related information to promote appropriate Health Care

- Health care providers who may give information
 - Physicians
 - Nurses
 - Diagnostic medical service providers
 - OB/GYN, Nurse Practitioner, Physician Assistant, Mid-wives
 - Providers for persons with a mental disability
 - Other persons involved in health care

In some instances health care providers and other social service providers may need to provide HIV-related information to other providers and facilities in order to ensure that the patient gets appropriate care. The questions that health care providers need to ask themselves to determine the circumstances under which information can be shared without a HIV-specific release is outlined in this section.

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Providing HIV related information to promote appropriate Health Care

- “Health Facilities” who may be given this information:
 - Hospitals
 - Blood & Tissue Banks
 - Laboratories
 - Treatment facilities
 - Mental disabilities, substance treatment, etc.

Summary/Review of the health care provider rule: Persons and providers who must comply with Article 27-F are permitted to disclose HIV-related information about a protected individual, **without consent**, to a health care provider or health facility when – knowledge of the HIV-related information is necessary to provide

appropriate care or treatment to the protected individual, or his or her child, or a contact of the protected individual (or a person authorized to consent to health care for the contact). (PHL §2782.1(d); DOH Part 63, § 63.4.). The law provides that individuals and providers may disclose confidential HIV-related information under this rule to specified “health care providers” and “health facilities.”

The “**health care providers**” who may be given this information include:

- physicians
- nurses
- licensed or certified providers of diagnostic medical services, including nurse practitioners, midwives and physician assistants [according to DOH regulations]

- providers of services for persons with a mental disability, who are defined to include people with mental retardation, developmental disabilities, and alcohol or substance dependence
- other persons involved in providing medical, nursing, counseling or other health care or mental health services (including those associated with or under contract to an HMO or medical services plan).(PHL § 2780.13.)

The specified “**health facilities**” that may also be given this information include:

- hospitals (as defined in PHL § 2801)
- facilities providing care or treatment to persons with a mental disability (mental retardation, developmental disabilities, alcohol or substance dependence)
- blood banks, tissue banks, organ procurement organizations
- laboratories. (PHL § 2780.12, 2782.1(d).)

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The standard for when disclosure is appropriate

- The law permits disclosure without specific HIV consent when & ONLY when:
 - It is disclosed to one of the health care providers previously mentioned
 - It is necessary for that health care provider to know the HIV-related information in order to provide appropriate care
 - To a protected individual, their child, and/or their sexual or needle sharing contact/partner
 - Occupational exposure (see section 8 of your manual)

The law permits confidential HIV-related information to be disclosed without a HIV specific authorization under this rule when – and only when – it is disclosed to one of the health care providers or health care facilities designated in the law (see above), and it is necessary for that specific health care provider/facility to know the HIV-related

information about the protected individual in order to provide appropriate care or treatment to the protected individual (who is the subject of the information), or his or her child, or one of his or her contact(s) – identified spouse or sexual partner, needle-sharing partner, or occupationally exposed person.

Note: The provider or individual with the confidential HIV-related information is the one who decides and has the right to decide -- whether to disclose it to a health care provider/facility under this rule.

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Healthcare facilities/providers may be given HIV-related information, but are not entitled to it!

- Do not have a “right” to it
- No liability on yours or their part if you/they are following procedure
- How to decide when it’s appropriate
 - Is the recipient one of the specified providers under the law? (Doctor, nurse, etc.)
 - Does the health care provider need to have this information to provide appropriate care or treatment?
- If yes to both = Disclose.
- If no to one or both = Do not Disclose

It is not required or mandated that health care providers or facilities be given HIV-related information (with or without an individual’s consent). The information may be given at the discretion of the person/agency that has it, if that person decides the disclosure is appropriate and permitted by this rule -- but they are not entitled to it. If a provider or individual

either discloses or decides not to disclose information to a health care provider or facility, after complying with the applicable standards and procedures required in this rule, there will be no liability.

How to decide:

There are two questions to ask. The person deciding whether to disclose confidential HIV-related information to a designated health care provider or facility under this rule should ask these two questions:

Question #1

Is the proposed recipient of the information one of the specified, authorized health care providers or health facilities under the law?

Question #2

Does that health care provider/facility need to know the HIV-related information, and need to know it in order to provide appropriate care or treatment to one of the individuals named in the law? This individual must be either the person who is the subject of the information (protected individual), or a child or contact of that individual.

If the answer to both questions is yes, the law permits the disclosure to be made. If the answer to either is no, no disclosure is permitted without consent.

Reasons why disclosure to a health care provider/facility would not be justified include:

Point #1

A health care provider/facility does not need to know the HIV-related information about the protected individual because the information is not needed to treat the medical problem being treated – that is, is not needed to give appropriate care or treatment to the person being treated -- whether it is the protected person or someone else.

Point #2

A health care provider does not need to be told, HIV-related information about the individual, because the health care provider already knows it.

Point #3

The person wanting to disclose the HIV-related information is doing so for a reason other than for the purpose of treating or caring for the protected individual, his/her contact or his/her child. The law does not allow disclosures for some other purpose – like trying to protect a health care provider from being exposed to HIV, or trying to facilitate the care or treatment of some person other than the protected individual, his/her child, or his/her contact.

Reasons why disclosure to health care provider/facility might be justified include:

Point #1

A health care provider who is treating a protected individual for a particular medical problem needs to know the HIV-related information in order to properly treat that medical problem -- and the protected individual cannot or may not be able to tell the health care provider directly.

Point #2

A physician who is treating the contact (partner) of a protected individual for a particular medical problem (e.g., an STD) needs to know the partner's HIV status in order to provide appropriate medical counseling and care to the contact.

If the disclosure is permitted, steps on how to proceed are:

1. If no emergency or undue time pressures make authorization impractical to obtain, it makes sense to consider whether it's possible or feasible to ask the protected individual to consent to the disclosure, rather than disclosing without consent.
2. Disclosures may be made only to employees of the health care provider or facility who are authorized to have access to HIV-related information, under that provider's or facility's **"need to know"** list and protocol.
3. Documentation requirement: Any disclosures under this rule must be documented in the disclosing agency's records.
4. The Notice Prohibiting Redisclosure must be sent to the recipient.

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Appropriate care or treatment

- Is there a need to know?
 - Remove stitches
 - Remove a cast
 - Cosmetic surgery
 - MRI
 - Cat scan
 - mammogram

Notes:

Capacity to Consent to a Disclosure

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Disclosing with an HIV specific consent

- Capacity to consent to a disclosure of HIV related information means an individual's ability, without regard to age, to understand the nature and consequences of disclosure and whether to permit the disclosure
 - Age does not determine capacity to consent
 - Mental or physical ability does not determine capacity (unless person is adjudicated incompetent)
- This applies to HIV test decisions

Capacity to consent – and who has capacity to consent to a disclosure; and the specific requirements for proper HIV consent forms, and rules for disclosing with consent.

The Capacity to Consent Rule: If a protected individual has “capacity to consent,” he/she decides to authorize a disclosure, and signs the consent form authorizing the disclosure. If an individual lacks capacity to consent, a person “authorized pursuant to law to consent to health care” for that individual – if there is one – decides whether to permit the disclosure, and signs the consent.

Definition of capacity to consent

Capacity to consent to a disclosure of HIV-related information means an individual's ability, without regard to age, to:

- understand and appreciate the nature and consequences of a proposed disclosure of HIV-related information about him/herself, and
- make an informed decision about whether to permit the disclosure. (PHL §2780.5.)

What this means in practice

Point # 1

Age does not determine whether an individual has capacity to consent to a disclosure under Article 27-F. Capacity to consent is a functional (“real world”) concept, not a legal one based on whether a person is a minor (under age 18) or legally an adult. Some minors – children and adolescents – will have capacity to consent, and others will not. **Each minor's capacity to consent must be individually assessed, with one exception:** Infants and very young children will always lack capacity to consent to a proposed disclosure, because they are too young to be able to understand what they need to know to make an informed decision about it.

Point #2

The fact that an individual may have a mental or physical disability or problem—permanent or temporary -- does not automatically determine capacity to consent or lack of capacity. Individuals with mental or physical disabilities cannot automatically be assumed to lack capacity to consent for purposes of Article 27-F, with one exception:

If a person has been adjudicated as incompetent (judicially declared to be incompetent to make health care decisions), it is permissible to assume the person lacks capacity to consent for purposes of Article 27-F. There must be a formal court adjudication of incompetence, though.

In cases where a person has not been adjudicated as incompetent, an individualized assessment of his or her capacity is needed. Disability or other mental or physical problems may be a factor but are not the only or conclusive factors in deciding capacity to consent.

Example. A person with developmental disabilities, mental retardation, cerebral palsy or other problems may still possess the basic understanding and decision-making abilities needed to meet the law’s concept of capacity to consent. Or the person may possess the necessary understanding some days, but not others.

An individual’s capacity to consent may vary at different times; this is why it must be individually assessed and may need to be assessed more than once. The law requires an individualized assessment of a person’s capacity to consent at the time a proposed disclosure is being considered. This is to make sure that the person being asked to consent to the disclosure can make an informed decision about whether to permit that particular disclosure.

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<p>Capacity</p> <p>Capacity to consent may vary at different times Must be assessed individually & may be more than once</p> <p>Article 27-F only gives the right to decide about an HIV test or disclosure NOT other health decisions</p> <p>How about someone who is drunk or high?</p>
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Example: Persons who are temporarily incapacitated – for instance, by drug or alcohol use, or by psychiatric problems – may not have capacity to consent during those times. But they may regain capacity to consent at other times. In these circumstances, it is wise to defer the capacity assessment and disclosure decision until the temporary incapacity ends or eases.

Point #3

The same concept of capacity to consent applies to HIV test decisions and disclosure decisions – but it applies to only those decisions.

- Article 27-F uses the same definition of capacity to consent to determine who has the ability – and right – to decide whether to be tested for HIV, and to decide whether to allow a proposed disclosure of HIV-related information. But having capacity to consent under Article 27-F only gives the person the right to decide whether or not to have an HIV test or allow an HIV-related disclosure. It does not give an individual the right to make other health care decisions on his/her own. Other provisions of law govern this.
- Another part of the PHL governs who has the legal authority and right to consent to health care for themselves – that is, make decisions about health care and treatment.(PHL § 2504.)

For instance, parents usually have the authority to consent to health care for their minor children (under age 18) – and minor children cannot consent to health care on their own. Example. This means that someone – like a 15-year old – may have capacity to consent to an HIV test or HIV-related disclosure about herself. BUT, because she is a minor, she may not have the legal authority to make decisions on her own about HIV treatment.

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Who assesses a persons capacity to consent?

- The law does not require a specialist
- The law requires a common sense assessment
- The law assumes the provider will be familiar with the legal standard
- Designating a staff person may make sense

Who assesses a person's capacity to consent?

- The law does not specify who assesses capacity and does not require a specialist. In general, the person proposing to make a disclosure about a protected individual must assess the individual's capacity to consent.
- The law requires a common-sense

assessment of capacity and assumes many providers can and will be able to do these simple assessments.

- The law requires that any provider who assesses an individual's capacity must be familiar with the legal standard for capacity and the individual whose capacity is being assessed.
- Designating a staff to be responsible for assessing capacity may make sense in some settings.

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How to assess capacity

1. Does the person understand the nature and possible consequences of the disclosure
 2. Is the person able to make an informed decision to say “yes” or “no” to a proposed disclosure?
- If the answer is “yes” to both questions, the person has capacity.

How to assess capacity to consent to disclose information.

Providers assessing capacity need to ask and answer two questions. If the answer to both is yes, the individual has capacity to consent – and the provider must respect the individual’s decision whether to agree or refuse to allow a disclosure.

The capacity to consent questions are:

Question #1

Does this person understand the nature and possible consequences of the disclosure of HIV-related information I am proposing to make about him or her? That is, does he or she – understand what I am going to disclose, to whom, and why? Understand what might happen (good and bad) if I make the disclosure? and

Question #2

Is this person able to make an informed decision about whether to say “yes” or “no” to my proposed disclosure of HIV-related information about him or her? Does he or she – know what I am proposing to disclose, to whom and why, and understand the possible consequences ? (This is the information needed to make an informed decision.)

Note: The rule: When a protected individual lacks capacity to consent, a “person authorized pursuant to law to consent to health care” for him or her can decide and consent to the disclosure -- refuse consent. (PHL § 2782.(a), (b).)

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Who is a person authorized by law to consent to health care

1. Parent/legal guardian of a child under 18
2. Legal guardian of person adjudicated as incompetent
3. Health care agent when there is a health care proxy & authority has shifted & patient cannot consent

Who is a “person authorized by law to consent to health care” for a protected individual?

- This is a natural person (not an institution or agency) who has been given the legal authority to make health care decisions for another individual – that is, to consent to health care for him or her.

There are three basic categories of persons authorized by law to consent to health care for another individual:

- The parents or legal guardians of minor children (under 18) who lack capacity to consent. Remember, if a minor has capacity to consent under Article 27-F, he or she decides about disclosures, not a parent – even though the parent is still a person “authorized by law to consent to health care” for the minor. When a child or adolescent lacks capacity to consent under Article 27-F, the parent(s) -- as persons “authorized by law to consent to health care” for their minor child -- are given the legal authority to decide about and consent or refuse to allow disclosures of HIV-related information about their child.
- The legal guardian of a person who has been adjudicated as incompetent. When legal guardians are appointed to act on behalf of persons who are judicially declared incompetent, they are given the legal authority to make health care and other decisions for the individual.
- The health care agent of a protected individual, when there is a health care proxy and the health care decision-making authority has shifted from the protected individual to the health care agent

The legal authority to make health care decisions (and consent to health care) for someone with a health care proxy shifts to the health care agent when the person’s physical or mental condition makes him/her unable to make those decisions. But if a person with a health care proxy regains the ability to make health care decisions on his/her own, then that person again has the authority to consent to health care for him/herself; and that person has capacity to consent to disclosures under Article 27-F. When this happens, the health care agent is no longer a person “authorized by law to consent to health care” or make disclosure decisions for the individual.

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<p>What to do when an individual is comatose and/or lacks capacity</p> <ol style="list-style-type: none">1. Do not disclose2. Defer the decision until they regain consciousness3. Assess options for disclosure without consent (can it be made? Should it be made?)4. Look for a legal guardian (appointed or going to be appointed)

How to handle situations where an individual is comatose and/or otherwise lacks capacity to consent and there is no “person authorized by law to consent to health care” for him/her.

An individual can lack capacity to consent and there is no person authorized by law to consent to health care for him

or her – and therefore no person with legal authority to make decisions about whether to consent to a HIV-related disclosure about (or an HIV test for) the individual. This can happen in situations involving:

- an individual who is comatose or unconscious without immediate prospect of regaining consciousness,
- a person temporarily incapacitated by, for example, drug or alcohol use,
- a person suffering psychiatric or physical problems severe enough to make him lack capacity to consent, but who has not had a legal guardian appointed (with health care decision-making authority)
- individuals in all three of these or comparable situations where the person lacks capacity to consent, but has no health care proxy – and no health care agent to act for him or her when needed.

What to do? There are four possible options for these situations:

Option #1

Do not disclose: Decide not to make the disclosure.

Option #2

Defer the decision and disclosure: Defer making the disclosure, until the individual regains consciousness (or is no longer impaired by the substance abuse, psychiatric or physical condition) and has capacity to consent.

Options #3

Assess options for disclosure without consent. Determine if the proposed disclosure may legally be made without the individual’s consent, under one of the special exceptions.

Option #4

Look for legal guardian on the horizon. Determine whether a legal guardian can be/is being appointed for the individual, and act accordingly.

Sharing Information/Inter-Agency Issues

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Sharing information within an agency

- Internal Communication Rule:
 - Access and share confidential information within an agency’s health or social services without consent
 - Only when authorized by the agency’s written need-to-know protocol
 - AND the employees reasonably need to know

The Internal Communications Rule: Authorized employees only within an authorized agency may have access to and share confidential HIV-related information about recipients of the agency’s health or social services, without consent – but only when authorized by the agency’s written need-to-know protocol, and when the

employee(s) reasonably need the information in order to carry out their authorized duties in providing services to the individuals involved.

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What does the internal communication rule allow and require?

1. Certain employees have access & are able to share confidential information internally
2. Requires
 - Employee access to client/patient records, AND
 - “need to know” protocol, AND
 - There’s a reasonable need for the information

The Internal Communications Rule applies to designated health care providers and facilities, and the providers of and government agencies involved in covered health or social services listed in the law.

The health care providers and health facilities include:

- hospitals
- physicians
- nurses
- facilities and other providers of care or treatment to persons with mental disabilities, alcoholism or substance abuse, blood banks, blood centers, organ or tissue banks

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How to apply the internal communication rule in practice

1. Conduct an agency-specific assessment
2. Develop, write, and obtain necessary approval
3. Train all staff on protocol (Not just authorized staff...)

Notes:

Policies, Procedures and Violations of the Law

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**Policies and Procedures
to ensure confidentiality**

1. Written need to know list by job title
2. Employee training (initial & annual)
3. Protocol to insure security of written & electronic records
4. Procedures for handling requests
5. Protocol prohibiting discrimination

Notes:

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Sanctions & liability issues

1. Establish or know your agency sanctions for inappropriate disclosures/violations of protocol
2. Liability – who is liable?

Notes:

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Who is Liable?

- Employee if employer has policies & training has been provided
- Employer if no policies or no protocols for training
- Both if they knew or should have known that the disclosure violated the law
- It is an employees responsibility to know policies & procedures, and to know your agency's sanctions

Notes:

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Remedies & Recourse

- Violations – Civil fines up to \$5,000 per violation, and/or 1 year in jail
- Department of Health imposes fines
 - Special Investigation Unit takes reports of alleged confidentiality violations
 - Complaints must be made by calling 212-268-6108
 - No special form is necessary
 - Who gets the \$\$\$?

Often health and human services providers, especially case managers, are approached by a client who feels that his/her HIV-related confidentiality has been violated. It is important for health and human services providers to be aware of the recourse that clients can take if they have had their rights violated so that they can provide that client with

helpful referrals and resources. This section outlines the options that people have if they believe that their rights have been violated under the NYS HIV Confidentiality Law.

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Remedies & Recourse

- Private lawsuits – people can bring civil lawsuits to recover money damages
- You do not have to file a complaint with the Special Investigation Unit
- Article 27-F does not address discrimination
 - NYS Human Rights Law 800-523-AIDS
 - Federal Americans With Disabilities Act 800-949-4232

Notes:

Documentation

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Documentation

- Only in medical record
- Other records
 - Law’s documentation rules only apply to medical records
 - Law does not mention other client records
- Every disclosure must be documented
- Clients have a right to be informed of all disclosures
 - Oral & written
 - Intra-agency
 - Made with consent

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Documentation

- Providers of services other than medical may be required to document
- All human service providers are obligated to maintain client records
- When an agency is not regulated they still SHOULD develop their own policies
- Once you write something down it’s protected under 27-F

It is important for health and human services providers to understand how to properly document HIV-related information. This section outlines the legal requirements and some other considerations concerning when and in what records HIV-related information must be documented.

When and in what records must HIV-related information be documented?

”Article 27-F specifically states that confidential HIV-related information “shall be recorded in the medical record” of a protected individual (person tested for or diagnosed with an HIV-related condition). (PHL § 2782.8.) Medical records are the only records in which HIV-related information must be documented, according to the law.

Health care providers and health facilities that provide direct medical care to protected individuals must document HIV-related information in their patients’ medical records. The purpose of this requirement is to ensure that HIV-related information is readily accessible to medical care providers who need it in order to provide proper care and treatment to their patients. (DOH Part 63, § 63.7.)

Other providers’ client records:

The law does not specify. Article 27-F does not specify whether confidential HIV-related information must – or must not -- be documented in any kind of client record other than an individual’s medical records. The law’s documentation requirement refers only to medical records. The law does not mention any other kind of client record.

Disclosures of HIV-related information about each client must be documented, at a minimum. Article 27-F does require that – with only a few exceptions, every disclosure of confidential HIV-related information by a person covered by the law must be documented; and every protected individual has a right to be informed, upon request, of all disclosures made about him or her. (PHL § 2782.5(b).)

These requirements apply to (1) oral as well as written disclosures; (2) intra-agency disclosures (except certain internal communications); and (3) disclosures made with consent as well as those made without consent.

So, as a practical matter, these requirements mean that providers covered by the law must document at least some HIV-related information – about the disclosures they have made about each client – in their records. (Sometimes this happens as a result of regulations sometimes it happens as a result of policy)

Wrap-Up

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Have a Doubt?

- What do I do?
- Should I tell?
- What if?

Simple answer....

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Doubts?

•DEFER!!!!

When in doubt and you do not know the answer to a confidentiality issue, and have no easy resources, defer the issue to your supervisor.