Legal and Policy Information for HIV Counselors: Confidentiality and Anonymity

Confidentiality Described

Laws in California in certain circumstances prohibit disclosure of medical information without the written authorization of the client. In the absence of written authorization, the information may be disclosed only under very specific circumstances, such as pursuant to a court order, or to health care providers for purposes of diagnosis and treatment.

Special laws in California provide additional protection for the confidentiality of HIV test records. (Note: Public health records cannot be subpoenaed.) In most cases, a special release is required for disclosure of HIV-antibody test results. Clients must give separate authorization to release HIV test results to a third party. The disclosure of HIV test results is not covered by a general medical release form.

Office of AIDS Guidelines

In Office of AIDS funded confidential test sites, HIV test results may only be released by the specific, written authorization of the client. These records may not be released under any other circumstance, including by court order (such as subpoenas), except by written authorization of the parent or legal guardian of a child under the age of 12 years old, or the legal conservator of a mentally incompetent adult.

In Office of AIDS funded anonymous test sites, no mechanism exists for linking a client's name or other identifying information with the testing record, therefore release of results is non-issue in the ATS.

Relevance

In Office of AIDS funded test sites, confidentiality is relevant for every client seen in confidential settings, and anonymity is relevant for every client seen in anonymous settings.

Counselor Responsibilities

All counselors have an individual responsibility to protect the confidentiality or anonymity, respectively, of HIV counseling clients.

Standards

A high standard of confidentiality and anonymity is expected at Office of AIDS-funded test sites. No employee of a test site should take any steps that compromise the confidentiality or anonymity of clients. This means not only that staff should not improperly disclose a client's HIV results, but that the identity of persons who come to a site for counseling and testing should also be protected.

In anonymous test sites, the protection of anonymity is paramount to other laws when these come into conflict.

Anonymous Testing

Technically, confidentiality is not an issue in anonymous test sites because a client's test result is never linked to a name or identifying information. However, counselors and sites should always protect the anonymity of clients and should never take any steps that link clients identity with their testing history or test results.

Confidential Testing

Confidentiality is an overriding concern in confidential test sites. Counselors and sites should take all reasonable steps to protect the confidentiality of clients.

Consequences For Improper Disclosure of HIV Test Results

For provider: Individuals who disclose HIV test results without the proper consent or without meeting other criteria (refer to next page for specifics) that allow disclosure are subject to fines, court costs, and jail terms. Civil suits for damages may also be filed. This is the case whether the disclosure is through negligence or maliciousness.

For client: Improper release of HIV testing and treatment records could prevent an individual from obtaining insurance at a future time. Clients might also suffer discrimination in employment, housing, and child custody.
Charting

There are no specific guidelines or limits to the charting of HIV test results in a client's medical record kept by confidential test sites. However, disclosure of this information outside the agency where the information is kept would require an HIV-specific authorization.

A general recommendation is to maintain records on HIV results in a separate part of the chart. Some agencies keep the results in an envelope attached to the back of the chart. Most agencies use codes (either a word or a color) for easy quick access for medical staff. This way, the information covered by a general medical release is included in the medical chart, and the more restricted (coded) information on HIV testing is not likely to be released inadvertently or improperly. However, to fully protect confidentiality, it would be important to include an identical envelope in all client charts so that clients who took the test are not easily distinguished from those who had not.

In anonymous sites, there are no test records that can be linked to any client by name. Any charting concerning clients (for example, notes on a CIF or special notes recording an unusual incident) must respect client anonymity, and therefore avoid including any identifying information.

Who Can Be Informed of HIV Test Results Without A Client’s Consent?

Even though laws in California do permit disclosure of HIV test results without consent under very specific circumstances, the Office of AIDS has established policies that provide an even higher level of protection for clients of HIV test sites.

In Office of AIDS funded test sites, no one, under any circumstances, may be informed of a client’s HIV test results without the client’s specific, written authorization except in the following circumstances:

a. If records are requested by the legal conservator of a mentally incompetent person (that is, the court-appointed guardian of someone who is developmentally delayed, mentally ill or cognitively impaired to an extent that prevents that person from making sound judgments about his or her life).

b. If records are requested by the parent of a child under 12 years of age.

c. Pursuant to a court-order (see page 483).

d. Or to healthcare providers for purposes of diagnosis and treatment.

(From a counseling perspective, the preferred testing venue for incompetent persons or children under 12 would be a confidential site other than an Office of AIDS program, where more in-depth services might be available for that client’s particular needs. However, because the law also guarantees equal access to services, such individuals are not restricted from using the services of Office of AIDS confidential testing programs.)

Statistical reports on test site activities, including demographic data and test results, are provided to the California Department of Health Services. These reports never provide identifying information (name, address, etc.) of clients of the test site.

Office of AIDS test sites abide by policies that provide a higher standard of confidentiality than is required by California law. However, in confidential sites following the standards of California law, a person’s HIV test results may be disclosed without consent in the following circumstances:

a. To other health care providers directly involved in a client’s care, for purposes of diagnosis, care, and treatment. This includes virtually all licensed health care providers. However, the wisest course of action is always to obtain a signed, written HIV-specific authorization before releasing such records.

b. For mentally incompetent persons, as authorized by their legal representative, conservator or guardian.

c. For children under the age of 12, as authorized by their parent or guardian.

d. To designated public health agencies, such as the California Department of Public Health or the Centers for Disease Control and Prevention, to the extent required by law.

Presentation of Subpoena for HIV Testing Records at Office of AIDS Funded Test Sites

The Office of AIDS has responded clearly and firmly to the question of subpoenas, in a memo dated February 28, 1991, sent to “All County Health Officers, Confidential Testing Programs,” and signed by Wayne Sauseda, Chief, Office of AIDS. This memo states:

It has recently come to our attention that some confidential test sites are reporting that their local court magistrate has, on occasion, subpoenaed confidential HIV test results in order to...
meet the testing requirements of court-ordered HIV testing. For example, in the investigation of a criminal complaint, the District Attorney may ascertain that the defendant has, prior to his/her arrest, already been tested for HIV at a local STD clinic. The District Attorney then issues a subpoena for these test results.

This request is in direct violation of . . . [Sections 121015 and 120980] . . . of the Health and Safety Code. These sections prohibit disclosure of HIV test results without the written consent of the client. In the case of Section . . . [120980] . . ., it is specifically stated that “no confidential public health record . . . shall be disclosed, discoverable, or compelled to be produced in any civil, criminal, administrative or other proceedings.

Further, these court-ordered disclosures could potentially undermine the integrity of the voluntary testing programs in the State. The test-linked education and prevention efforts sustained by these programs should not be compromised by any breach of confidentiality. This guarantee of confidentiality continues to be the foundation of voluntary HIV testing in California, and disclosure without written consent is prohibited by law.

In the event that confidential HIV testing programs under your administration are confronted with a subpoena, the Department recommends that you refer the court official who is requesting the test results to your local county counsel for further direction in this matter. It is imperative that court-ordered HIV testing remain completely separated from confidential testing programs.

**People Sitting In On Disclosure Sessions**

As a matter of policy, third parties (anyone who is not a staff member of the test site) may not be present during the actual disclosure of test results at Office of AIDS funded test sites. This policy is in effect in both anonymous and confidential test sites, and is consistent with laws of the California Health & Safety Code (Sections 120980 and 121025), which prohibit disclosure of HIV test results without the signed, written consent of the client.

Even while it is technically legal for a client of a confidential test site to sign an authorization for a third party to be present during disclosure of test results, Office of AIDS policy prohibits this, thereby establishing a higher standard of confidentiality and providing the greatest possible protection of test site clients.

**Friends Acting As Translators**

As stated above, third parties should not be present during the actual disclosure of test results at either confidential or anonymous Office of AIDS funded test sites. Additionally, the use of a client’s friend or acquaintance as a translator raises special counseling concerns.

All test site programs should have translation policies and procedures in place to ensure qualified translators are available either on staff or through a community agency and are consistent with Office of AIDS policy. (See “Recommendations: Translation Services” from the Department of Health Services, Office of AIDS Testing and Counseling Guidelines.)

**Vignettes Regarding Confidentiality**

The following vignettes present hypothetical situations and then describe important points and laws to consider in addressing these situations. Remember, as an HIV counselor, you are not expected to intervene in crisis situations or know every aspect of law or ethics that may arise in your work. It is part of your job, as an HIV counselor, to know the appropriate people and resources to access in crisis situations or situations which may require legal consultation.

1. **General release for medical records**

A general release for medical records is received on a client at a confidential site who has received medical services as well as HIV testing. There is no HIV-specific release included. What do you do?

**Points to consider:**

a. In California, medical information can be disclosed with the written authorization of the client.

b. The disclosure of HIV test results is not covered by a general medical release form.

   **Answer:** Release the general medical information. Do not release HIV-specific information.

2. **Friends as translators**

A Spanish-speaking client appears for her counseling session and brings along a friend as an interpreter. She explains that while she speaks some English, she really does not understand enough and wants the help of her friend, who will interpret the counseling session for her.

   **You are in an anonymous test site. What do you do?**
Would your choices be different in a confidential test site?

**Points to consider:**

a. Third parties cannot be present during the counseling at either confidential or anonymous Office of AIDS funded test sites.

b. The use of a client’s friend or acquaintance as a translator raises special counseling concerns.

Answer: Third parties cannot be present during the disclosure of HIV test results. In both anonymous and confidential settings, a third party may not be present during the disclosure of HIV test results. Anyone who is not an employee or contracted translator of the test site (staff or volunteer) is considered a third party. This client’s friend, then, may not be present during the disclosure of HIV test results.

Using a staff translator: In this situation, if a counselor with Spanish language competency is available, the easiest and best solution is to have that person counsel this client, or translate for the session. An employee of the test site who is not a counselor but speaks Spanish could also translate for the session. If not, the client could be re-scheduled for an appointment time when a Spanish-speaking counselor or translator is available.

Using a friend as a translator after results are disclosed: The client’s friend may be invited into the session after the results are disclosed, as long as the client herself reveals the results to the friend. There are many potential problems with friends acting as interpreters, however, including uncertainty about the accuracy of the translation; discussion of risk history the client may wish to keep private; and awkwardness friends may feel in translating explicit information about sexual and needle sharing risks.

No translator available: If the client’s language was an uncommon one in the region and there was no counselor with that language competency and no translator available, the client could be referred to a confidential setting. Section 120980 of the Health & Safety Code prohibits unauthorized disclosure of HIV test results to third parties. However, at a confidential site, a client could provide written authorization for disclosure of results to the friend/translator after the results have disclosed to the client without the third party present.

The Office of AIDS Policies and Guidelines for both confidential and anonymous sites specify that the client may use his or her own translator “as long as the client discloses the result to the translator before the post-test counseling/education session.” That is, the client receives the actual result, personally discloses this result to the friend/translator, and then counselor, client and translator continue with the session.

A prudent way to proceed: Here, then, is a prudent way to proceed with a client at a confidential test site using a friend as a translator. First, at the risk assessment session, the information is thoroughly reviewed with client and translator, including of course the meaning of a preliminary positive, negative, confirmed positive and invalid results. All parties establish a mechanism by which the test result will be disclosed by the counselor directly to the client, and then by the client directly to the translator. For example, a “+” written on a sheet of paper will mean the result is positive, a “-” will mean the result is negative, a “?” will mean the result is inconclusive. Then, at the disclosure session, the client signs an HIV-specific authorization releasing test results to the translator. The counselor communicates the test results to the client using the agreed-upon system (marks on a sheet of paper), the client shows the paper to the translator, and the session proceeds.

Best option(s): Obviously, in either an anonymous or confidential setting, the best choice is to have a trained counselor with the necessary language competency provides the counseling. Second choice is the use of a trained translator who is hired by the testing program. The use of a friend or family member is possible, but this is the last option and should only be used where there is truly no alternative.

Counseling issues: This vignette also raises questions about informed consent, because the client says she did not really understand much of the information in the risk assessment session.

3. Contact with clients outside the test site

You work in an anonymous test site. You are ordering coffee at the counter of a local cafe and a former client approaches you. She recognizes you, speaks to you familiarly, talks about her experience taking the test and how much she liked you during the risk assessment session. Other people are within earshot and can easily
hear what she says. She tells you she saw another counselor for her session and did not find this person helpful. "My friend Frankie saw you when he got his positive result, and he said you were great. And I'm just not sure about what went on in my session. I don't know whether I'm supposed to go back for another test, or if the test I already had was enough. What do you think I should do? Do you remember Frankie? He's a small guy, curly hair, kind of a dope fiend. He really liked you a lot." What do you do?

Is your answer different if you work in a confidential setting?

Points to consider:

a. Medical information and HIV test results cannot be disclosed without the authorization of the client.

b. Confidentiality is an overriding concern at test sites. Counselors and sites should take all reasonable steps to protect the confidentiality of clients.

c. In anonymous settings, counselors and sites should always protect the anonymity of clients and should never take any steps that link a client's name and testing history or result.

Answer: Protect the confidentiality/anonymity of both clients. To protect this client’s confidentiality or anonymity, avoid any specific references to her situation where others can hear the discussion (for example, avoid acknowledging the fact that you counseled her and do not discuss her results). Though legally it is not your responsibility to keep her from disclosing personal information in this setting, it would certainly be prudent to discretely warn this naive client that the open discussion of information related to her visit to the test site could compromise her privacy and confidentiality.

Avoid any acknowledgment of your contact with Frankie or knowledge of his test result. Again, legally, if Frankie has shared this information with others, you are not obligated to protect the information, but the wisest and most ethical course is always to avoid discussion of Frankie's situation. Your former client might not really know Frankie's status, for example, and if you acknowledged he was positive, you would be violating his confidentiality or anonymity. In fact, even acknowledging you had seen Frankie would be a violation of confidentiality or anonymity.

Offer her options for gathering further information. Depending on your test site's set-up and local resources, you may want to encourage this client to call you at your site, to call the appointments desk for HIV testing or to call an AIDS hotline to talk further about her concerns. If you have the time and inclination, you could also offer her some education and information at that time, in a place where private conversation is possible. While these are not legally required steps, they do demonstrate good ethical practice.

Act with the greatest possible discretion. By acting with the greatest possible discretion in a situation like this, you protect yourself legally, you act in an ethical fashion in terms of your clients’ confidentiality and anonymity, and you set an admirable standard that members of the community you serve will appreciate. Your course of action is the same whether you work in an anonymous or confidential setting.

4. Child abuse

You work at a confidential test site. A 16 year-old-client at a risk assessment session describes being sexually molested by her stepfather and tells you she is worried that he is now beginning to molest her 13-year-old sister. What do you do?

Is your answer different if you work in an anonymous setting?

Points to consider:

a. The confidentiality or anonymity of clients at HIV test sites must be protected.

b. State laws exist that require reporting of suspected child abuse under certain circumstances.

c. In anonymous test sites, the protection of anonymity supersedes other laws when these come into conflict.

Answer: Confidential site: Confidential test sites should have specific protocols in place to deal with issues of child abuse reporting. The sites are responsible for training staff on these issues and protocols. Counselors should be sure to ask for this training and be familiar with these protocols.
In a confidential site, standard child abuse reporting laws would be in operation here, and a report (involving your supervisor) would need to be made of this situation to child protective services or local police. A situation like this must also be handled in a sensitive and appropriate manner.

It would be important not to disclose to child protective services or to the police that the client presented for HIV testing. If the client feels it is appropriate to do so, she may disclose this at her discretion, but it would be prudent to counsel the client about the pros and cons of such a disclosure.

If the client is 18 years old or older and was the victim of abuse before the age of 18, it is his or her responsibility to report the abuse. However, if a child under 18 years continues to be abused (for example, a younger sibling as in this vignette), a report would be necessary.

Counseling issues: From a counseling perspective, it may be preferable to focus on the client’s disclosure about the sexual abuse, and postpone the risk assessment session to a later time.

Anonymous site: In an anonymous site, laws protecting anonymity supersede other laws, including child abuse reporting laws. In this situation, no report to authorities can be made. It is possible and clinically appropriate, however, to work with this client on ways she can get the support necessary to take steps to protect herself and her sister, and to make effective referrals to help her in this effort or to self-report if she so chooses. Again, this may be a more pressing and immediate issue, and HIV testing might be postponed to a later date.

5. Subpoena for medical records

You work at a confidential test site. Someone shows up during testing hours and serves you with a subpoena for medical records on a former client. What do you do?

Is your answer different if you work in an anonymous setting?

Points to consider:

a. In Office of AIDS funded confidential test sites, HIV test results may only be released by the written authorization of the client. These records may not be released under any other circumstance, including by court order (such as subpoenas), except by written authorization of the parent or legal guardian of a child under the age of 12, or the legal conservator of an incompetent adult.

Answer: HIV test records from an Office of AIDS funded confidential test site may not be released without a client’s specific authorization, even where a court subpoena is presented. Front-line workers should refer such requests to their supervisors or test-site administrators.

All confidential test sites should have specific protocols in place to deal with such requests. Be familiar with these, and refer the server to the appropriate person.

In an anonymous setting, there are no records to be released, since no test results are ever linked with a client’s identifying information. Inform the server of this fact, and refer him or her to the appropriate supervisor or administrator.