

HIV-Related Stigma: Protecting the Confidentiality of Clients Living with HIV/AIDS

(adapted from a manuscript co-written with Allison Rice, Senior Lecturing Fellow, Duke AIDS Legal Project)

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I. Introduction

Clients with HIV are in many ways like other clients with a serious illness. They share many of the same concerns about access to health care, insurance, public benefits, and the need to plan for the future with wills and advance directives. But HIV is not just another serious illness. It carries with it a unique stigma that can insidiously affect almost every aspect of a client's life, often completely cutting them off from social and familial ties. As a consequence, most HIV-positive people in the Southeastern United States keep their diagnosis a secret, hidden from employers, coworkers, members of their church, neighbors, family and friends. HIV carries with it a unique stigma that affects nearly every aspect of the client's life.

Lawyers working with HIV-positive clients need to understand the role of HIV stigma so that they may more effectively represent their clients. For starters, lawyers must think carefully about how to safeguard their client's confidentiality. Although often unintended, unauthorized disclosures of HIV status have devastating consequences for our clients. Our clients have been shunned by their families, refused a hug or touch, and forced to use separate dishes and utensils. They have been thrown out of churches and fired from jobs. They have faced community harassment as word of their HIV status spread. This vilification happens all too frequently – even today.

Lawyers must become aware of the special privacy concerns of people living with HIV/AIDS (“PLWHA”) and the legal framework around privacy. And they must understand how discrimination may affect people with HIV and how discrimination may be redressed. This manuscript attempts to provide lawyers with some of the background information needed to be effective, compassionate advocates for people living with HIV/AIDS.

II. Understanding HIV Stigma

“Stigma” is defined as “a mark of disgrace or infamy; a stain or reproach, as on one's reputation.”¹ Goffman defined “stigma” in 1963 as “an attribute that is significantly discrediting which, in the eyes of society, serves to reduce the person who possesses it.”² Stigma can be the result of particular characteristics perceived to be undesirable, such as physical differences, or it can stem from negative attitudes toward an entire group and the behaviors associated with that group, such as homosexuals and sex workers.³ “Under Goffman's definition, stigmatization is the societal labeling of an individual or group as different or deviant.”⁴ Some HIV/AIDS related stigmatization research has focused on stigmatizing attitudes and the correlation between such attitudes and misunderstanding and misinformation about the modes of HIV transmission or the risk of infection through normal social behavior.⁵

Social science researchers generally agree that HIV/AIDS-related stigma undermines public health efforts to combat the epidemic.⁶ AIDS stigma negatively affects preventive behaviors such as condom use, submitting to HIV testing, and seeking appropriate care following diagnosis, to name a few.⁷ This stigma also diminishes the quality of care given to HIV-positive patients and the perception and treatment of PLWHA by their communities, families, and partners.⁸ Decreasing HIV-related stigma is a vital step in stemming the epidemic.

A. The Historical Underpinnings of the AIDS Epidemic

HIV/AIDS has been stigmatized since it was first diagnosed in the United States. AIDS was first recognized as an unexplained pattern of illness in 1981,⁹ and the American public has since undergone episodes of panic, witnessed the identification of HIV as the cause of AIDS, and experienced the development and dissemination of promising antiretroviral drugs.¹⁰ This illness

¹ "stigma." Dictionary.com Unabridged. Random House, Inc. 11 Jul. 2011. Dictionary.com <http://dictionary.reference.com/browse/stigma>

² Richard Parker, Peter Aggleton, *HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action*, 57 SOCIAL SCIENCE & MEDICINE, 13,14 (2003).

³ Lisanne Brown, Lea Trujillo, Kate Macintyre, *Interventions to Reduce HIV/AIDS Stigma: What Have We Learned?* Horizons Program - Tulane School of Public Health and Tropical Medicine, at 3 (2001).

⁴ *Id.*

⁵ Parker, *supra* note 2, at 15

⁶ Brown et al, *supra* note 3, at 3

⁷ *Id.*

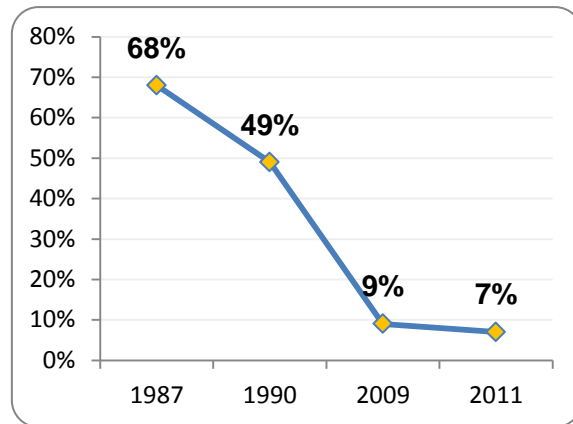
⁸ *Id.*

⁹ Centers for Disease Control and Prevention, *Thirty Years of HIV – 1981-2011*, 60(21) MORBIDITY AND MORTALITY WEEKLY REPORT, at 689 (2011). <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6021a1.htm>

¹⁰ Kaiser Family Foundation, Report, *HIV/AIDS at 30: A Public Opinion Perspective*, June 2011, 1, 3. <http://www.kff.org/kaiserpolls/upload/8186.pdf> [hereinafter “Kaiser, HIV/AIDS at 30”]

has morphed from being initially associated exclusively with Caucasian men to having an increasing impact on African Americans, Latinos, and women.¹¹

Despite the spread of the disease into increasingly more communities, the Kaiser Family Foundation has found that the percentage of Americans reporting AIDS as the most urgent health problem facing the country declined from 68% in 1987 to 49% in 1990, to single digits in 2009 and 2011, and 10% in 2012.¹² Thus, the perceived urgency of AIDS has decreased, but stigmatizing perceptions of the disease remain entrenched.



Stigma toward people living with HIV has had a devastating impact on the HIV epidemic. The World Health Organization cites “fear of stigma and discrimination as the main reason why people are reluctant to be tested, to disclose their HIV status or to take antiretroviral drugs.”¹³

In the Southeastern United States, AIDS continues to conjure thoughts of death and for many, embarrassment. Many HIV related deaths have been hidden by families and explained away as cancer or other diseases because of possible shame to the family. This perpetuates stigma and leaves families with the burden of heavy secrets and questions unanswered for those family members who may want to openly discuss HIV.

Denial and lack of communication is common when there is an overriding fear of stigma. The very basic fear of rejection and loss of privacy can hamper a person’s ability to communicate effectively. This can lead to failure to negotiate condom use and often leads to more sexual behavior, where methods of safer sex are not used to prevent HIV transmission. Ignorance around HIV transmission and the fact that many people are indeed ostracized after revealing their HIV positive status makes disclosure a difficult step for many to take. For this reason, many PLWHA are still finding it challenging to tell new partners about their status and negotiate sexual encounters, despite legal requirements to notify past and present partners.

1) *In the Southeastern United States*

The Southern Region¹⁴ has the highest rate of new HIV diagnoses in the US.¹⁵ In 2011, nearly half (49%) of new HIV diagnoses were located in the Southern US, while the Southern

¹¹ *Id.*

¹² Washington Post/Kaiser Family Foundation 2012 Survey of Americans on HIV/AIDS (conducted June 11–24, 2012), at 6; <http://kaiserfamilyfoundation.files.wordpress.com/2013/01/8334-f.pdf>. (hereafter Kaiser 2012 survey)

¹³ *Towards universal access : scaling up priority HIV/AIDS interventions in the health sector: progress report 2008*. Geneva, World Health Organization, at 113 (2008) http://www.who.int/hiv/pub/towards_universal_access_report_2008.pdf

Region accounted for only 37% of the US population.¹⁶ All ten of the metropolitan areas with the highest AIDS diagnosis rates in 2011 were in the Southern Region.¹⁷

People living with HIV/AIDS in the Southern US have significantly lower 3-year survival rates than the US average.¹⁸ Nine deep south states,¹⁹ targeted because they have been disproportionately affected by HIV disease and share characteristics such as overall poorer health, high poverty rates, an insufficient supply of medical care providers and a cultural climate that likely contributes to the spread of HIV, when taken together as a region had the highest HIV case fatality rate²⁰ in the country.²¹

African Americans and Latinos are disproportionately affected by HIV in the South with African Americans accounting for 56% of new HIV diagnoses in the South between 2005 and 2008 and half of the new HIV diagnoses among Latinos occurring in the South.²² Fifty percent of men and 71% of women diagnosed with HIV in the South between 2005 and 2008 were African American.²³ African American women represent the largest recent disparity as the majority of new HIV diagnoses (71%) among women in the South between 2005-2008 were among African-American women.²⁴

Young MSM (men who have sex with men) are particularly impacted by HIV. MSM accounted for 49% of HIV transmissions in the 9 deep south states in 2009, followed by heterosexual contact (27%).²⁵

¹⁴ The Census Bureau defines the South as including Alabama, Arkansas, Delaware, District of Columbia, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, Oklahoma, North Carolina, South Carolina, Tennessee, Texas, Virginia, West Virginia.

¹⁵ Centers for Disease Control and Prevention. HIV Surveillance Report 2011, vol 23. 2013; <http://www.cdc.gov/hiv/topics/surveillance/resources/reports/>. Accessed March, 2013.

¹⁶ *Id.* US Census Bureau. Annual estimates of the resident population for the United States, regions, states, and Puerto Rico. 2011; <http://www.census.gov/popest/data/state/totals/2011/>. Accessed March, 2013.

¹⁷ Centers for Disease Control and Prevention. HIV Surveillance Report 2011, vol 23. 2013; <http://www.cdc.gov/hiv/topics/surveillance/resources/reports/>. Accessed March, 2013.

¹⁸ Hanna, D., Selik, R., Tang, T., & Gange, S. *Disparities among states in HIV-related mortality in persons with HIV infection, 37 U.S. STATES, 2001-2007. AIDS, Early Release.* (2011). Reif, S, Safley, D, Wilson, E, Whetten, K (2014). Southern HIV/AIDS Strategy Initiative Report: *HIV/AIDS in the Southern US: Trends from 2008-2011 Show a Consistent Disproportionate Epidemic*, <http://southernaidsstrategy.org/research/>. Accessed February, 2014.

¹⁹ Alabama, Florida, Georgia, Louisiana, Mississippi, North Carolina, South Carolina, Tennessee and Texas.

²⁰ Deaths among individuals estimated to be living with HIV.

²¹ Southern HIV/AIDS Strategy Initiative Report: Reif, S et. al *HIV/AIDS in the Southern US: Trends from 2008-2011 Show a Consistent Disproportionate Epidemic*, (2014) <http://southernaidsstrategy.org/research/>.

²² Reif, S et. al *HIV/AIDS in the Southern USA: A disproportionate epidemic*, AIDS Care, Vol. 26, Issue 3, 2014. <http://southernaidsstrategy.org/research/>

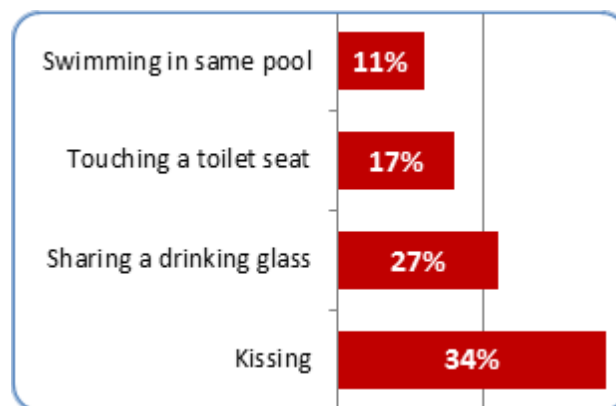
²³ Centers for Disease Control. *Disparities in Diagnoses of HIV Infection Between Blacks/African Americans and Other Racial/Ethnic Populations – 37 States, 2005—2008. Mortality and Morbidity Weekly Report*, 2011.60(4):93-98.

²⁴ *Id.*

²⁵ Southern HIV/AIDS Strategy Initiative Report: Reif, S et. al, *HIV/AIDS Epidemic in the South Reaches Crisis Proportions in Last Decade.* (12/2011), <http://southernaidsstrategy.org/research/hivaids-epidemic-in-the-south-reaches-crisis-proportions/>

2) **Current Misconceptions About Transmission**

Enduring public misconceptions about HIV transmission are at the root of much HIV stigmatization. While Americans have learned a great deal since the beginning of the so-called “AIDS Epidemic,” the learning curve flattened out in the early 1990’s, and the remaining myths about modes of transmission stubbornly remain.²⁶ Over the past twenty years, roughly one in four Americans have continued to either believe that one can get HIV from sharing a drinking glass, or remain unsure whether this is the case. Similarly, one in six believe the same about HIV transmission via shared toilet seats, and 11% either think you can get HIV by swimming in a pool with someone with HIV, or are not sure. Overall, in 2012, one in three gave an incorrect answer to at least one of these three questions about means of transmission. This chart shows the percentage of people in the United States who have certain misconceptions about the transmission risk posed by common activities.²⁷ In addition, 34% had an incorrect answer to at least one of the questions about whether HIV could be transmitted these ways.



Research with clinicians and patients has also identified knowledge deficits and misconceptions among HIV-positive people themselves, as well as difficulty using the HIV knowledge they possess.²⁸

²⁶ Kaiser 2012 Survey, *supra* at note 12, at 13.

²⁷ *Id.*

²⁸ Jeffrey Fisher, Deborah Cornman, Chandra Osborn, K Rivet Amico, William Fisher, Gerald Friedland, *Clinician-Initiated HIV Risk Reduction Intervention for HIV-Positive Persons: Formative Research, Acceptability, and Fidelity of the Options Project*, J. OF AIDS 37 Supp.2, 78-87, 80 (2004).

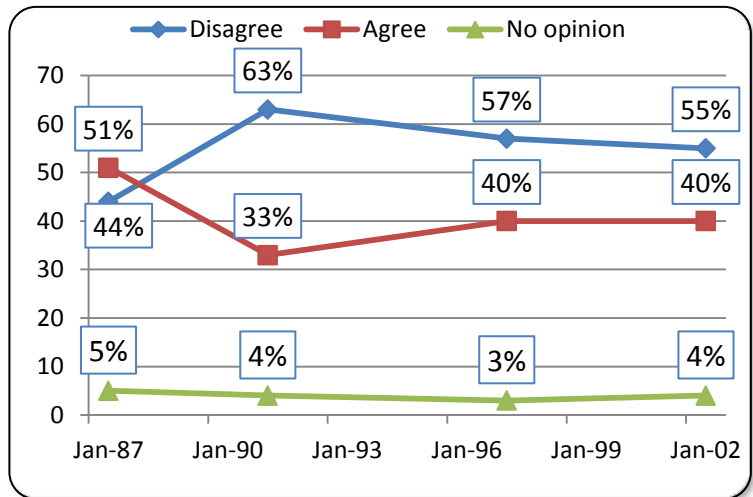
3) The Role of Moral Condemnation

A recent Kaiser Family Foundation survey asked participants to agree or disagree with this statement: “In general, it’s people’s own fault if they get AIDS.”²⁹ The number of people who agree with that statement has *increased* since the 90s. (see chart to the right.) This blame-the-victim mentality works to maintain HIV stigma.

The reasoning fueling this stigma is multi-faceted, complex, and fluid,

often layered atop other stigmas associated with homosexuals, sex workers, intravenous drug-users and those who engage in casual sex.³⁰ The interconnected nature of these stigmas deepens the prejudice against those with HIV.³¹

Additionally, lingering misconceptions about how HIV is transmitted contribute to prejudice against PLWHA.³² “People who harbor misconceptions about how HIV is transmitted are much more likely to express discomfort about working with someone who has HIV or AIDS than those who know that HIV cannot be transmitted in these ways.”³³ In their research on HIV/AIDS and stigma, the Kaiser Family Foundation discovered a statistically significant correlation between misconceptions about means and modes of transmission and an individual’s inclination to stigmatize PLWHA. Respondents were asked, “In general, how comfortable would you be working with someone who has HIV/AIDS?” The chart below shows that people who gave correct answers about HIV transmission were also much more likely to be comfortable working with someone with HIV/AIDS or having their food prepared by someone who is HIV-positive.³⁴



²⁹ Kaiser, HIV/AIDS at 30, *supra* note 10, at 8.

³⁰ Brown, “Interventions to Reduce HIV/AIDS Stigma,” *supra* note 3, at 5.

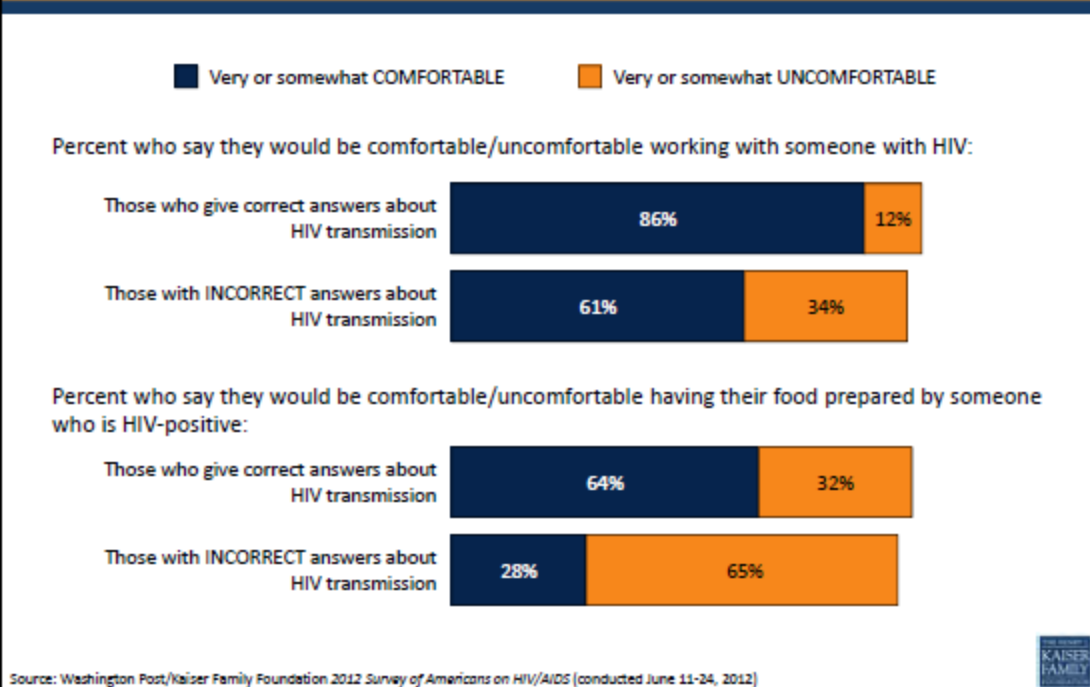
³¹ *Id.*

³² Kaiser 2012 Survey, *supra* at note 12, at 17.

³³ *Id.*

³⁴ *Id.*

Relationship Between Stigma And Knowledge



HIV stigma is a complex part of a larger societal prejudice toward people who are *other*—those who are: HIV positive, of color, gay or lesbian, transgender, addicted to drugs or alcohol, homeless, or mentally ill. Moreover, these struggles contain deeply embedded external and internalized racism, sexism and homophobia and affect the well-being of the community and how individuals adapt to hardships.

III. The Rights of Clients with HIV/AIDS to Expect Confidentiality

PLWHA have certain rights and certain responsibilities with regard to their positive status. One of the most important rights is the right to confidentiality regarding health status.

I) Confidentiality: What's at Stake?

There is an old Jewish story that illustrates the difficulties of undoing a disclosure:

A man goes before his Rabbi and admits to having spread harmful information about his neighbor. He asks the Rabbi what he should do to repent. The Rabbi says, "You need to do the following: go home, find a feather pillow, and release the feathers into the wind." The man follows the Rabbi's instructions and returns the next day. The Rabbi then says, "Now, to gain forgiveness, you must go back to your home and retrieve all of the feathers." "But Rabbi," the man exclaims, "the feathers by now have

scattered throughout the village!” “Precisely!” the Rabbi says. “And so too has the damage you have caused your neighbor’s reputation.”

Persons living with HIV and other stigmatizing conditions have justifiably high levels of concern about confidentiality. They do not need to be told this story. Those of us who work with these clients need to be repeatedly reminded of just how devastating a careless disclosure can be. The Duke Legal Project has represented many clients who have faced discrimination after their HIV status was disclosed without permission. We have had clients fired from jobs in restaurants, nursing homes, health care facilities, a homeless shelter, and a poultry factory; we’ve had other clients who have faced adverse employment actions due to their HIV status—a nurse’s aide moved to the file room, a deli worker moved to the warehouse, for example. Other clients have been refused services by medical providers, hospitals, chiropractors, and others. Many others have been shunned by families, friends, classmates, and/or church communities because of unauthorized disclosures. A report by the ACLU AIDS Project documents how “[b]reaches of confidentiality can and do unravel people’s lives, forcing them to find new jobs, new schools, and new homes.”³⁵

2) Categories of Confidentiality Breaches

The motivations of the persons responsible for unauthorized confidentiality breaches of sensitive information like HIV status or mental illness can be described as follows:

a) Inadvertent or unplanned breaches without malicious intent

Many professionals, especially in high stress situations like emergency departments or courtrooms, may be desensitized to the stigma that an illness like HIV or substance addiction presents. When a physician or an attorney talks openly about someone’s HIV status in the emergency room (ER) waiting area or during a trial, it is unlikely that s/he does so with malicious intent. The damage done to the patient or client whose friends and neighbors now know his or her health status is no less, however, than if the physician or attorney intentionally set out to breach his or her confidentiality.

b) Gossip

Another category of breach can be characterized as simply gossip. A person discovers someone’s sensitive health diagnosis and just has to tell. The Legal Project has had several clients who, while seeking treatment or services in the community necessitating a confidential disclosure of HIV status, have encountered a neighbor or church member working at the service provider’s office, and later discovered that the neighbor/church member talked about the clients’ health status in their community. Often the disclosers work for professionals—people the clients have reason to trust with their confidential information. This category of breach may not be intended to harm the clients, but they are certainly getting closer to a breach with malicious intent and again, the harm to the client can be substantial.

³⁵ Tamara Lange, *HIV & Civil Rights: A Report from the Frontlines of the HIV/AIDS Epidemic*, ACLU AIDS Project (Nov. 2003).

c) “Protective” Breaches

In the HIV context, many breaches occur in part because people feel the need to “protect” others. For example, the restaurant manager who erroneously feels that the HIV positive waiter poses a threat to customers or the teacher’s aide who erroneously feels that parents must be warned about the HIV positive student. More often than not the threat to others is nonexistent, but once the breach occurs, it cannot be undone.

d) Malicious Breaches

Finally, there are those who breach confidentiality of sensitive health information solely for malicious reasons—ex-spouses, estranged family members, former employers or employees can all have vindictive motives for spreading such information.

3) *Suggestions for Protecting Client Confidentiality*

Having a client with HIV or another stigmatizing disease may provide an opportunity to assess your practices, office procedures, and staff training around confidentiality. Here are a few specific suggestions to protect the confidentiality of HIV or similar diagnoses.

a) Never assume that an HIV positive client’s friends or family know about the diagnosis.

People with stigmatizing illnesses such as HIV may not tell anyone other than their medical providers about their diagnosis. Even when friends and family may be serving as witnesses or supporters in a client meeting, they may not know about the diagnosis, even if the diagnosis is germane to the case. If there is a possibility that HIV may come up in a meeting with a client and others, first ask the client whether the other person(s) know about the diagnosis.

In one case we handled, our client was seeking the appointment of a standby guardianship for her minor child. Under this law, a parent with a terminal or chronic disease can have a guardian appointed to serve in the event that she can no longer care for the minor child. Our client planned to appoint her mother as the standby guardian. We assumed the client’s mother must know about her diagnosis. Wrong. Before interviewing the proposed guardian to assess her fitness, we learned that our client had never told her mother about her diagnosis. Or even that she was sick. She asked us to say she had cancer.

b) Be careful with any paperwork in your office that references HIV status.

There is little gossip as juicy as a diagnosis of HIV or another STD. Even if you are careful about medical or other records that reference your client’s HIV status, others who have access to your office may not be. Consider your staff, other clients you see in your office, the cleaning crew or the tech guy when you think about where to put that piece of paper. At the Duke Legal Project, we avoid leaving sensitive paperwork face up on our desks at night or when others visit our offices.

- c) Be careful about referring to the HIV diagnosis in correspondence with the client or others.

If there is a need to refer to the client's illness in a letter, consider whether the letter could be seen by unintended eyes. A letter to a client with a reference to her HIV status could be seen by others in the home who are unaware of the diagnosis. Consider whether the reference is necessary. Or check with the client before sending the letter. In any correspondence that might reference the diagnosis, consider whether there is a need to explicitly reference HIV.

- d) Properly dispose of medical records and other papers referencing HIV.

Is there anyone left who doesn't have a shredder? If nothing else, waste paper with this level of sensitive information should be shredded. In our office, our waste paper is either shredded or placed in a locked bin that is disposed of by a company that also disposes of sensitive waste paper from the Duke medical center. Place a shredder or shredding box next to the printer/copier so that mistakes are disposed of appropriately

- e) Be discreet in discussing HIV and other sensitive information in your office or elsewhere.

Just like the busy physicians, lawyers can easily make inadvertent disclosures when talking in the office within earshot of other clients, or in the elevator or courthouse hallways.

- f) Train your staff well.

If you have clients with HIV or other stigmatizing illnesses, make sure they are trained to take the same precautions you do. In dealing with breaches of confidentiality in the medical setting, we find that it is often low level employees with access to sensitive information (e.g. the medical records clerk or lab tech) who finds it irresistible to gossip about an HIV positive patient. This is particularly a risk in small communities where everyone knows everyone else. Make sure your staff understand the potentially devastating consequences of a breach of confidentiality as well as the impossibility of fixing it – once the information is disclosed, it cannot be undisclosed.

- g) Try to protect your client's diagnosis within the court system.

As discussed above, be aware of the damage that can be done by having your client's HIV status disclosed in legal proceedings. We are aware of an episode in which a criminal defense attorney disclosed the HIV status of his client's mother in open court in an attempt to gain sympathy for his client. This not only harmed the mother, but, by association the client. And we know that in many other instances, a client's HIV status has been referred in open court without consideration of the effect this disclosure would have on the client.

- i. *Is the diagnosis relevant?* If you have a client with HIV or another stigmatizing condition in the court system, and you expect that the client’s status will be raised in the proceeding, first determine whether the diagnosis is even relevant. Often, it may not be. In such cases you may want to file a **motion in limine** to have the information excluded.
- ii. *If the diagnosis is relevant.* In some cases, the HIV status may arguably be relevant. Such instances might include a custody case where a parent’s health may be an issue. If records are to be released under a subpoena or court order, request that those records be reviewed in camera. If testimony is to be taken, ask the court to close the courtroom during testimony. If the setting is more chaotic, such as a first appearance session, seek to have the matter heard at the bench. Try to persuade the judge and/or prosecutor that disclosure of the health information would be damaging to the client. Educate opposing counsel about the stigma of HIV or other similar diseases.
- iii. *Proceed anonymously in a civil case.* If you are prosecuting a civil case in which the client’s HIV or other stigmatizing condition must be disclosed, such as a discrimination or breach of confidentiality case, we recommend that you move to file anonymously using Jane/John Doe filings. Clients should be informed, of course, that even proceeding anonymously, there is no guarantee that the client’s identify will not be revealed as a result of the litigation.
- iv. *Seek a protective order.* If you anticipate that an opponent intends to delve into the client’s HIV or other stigmatizing condition in discovery, consider filing a motion for a protective order under Rule 26(c) of the Rules of Civil Procedure. The court may issue an order to “protect a party or person from annoyance, embarrassment, [or] oppression.”³⁶ The relief can take the form of forbidding inquiry into certain matters or requiring a deposition to be sealed and opened only in court.

**Protecting
Confidentiality-At a
Glance:**

1. Never assume that an HIV positive client’s friends or family know about the diagnosis.
2. Be careful with any paperwork in your office that references HIV status.
3. Be careful about referring to the HIV diagnosis in correspondence with the client or others.
4. Properly dispose of medical records and other papers referencing HIV.
5. Be discreet in discussing HIV and other sensitive information in your office or elsewhere.
6. Train your staff well.
7. Try to protect your client’s diagnosis within the court system.

³⁶ E.g. Rule 26 (c) N.C. Rules of Civil Procedure.