

CONFIDENTIALITY CONCERNS OF LITIGANTS LIVING WITH HIV/AIDS

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

I. Introduction

Litigants with HIV/AIDS are in many ways like other litigants with serious illnesses. But HIV/AIDS is not just another serious illness. It carries with it a unique stigma that can insidiously affect almost every aspect of a person's life, often completely cutting them off from social and familial ties. As a consequence, most HIV-positive people in North Carolina 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 person's life.

It is important that judges presiding over courtrooms in which a litigant might be HIV+ understand the role of HIV stigma so that they may take steps to safeguard litigants' confidential health information where possible. Often unintended, unauthorized disclosures of HIV status in courtroom settings have had devastating consequences for clients of the Duke Legal Project. 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.

Judges should become aware of the special privacy concerns of people living with HIV/AIDS ("PLWHA") and understand how stigma and discrimination may affect people with HIV/AIDS. This manuscript will provide a conceptual framework for understanding the experience of people living with HIV/AIDS and the pervasive stigma associated with HIV and assigned to PLWHA. It aims to convey the importance of maintaining the confidentiality of sensitive health information, HIV status in particular, where feasible in the courtroom setting.

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 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

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.*

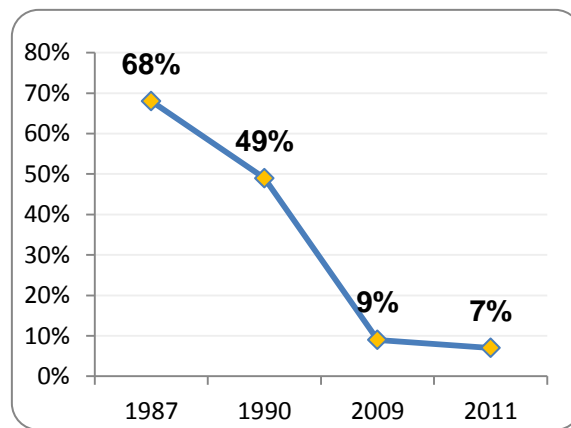
⁹ Centers for Disease Control and Prevention, *Thirty Years of HIV – 1981-2011*, 60(21) MORBIDITY AND MORTALITY WEEKLY REPORT, at 689 (2011). <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6021a1.htm>

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”]

¹¹ *Id.*

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 North Carolina, HIV/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.

I) In North Carolina

North Carolina has one of the highest rates of HIV infection in the United States. In 2011, 1,563 new HIV/AIDS cases were diagnosed and reported in North Carolina, up slightly from the previous year. According to the CDC, North Carolina ranked 12th among all states and the District of Columbia in the rate of new HIV/AIDS cases diagnosed in 2011.¹⁴ These new diagnoses added to the population already living with HIV for an estimated 36,500 HIV-positive people in North Carolina, which includes those unaware of their status.¹⁵

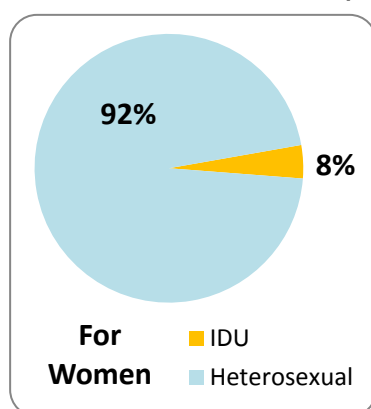
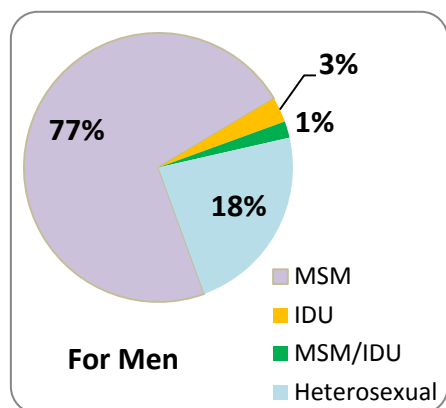
¹² Washington Post/Kaiser Family Foundation 2012 Survey of Americans on HIV/AIDS (conducted June 11–24, 2012), at 6; <http://kaiserfamilyfoundation.files.wordpress.com/2013/01/8334-f.pdf> (hereafter Kaiser 2012 survey)

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

¹⁴ Evelyn Foust, Jacquelyn Clymore, *North Carolina Epidemiologic Profile for HIV/STD Prevention and Care Planning*, NC Department of Health and Human Services Communicable Disease Branch, December 2012, at iii [hereinafter “NC Epidemiologic Profile”]

¹⁵ *Id.*

These two charts show the breakdown in HIV disease cases by transmission category in North



Carolina in 2011: MSM (men who have sex with men, transmission via sex), IDU (intravenous drug users, transmission via needle), MSM/IDU (men who have sex with men and also use intravenous drugs), and heterosexual (transmission via sex). It is apparent that the primary means of transmission for women in

North Carolina is through heterosexual sex, whereas for men in North Carolina, it is through homosexual sex. The rates of transmission via intravenous drug use are small for both men and women.¹⁶

African American adolescent and adult women in North Carolina represent the largest recent disparity with rates of new HIV cases at 31.9 per 100,000. This was nearly 19 times higher than of white, non-Hispanic females at 1.7 per 100,000.¹⁷ Common reasons reported by HIV seropositive African-American women in North Carolina for engaging in risky behaviors include financial dependence on their male partners, feelings of invincibility, a need to feel loved by a man coupled with low self-esteem, and alcohol and drug use.¹⁸

Another marginalized group impacted early in the HIV epidemic and more recently, are gay and bisexual men. In North Carolina, young African American men are particularly impacted by HIV as they are more likely to identify MSM (men who have sex with other men) as a risk factor than other groups. In 2011, MSM activity accounted for 79 percent of all new HIV reports (including MSM/IDU) in North Carolina. This represents a notable increase in MSM reports over the last five years (79% in 2011 compared to 67% in 2005). In addition MSM contact accounts for the highest number of new HIV infections for adolescent men. Specific risk factors for young African American males in North Carolina are homophobia, racism, and poverty (N.C. Department of Health and Human Services, EPI Profile, 2011). "Homophobia, stigma, and discrimination are social determinants of health that can affect physical and mental health, whether MSM seek and are able to obtain health services, and the quality of the services they receive. Such barriers to health need to be addressed at different levels of society, such as health care settings, work places, and schools in order to increase opportunities for improving the health of MSM."¹⁹

¹⁶ *Id.* at 26

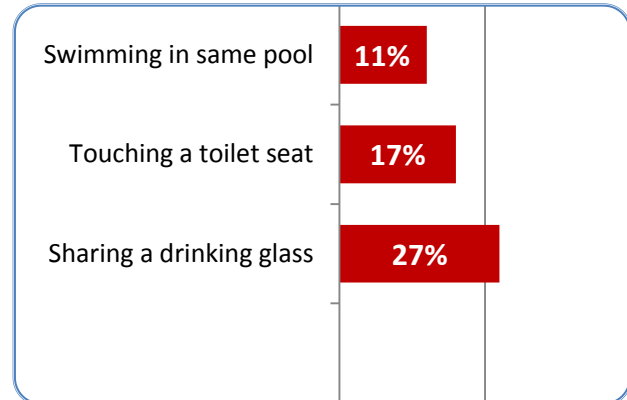
¹⁷ *Id.* at 22

¹⁸ Leone, P, Hightow, L, Foust, E, Owen-O'Dowd, J, Phillip, S, Gray, P, et al. *HIV transmission among black college student and non-student men who have sex with men—North Carolina, 2003*, 53, 32 MORBIDITY AND MORTALITY WEEKLY REPORT, at 731.

¹⁹ *Stigma and discrimination*, <http://www.cdc.gov/msmhealth/stigma-and-discrimination.htm>, CDC, 2011.

2) Current Misconceptions About HIV 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 many myths about modes of transmission stubbornly remain.²⁰ 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.²¹ 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.²² Overall, in 2011, one in three gave an incorrect answer to at least one of these three questions about means of transmission.²³ This chart (above, right) shows the percentage of people in the United States who have certain misconceptions about the transmission risk posed by common activities.²⁴ In addition, 34% had an incorrect answer to at least one of the questions of whether HIV could be transmitted these ways.



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.”²⁵ The number of people who agree with that statement remains high. (see *chart below*.) This blame-the-victim mentality works to maintain HIV stigma.

²⁰ Kaiser, HIV/AIDS at 30, at 6.

²¹ Kaiser 2012 Survey, *supra* note 12 at 13.

²² *Id.*

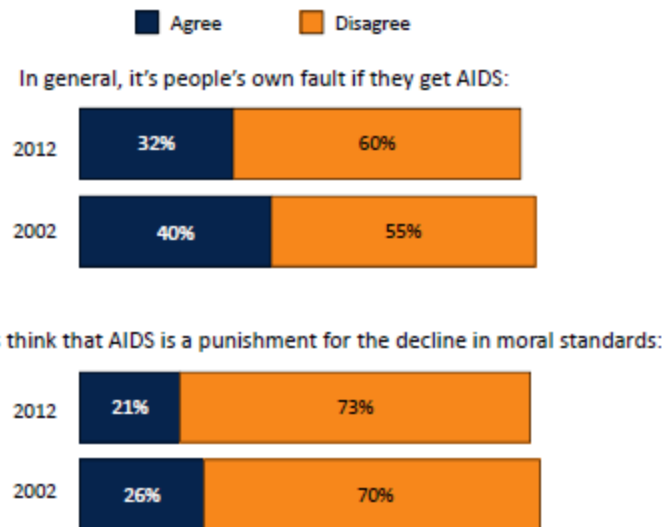
²³ *Id.*

²⁴ *Id.*

²⁵ *Id.* at 18.

Some Still See AIDS As Punishment/Fault

Please tell me whether you agree or disagree with each statement:



Note: Don't know/Refused answers not shown.
Source: Kaiser Family Foundation surveys



The reasoning fueling this stigma is multi-faceted, complex, and fluid, often layered atop stigmas associated with homosexuals, prostitutes, intravenous drug-users and those who engage in casual sex.²⁶ The interconnected nature of these stigmas deepens the prejudice against those with HIV.²⁷

Additionally, lingering misconceptions about how HIV is transmitted contribute to prejudice against PLWHA.²⁸ “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.”²⁹ In their research on HIV/AIDS and stigma, the Kaiser 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 thought AIDS could be transmitted via drinking glasses and toilet seats were also much more likely to be uncomfortable working with or having their food prepared by someone with HIV/AIDS.³⁰

²⁶ Brown, “Interventions to Reduce HIV/AIDS Stigma,” *supra* note 3, at 5.

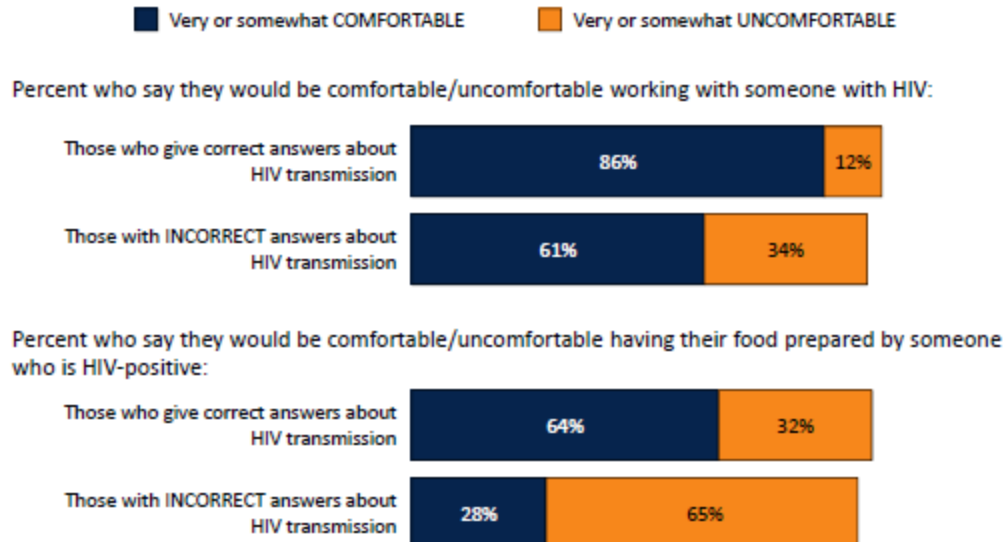
²⁷ *Id.*

²⁸ Kaiser 2012 Survey, *supra* note 12, at 17.

²⁹ *Id.*

³⁰ *Id.*

Relationship Between Stigma And Knowledge



Source: Washington Post/Kaiser Family Foundation 2012 Survey of Americans on HIV/AIDS (conducted June 11-24, 2012)



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. Protecting the Medical Confidentiality of Litigants Living with HIV

As discussed in more detail above, persons living with HIV/AIDS risk serious consequences when their HIV status is disclosed without consent. Unauthorized disclosures serve to increase stigma and discrimination, which, in turn, can deter HIV+ persons from seeking testing and treatment.

The next section discusses the effects of unauthorized disclosure of seropositive status on the lives of HIV positive persons as well as applicable legal and ethical provisions. Finally, suggestions are made for best practices related to HIV and the courts.

A. Need for Confidentiality

1) *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.

2) North Carolina Law

a. N.C. GEN. STAT. § 130A-143. Confidentiality of records (specific to HIV)

North Carolina law specifically protects HIV confidentiality. All information and records, whether publicly or privately maintained, that identify a person with “AIDS virus infection” are protected.³¹ The statute allows disclosure in certain circumstances including release made with the person’s written consent, release to protect the public health under rules related to control measures for infectious diseases, or release made for research purposes as long as no identifying information is released.³²

NC Statutory Provision relating to Protection of HIV information in the Courtroom

Of particular interest to judges, the NC HIV confidentiality statute allows release of HIV status if it is made “pursuant to subpoena or court order.” The statute goes on to provide the following:

*‘Upon request of the person identified in the record, the record **shall** be reviewed in camera. In the trial, the trial judge may, during the taking of testimony concerning such information, **exclude from the courtroom** all persons except the officers of the court, the parties and those engaged in the trial of the case;’(emphasis added)³³*

³¹ N.C. Gen. Stat. §130A-143

³² *Id.* See Statute for full list of disclosure exceptions.

³³ N.C. Gen. Stat. §130A-143 (6)

b. Enforcement of Confidentiality Statutes

The NC HIV Confidentiality law is contained in the Public Health Chapter 130A of General Statutes. Pursuant to N.C. Gen. Stat. 130A-25, it is a misdemeanor to violate a provision of the Public Health Chapter.

3. NC Code of Judicial Conduct and the Special Functions of the Trial Judge

Trial judges in North Carolina are responsible for managing their courtrooms with integrity and impartiality. In addition to the NC HIV Confidentiality statute, the NC Code of Judicial Conduct contains provisions supportive of appropriate treatment for HIV+ litigants.

Canon 1. A judge should participate in establishing, maintaining, and enforcing, and should personally observe appropriate standards of conduct to ensure that the integrity and independence of the judiciary shall be preserved.

Canon 2. A. A judge should respect and comply with the law and should conduct himself/herself at all times in a manner that promotes public confidence in the integrity and impartiality of the judiciary.³⁴

As discussed in detail above, persons living with HIV guard the confidentiality of their diagnosis carefully fearing the stigma and discrimination that can occur once their status is widely known. Unnecessary and involuntary disclosure of HIV status can lead to a mistrust of the court system. HIV positive individuals may be reluctant to seek access to the courts if doing so requires a public disclosure of their HIV status.

4. American Bar Association Policy re: HIV Confidentiality in the Courtroom

The American Bar Association has a specific policy regarding HIV confidentiality in the Courtroom in criminal prosecutions:

...Unless the defendant's HIV status is at issue in the prosecution, only those with a demonstrable need or right to know should receive medical information about a defendant's HIV status. Criminal justice personnel who receive such information must safeguard its confidentiality.³⁵

HIV is not easily transmitted in any case.³⁶ Recent clinical trials have demonstrated further that for HIV+ persons on medication with undetectable viral loads, transmission risk is nonexistent.³⁷ The HIV status of a litigant is therefore rarely relevant, and when it is, courts should make every effort to safeguard the confidentiality of the diagnosis.

³⁴ N.C. Code of Judicial Conduct, Canon 1 and 2.

³⁵ ABA Report 109A, at 2.

³⁶ Centers for Disease Control and Prevention, *HIV Transmission*, <http://www.cdc.gov/hiv/basics/transmission.html>.

³⁷ No-one with an undetectable viral load, gay or heterosexual, transmits HIV in first two years of PARTNER study, <http://www.aidsmap.com/No-one-with-an-undetectable-viral-load-gay-or-heterosexual-transmits-HIV-in-first-two-years-of-PARTNER-study/page/2832748/>; http://www.chip.dk/portals/0/files/CROI_2014_PARTNER_slides.pdf.

B. Suggested Best Practices Related to HIV and the courts:

1. Know the scientific facts about how HIV is transmitted.
2. Base judicial policies on the scientific evidence that HIV+ people do not pose a risk of transmission through casual contact.
3. When you learn of a litigant's HIV positive status, take steps to safeguard the confidentiality of the person's HIV status:
 - a. *Is the diagnosis relevant to the issues in the case?*
 - i. Consider carefully whether the diagnosis is relevant. In most circumstances, a person's HIV status is irrelevant in court proceedings. If that is the case, take steps to prohibit the parties from disclosing a litigant's HIV status in statements in open court, through testimony, or in written documentation, and
 - ii. Consider entering a protective order pursuant to Rule 26(c) of the NC Rules of Civil Procedure forbidding inquiry into a litigant's HIV status or requiring depositions on the subject to be sealed and opened only by order of the court.
 - b. *If the diagnosis is relevant?*
 - i. Review HIV-specific records in camera pursuant to N.C.G.S. 130A-143(6).
 - ii. If testimony regarding a party's HIV status is relevant, exclude all persons from the courtroom except courtroom personnel, the parties and the attorneys when hearing the HIV-related testimony. (N.C.G.S. 130A-143(6))
 - iii. Treat the information regarding the litigant's HIV status with sensitivity to avoid unnecessary disclosure of the diagnosis.
 - iv. Do not assume that those accompanying an HIV positive litigant to court know about the diagnosis.
4. Train your staff well. It can be irresistible to gossip about an HIV positive person. This is particularly risky in small communities where everyone knows everyone else. Make sure your courtroom personnel know 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.

IV. Conclusion

Judge Richard T. Andrias, Associate Justice on the New York State Supreme Court, Appellate Division, has written a helpful chapter on Courtroom Management in the recent edition of the ABA HIV & AIDS Benchbook which I recommend as a resource. In his chapter, Judge Andrias states the following: “Given continuing medical advances and vigilance against even subtle forms of discrimination and bias, hopefully in the future HIV litigants will not be treated as “HIV litigants,” but as any other party in court.”

Judge Andrias goes on to write: “In the process of having their cases heard, all litigants have the right to have their confidential medical information remain so and to not be discriminated against, stigmatized, or harassed. No citizen utilizing the courts, even one who is ultimately successful on the merits, should end up worse off personally because of improper ...treatment in the course of the proceedings.”³⁸

³⁸ HIV and AIDS Benchbook, 2nd edition, Hon. Richard T. Andrias, “*Courtroom Management*,” Chapter 4, p. 104, American Bar Association, 2012.

