

COMMENTS

HIV CONFIDENTIALITY AND STIGMA: A WAY FORWARD

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We can fight stigma. Enlightened laws and policies are key. But it begins with openness, the courage to speak out.

....

. . . Schools should teach respect and understanding. Religious leaders should preach tolerance. The media should condemn prejudice and use its influence to advance social change, from securing legal protections to ensuring access to health care.

Ban Ki-moon, Secretary-General of the United Nations¹

INTRODUCTION

On May 25, 2012, an eight-year-old student at Summertown Elementary fell on the playground and scraped her knee.² When Anya Kaplan struggled to stand, another little girl came to her assistance.³ The other student helped Anya to the school nurse for care, getting a small amount of Anya's blood on her finger in the process.⁴

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¹ Ban Ki-moon, *The Stigma Factor*, WASH. TIMES, Aug. 6, 2008, <http://www.washingtontimes.com/news/2008/aug/06/the-stigma-factor>.

² Telephone Interview with Sarah Kaplan (July 2012). All names and locations associated with this case study have been changed to preserve the client's confidentiality.

³ *Id.*

⁴ *Id.*

Ms. Tiffany Redgrave, the school nurse, called Anya's mother when Anya arrived in her office.⁵ As the staff member responsible for administering medications to students, she knew Anya was HIV-positive.⁶ Ms. Redgrave wanted to know: could she call the other little girl's parents to tell them of the potential exposure, thus revealing Anya's status?⁷ Sarah Kaplan, Anya's mother, refused, asking if she could have some time to contact an immunologist before granting permission for the disclosure.⁸ Mrs. Kaplan was hesitant to allow any unnecessary disclosure of her daughter's status.⁹ The Kaplans had recently adopted Anya, who had yet to even learn to speak English. Mrs. Kaplan did not want her daughter to be subject to any more social alienation than she was already experiencing by not speaking the same language as her peers.¹⁰ She knew that attitudes regarding HIV in rural Pennsylvania were unpredictable and did not want to put her daughter at risk.¹¹

Mrs. Kaplan returned the nurse's phone call within one hour. Two disclosures had already taken place.¹² Ms. Redgrave reported the incident to the school principal immediately after her conversation with Mrs. Kaplan, mentioning Anya by name.¹³ The school principal then passed that information along to the other little girl's parents, including a warning that they should get their daughter tested for HIV.¹⁴ Mrs. Kaplan shared the immunologist's professional opinion on the incident anyway: there had been no transmissible event.¹⁵ Both disclosures were entirely unnecessary to preserve the safety of the other student.

Should this type of disclosure be permissible? Is the violation to Anya's privacy warranted due to concerns about the other girl's safety? Some might argue that the school's disclosure actually served the public interest. They would claim that disclosures such as this one are the best way to prevent HIV transmission. Ensuring Anya's privacy would violate other students' and their parents' abilities to protect themselves from contracting a dangerous and life-threatening com-

5 *Id.*

6 *Id.*

7 *Id.*

8 *Id.*

9 *Id.*

10 *Id.*

11 *Id.*

12 *Id.*

13 *Id.*

14 *Id.*

15 *Id.*

municable disease. But are privacy and public health concerns necessarily in conflict in this case, where there was insufficient exposure for a transmission to occur? Should the school nurse's first call be to the principal, or to a medical professional able to provide an opinion about the likelihood of transmission?

There are compelling reasons to protect the privacy of people living with HIV. HIV is far from a death sentence in modern industrialized societies.¹⁶ But HIV forces positive individuals to deal with more than just the physical elements of their disease: they must also live with the associated stigma.¹⁷ HIV-positive individuals—since the very start of the epidemic in the 1980s—are forced to live in the shadow of stigma.¹⁸ HIV-positive individuals have long been subjects of discrimination.¹⁹ They have been forced to keep their illness secret to avoid losing jobs and being socially alienated. Many people are afraid to be tested for HIV for fear that a positive result will be made public.²⁰ In fact, many experts believe that ensuring patients' confidentiality in their HIV-related information will encourage testing and reduce the spread of HIV.²¹

In response to this pervasive stigma, many states passed laws that provide increased levels of confidentiality protections for people with HIV. These laws are designed, in part, to avoid discrimination and encourage testing.²² But, could singling out HIV as a target for confidentiality actually contribute to stigma, rather than mitigate it?

This Comment argues that these HIV laws are not the best way to address HIV confidentiality and discrimination concerns. Though HIV-specific confidentiality laws are necessary to avoid discrimination based on HIV-related stigma, they are far from the ideal way to accomplish that goal. In fact, these laws may actually *perpetuate* the stigma, born with the epidemic in the 1980s, by singling out HIV spe-

16 See James Gallagher, *Is HIV Still a Death Sentence in the West?*, BBC NEWS (Nov. 30, 2011), <http://www.bbc.co.uk/news/health-15853743> (explaining that drug development has made HIV less likely to result in death).

17 Lance S. Rintamaki et al., *Social Stigma Concerns and HIV Medication Adherence*, 20 AIDS PATIENT CARE & STDS 359, 359–60 (2006).

18 *Id.* at 360. See Gregory M. Herek, *AIDS and Stigma*, 42 AM. BEHAV. SCIENTIST 1102, 1106 (1999) (discussing the stigma faced by people with HIV).

19 VICTORIA A. HARDEN, *AIDS AT 30: A HISTORY*, 7–10 (2012).

20 Rintamaki, *supra* note 17, at 360.

21 JOINT UNITED NATIONS PROGRAMME ON HIV/AIDS, *OPENING UP THE HIV/AIDS EPIDEMIC: GUIDANCE ON ENCOURAGING BENEFICIAL DISCLOSURE, ETHICAL PARTNER COUNSELING & APPROPRIATE USE OF HIV CASE-REPORTING* 12–13 (2000), available at http://data.unaids.org/publications/irc-pub05/jc488-openup_en.pdf.

22 DONALD T. DICKSON, *HIV, AIDS, AND THE LAW: LEGAL ISSUES FOR SOCIAL WORK PRACTICE AND POLICY* 48 (2011).

cifically. As we will see, a better way to preserve privacy while simultaneously reducing both HIV-based stigma and stigma around other health conditions would be to strengthen confidentiality laws around health-related information more broadly.

With this in mind, Part I discusses the development and persistence of HIV-related stigma in the United States. It will look into where the stigma started and why it still exists today. Part II explores general privacy protections around health-related information, including the constitutional right to privacy, the Health Insurance Portability and Accountability Act (“HIPAA”), and the Americans with Disabilities Act (“ADA”). This Part also demonstrates that all of these legal guarantees are insufficient for genuine health information confidentiality, largely due to either statutory exceptions or the courts’ interpretations. In Part III, the Comment explores the HIV-specific laws that have sprouted up nationwide. These HIV laws protect confidentiality for HIV-specific information in particular, but frequently still come short of removing the risk of disclosure for people with HIV. Here, the Comment argues that laws specifically targeting HIV may preserve confidentiality but that they also perpetuate the stigma associated with the disease. In differentiating between privacy requirements for individual diseases, such laws lead to more confusion about what protections are necessary, making it more likely that a disclosure will take place. Finally, Part IV offers solutions that will protect HIV-positive individuals’ privacy while also working to reduce stigma around the disease. By strengthening health-related privacy more generally, we will be able to provide privacy protections for health-related information (including HIV status), reduce confusion about the types of privacy protections that are legally mandated, and remove some of the stigma associated with HIV. This will make it less likely that a nurse in Ms. Redgrave’s position would make unnecessary disclosures. It will also come much closer to guaranteeing Anya’s privacy. Finally, it will reduce the social alienation that people in Anya’s position experience on a regular basis.

I. HIV-ASSOCIATED STIGMA

HIV-infected individuals must struggle with the stigma associated with the disease on a regular basis.²³ Before understanding the preva-

²³ Herek, *supra* note 18, at 1106; Rintamaki, *supra* note 17, at 359–60. See generally HARDEN, *supra* note 19, at 7–10; Betsy L. Fife & Eric R. Wright, *The Dimensionality of Stigma: A Comparison of Its Impact on the Self of Persons with HIV/AIDS and Cancer*, 41 J. HEALTH & SOC. BEHAV. 50, 50 (2000); D.D. Reidpath & K.Y. Chan, *A Method for the Quantitative Analysis of*

lence of HIV-related stigma, however, it is worthwhile to explore what impact stigma can have—from the perspective of both the stigmatized individual and society at large.

A. *An Introduction to Stigma*

A stigmatized individual is one who is treated differently from others based on a specific trait, generally one that is out of that person's control.²⁴ He or she may have been able to have normal social interactions, except for the one trait that “[obtrudes] itself upon attention and [turns] those of us whom he meets away from him, breaking the claim that his other attributes have on us.”²⁵ A person with a stigma is often perceived as something less than human.²⁶ There are three different types of stigma generally: stigma stemming from physical deformities, stigma caused by perceived blemishes of character—such as mental disorders, homosexuality, or drug use—and the stigma brought on by characteristics such as race, nationality, and religion.²⁷

Those responsible for stigmatizing often construct belief systems that somehow excuse their animosity for or poor treatment of stigmatized individuals.²⁸ Some might rely on other differences, such as social class, to rationalize their animosity toward HIV-positive people.²⁹ However, stigma is not always perpetrated by the more fortunate. In fact, anyone can stigmatize, including poorer or marginalized groups who might stigmatize wealthier or more powerful groups.³⁰ Stigma is often rooted in ignorance, but ignorance alone is not enough to warrant the “stigma” label. Ignorance only becomes stigma when associated with “othering, blaming and shaming.”³¹

Regardless of the reason for the stigma, stigma often has a negative impact on an individual's perception of herself. Though a stigmatized person may see herself as normal, she will also likely recognize that others treat her differently than most.³² She will often come

the Layering of HIV-Related Stigma, 17 AIDS CARE: PSYCHOL. & SOCIO-MEDICAL ASPECTS AIDS/HIV 425, 425 (2006).

24 ERVING GOFFMAN, STIGMA: NOTES ON THE MANAGEMENT OF SPOILED IDENTITY 5 (1986).

25 *Id.*

26 *Id.*

27 *Id.*

28 *Id.*

29 *Id.*

30 Harriet Deacon, *Towards a Sustainable Theory of Health-Related Stigma: Lessons from the HIV/AIDS Literature*, 16 J. COMMUNITY & APPLIED SOC. PSYCHOL. 418, 421 (2006).

31 *Id.* at 424.

32 GOFFMAN, *supra* note 24, at 7.

to agree with this perception of differences after an extended period of not being accepted by her peers.³³ Stigma can lead to loss of status, internalization, disinterest in taking advantage of social, economic, or health-related opportunities, and discrimination.³⁴ One researcher defines health-related stigma as a social process in which (1) an illness is seen as preventable, (2) “immoral behaviors” cause the illness, (3) the behaviors are associated with an “other” who is a carrier of the illness, (4) certain individuals get blamed for their disease, and (5) loss of status gets projected onto someone with the illness, which may disadvantage that person in some way.³⁵

1. HIV-Specific Stigma

In the context of HIV, many of these stigmatizing factors are present.³⁶ First, stigma is often attached to diseases that are seen as “the bearer’s responsibility.”³⁷ For instance, a disease caused by voluntary and unnecessary acts will often be blamed on the sick individual.³⁸ Because HIV is often contracted through sexual interactions and intravenous drug use, it falls into this category.³⁹ Second, degenerative or unalterable diseases are often associated with increased levels of stigma as well.⁴⁰ Though no longer a death sentence, HIV is also incurable, making it one that falls into this category as well.⁴¹ Third, contagious illnesses are often more stigmatized than others.⁴² As a disease that is passed through human contact—albeit very few types of human contact—HIV is also subject to fears of contagion.⁴³ Finally, there are increased levels of stigma for conditions readily visible to

³³ *Id.* at 7–8.

³⁴ Deacon, *supra* note 30, at 424.

³⁵ *Id.* at 421.

³⁶ *See* Herek, *supra* note 18, at 1106 (noting that historically AIDS stigma was associated with homosexuality).

³⁷ *Id.* at 1105.

³⁸ *See id.* (noting that an individual with an illness perceived as having been contracted through voluntary and avoidable behaviors is likely to be stigmatized rather than evoke empathy).

³⁹ *Id.*

⁴⁰ *Id.*

⁴¹ *See id.* (explaining that because AIDS had initially been described as fatal, “those who are diagnosed may represent a reminder—or even the personification—of death and mortality”).

⁴² *Id.*

⁴³ *Id.*

others.⁴⁴ Though much of the course of HIV is not at all visible, the final stages are very much so.⁴⁵

Instances of HIV discrimination also provide evidence of the stigma attached to the disease. In 2011, a boy was denied admission to the Milton Hershey School, a private boarding school in Pennsylvania, because he was HIV-positive.⁴⁶ Though he was an honor roll student, the school decided that his attendance at the school would be a “direct threat” to other students.⁴⁷ A former member of the U.S. Army sought employment with a State Department contractor, but was removed from consideration for the position due to his HIV-positive status.⁴⁸ A woman was tested for HIV during pregnancy without her consent. Her positive results were then used to prevent her from seeing her newborn child.⁴⁹

Americans also demonstrate a strong lack of tolerance for people with HIV—another indicator of stigmatizing elements. In 2009, twenty-three percent of Americans admitted discomfort about the idea of working with an HIV-positive colleague.⁵⁰ Thirty-five percent of parents felt uncomfortable about the prospect of an HIV-positive teacher for their children.⁵¹ Forty-two percent of Americans would be uncomfortable having an HIV-positive roommate.⁵² And fifty-one percent of American adults would be uncomfortable with HIV-positive individuals preparing their food.⁵³ The frequency with which HIV-

44 *Id.* at 1105–06.

45 *See id.* at 1106 (finding that the latter stages of AIDS “often dramatically affect an individual’s physical appearance and stamina, evoking distress and stigma from observers”).

46 Press Release, AIDS Law Project, Milton Hershey School to Pay \$700,000 to End Complaint over Discrimination (June 1, 2012), *available at* <http://www.aidslawpa.org/2012/06/abraham-smith-and-mother-smith-v-milton-hershey-school> (reporting that the boy and his mother will accept a \$700,000 settlement from the Milton Hershey School in a federal AIDS-discrimination lawsuit).

47 *Id.*

48 Complaint at 7–8, *Doe v. Rice*, No. 08-cv-1678 (PLF) (D.D.C. Dec. 22, 2008), *available at* https://www.aclu.org/files/pdfs/hivaids/doe_v_rice_complaint.pdf.

49 *See* Amended Complaint at 9–10, *Doe v. Div. of Youth & Family Servs.*, 148 F. Supp. 2d 462 (D.N.J. 2002) (No. 00-CV-3205 (GEB)). Proposals for mandatory HIV testing of pregnant women were pervasive in the 1990s. *See* Theresa M. McGovern, *Mandatory HIV Testing and Treating of Child-Bearing Women: An Unnatural, Illegal, and Unsound Approach*, 28 COLUM. HUM. RTS. L. REV. 469, 470 (1997) (highlighting the current political trend toward mandatory HIV testing and treatment of childbearing women).

50 2009 SURVEY OF AMERICANS ON HIV/AIDS: SUMMARY OF FINDINGS ON THE DOMESTIC EPIDEMIC, KAISER FAMILY FOUND. 4 (2009), <http://www.kff.org/kaiserpolls/upload/7889.pdf>.

51 *Id.*

52 *Id.*

53 *Id.*

positive individuals experience prejudice and discrimination suggests a clear HIV-associated stigma.

Evidence of stigma toward HIV-positive individuals becomes even stronger when this discrimination is viewed in conjunction with the ignorance surrounding the disease. There remains a great deal of misunderstanding about HIV transmission nationwide.⁵⁴ First of all, the number of exposures that actually become transmissions is much lower than commonly thought.⁵⁵ Second, many significantly overestimate the means of transmitting the disease.⁵⁶ For instance, a 2000 study found that just over forty percent of participants believed that sharing a glass could lead to HIV transmission.⁵⁷ Approximately forty-one percent of respondents thought that being sneezed or coughed on would be sufficient for HIV transmission.⁵⁸ As discussed above, ignorance only becomes stigmatized when combined with elements of shaming. The cases discussed above and the data demonstrating widespread discomfort with HIV-positive individuals go a long way toward demonstrating the stigma around HIV.

As the number of people infected has increased, the discomfort around the illness has not decreased significantly. What is preventing HIV-positive individuals from gaining societal acceptance? As we will see, there are a number of other contributing factors to the stigma surrounding HIV, including the historical progression of HIV, its means of transmission, and its association with homosexuality and minority groups.

B. Causes of HIV-related Stigma

1. History

When HIV first appeared in hospitals around the United States, physicians were perplexed. After the medical community discovered a cure for polio, few imagined that new infectious diseases would emerge in the near future.⁵⁹ The disease first came to light through an increase in the number of reported cases of uncommon illnesses,

54 Bennett Klein, *Legal Issues Related to HIV/AIDS*, in 2 MASS. CONTINUING LEGAL EDUC., INC., LEGAL RIGHTS OF INDIVIDUALS WITH DISABILITIES § 15.1 (2002).

55 *Id.*

56 *Id.*

57 Ctrs. for Disease Control & Prevention, *HIV-Related Knowledge and Stigma—United States, 2000*, 49 MORBIDITY & MORTALITY WKLY. REP. 1062, 1062 (2000).

58 *Id.*

59 HARDEN, *supra* note 19, at 24.

such as Kaposi's sarcoma.⁶⁰ As doctors puzzled over the phenomenon, there was one thing they knew relatively early on: something was preventing these patients from fighting off illness.⁶¹ Though they did not understand the specifics of HIV until later, doctors quickly realized that they were dealing with a contagious immunodeficiency.⁶²

The confusion about HIV's source and methods of transmission led physicians to over-protect themselves from the disease. Doctors and nurses would only enter HIV-positive patients' hospital rooms entirely "gowned."⁶³ Meals were left outside patients' doors, instead of being taken in to patients directly.⁶⁴ Even once more was known about the disease, the ease of transmitting Hepatitis B—spread through many of the same mechanisms—perpetuated doctors' and dentists' fears of contracting the more fatal illness.⁶⁵ Even the health care workers who were involved in researching HIV were stigmatized.⁶⁶ Neighbors, friends, and family were hesitant to be around those who worked with HIV-positive individuals.⁶⁷ Though HIV stigma in the medical community is often attributed to subconscious prejudices against the communities at highest risk for HIV, many physicians actually reported that they were not even aware that their patients were gay until much later.⁶⁸

The medical community was not the only group creating a stigmatized culture around the new disease. Celebrities brought attention to HIV when they became diagnosed. Many went on to die from HIV-related illnesses.⁶⁹ Without enough information about how HIV was transmitted and without a cure, this led to widespread panic.⁷⁰ Highly publicized incidents of blood contamination also contributed to the panic, as young children such as Ryan White contracted the disease.⁷¹

The fear surrounding HIV began before any other prejudices later associated with HIV could take hold. It was not until later that the

60 *Id.* at 21.

61 *Id.*

62 *Id.*

63 *Id.*

64 *Id.* at 77.

65 *Id.* at 81.

66 *Id.* at 80.

67 *Id.*

68 *Id.* at 80–82.

69 *Id.* at 82.

70 *Id.* at 81–82.

71 *Id.* at 83.

means of transmission and high incidence rates in minority communities became a problem.

2. Means of Transmission

The ways in which HIV is transmitted also contribute to the stigma associated with the disease. There are very few body fluids that can actually transmit HIV from one person to another. These include blood, semen, vaginal secretions, and breast milk.⁷² In the United States, the two most common methods of transmission are through sexual encounters and sharing needles, a common practice among intravenous drug users.⁷³

Sexual encounters in the United States are still stigmatized in many ways. Some religious groups abhor sex before marriage and use large pools of financial resources to advocate against it.⁷⁴ Conservatives advocate for abstinence-only sex education, on the premise that sex outside of marriage is unacceptable and must be discouraged.⁷⁵ That sex can lead to disease only contributes to the stigma around HIV.⁷⁶ Because of the relatively high rates of HIV transmission through sex, people with HIV are often seen as sexually promiscuous and, thus, connected with an “amoral” sector of society.⁷⁷ Victoria Harden writes in her book discussing the history of the HIV epidemic: “Because AIDS can be sexually transmitted . . . it is still imbued with the fear, guilt, and shame that attach to all sexually transmitted diseases.”⁷⁸ As patients with a sexually transmitted disease, HIV-positive individuals are subject to all prejudices associated with sex as well—regardless of whether they were infected through a

72 *HIV Transmission*, CENTERS FOR DISEASE CONTROL & PREVENTION, <http://www.cdc.gov/hiv/resources/qa/transmission.htm> (last modified Mar. 25, 2010).

73 *Id.*

74 *See, e.g., Why Wait for Sex?*, FOCUS ON FAM., http://www.focusonthefamily.com/marriage/preparing_for_marriage/why_wait_for_sex.aspx (last visited July 31, 2013) (discouraging premarital sex from a partly Biblical perspective).

75 *See, e.g., Abstinence-only Sex Education*, ADVOC. FOR ACAD. FREEDOM, http://advocatesforacademicfreedom.org/ressex.asp#.UMvjOOe_Uk (last visited on July 31, 2013) (identifying the promotion of abstinence-only sex education as an educational goal); Robert Rector, *Facts About Abstinence Education*, HERITAGE FOUND. (Mar. 30, 2004), <http://www.heritage.org/research/reports/2004/03/facts-about-abstinence-education> (arguing against comprehensive sex education).

76 HARDEN, *supra* note 19, at 124.

77 *Id.*

78 *Id.*

sexual encounter, a blood transfusion, or even through a mother's breast milk.⁷⁹

HIV's association with intravenous drug users also contributes to the stigma around HIV. Intravenous drug users are often considered part of the "underbelly" of society.⁸⁰ Intravenous drugs are largely illegal in the United States.⁸¹ This means that intravenous drug users must regularly break the law to feed their addictions. It also means that intravenous drug users often do not have access to safety provisions that would help to reduce the spread of HIV.⁸² Public health advocates recommend needle distribution programs as one of the most effective ways to reduce the spread of HIV among intravenous drug users in the United States.⁸³ However, until 2009, there was a ban on federal funding for needle exchange programs in the United States.⁸⁴ Though the ban has now been lifted, such programs are still underfunded and relatively uncommon.⁸⁵

The lack of sympathy for people struggling with illegal drug addiction extends to people with HIV, especially those who contracted the disease through their drug-using behavior.⁸⁶ However, the connection between HIV and intravenous drugs does not stop with those who contracted the disease through such illegal conduct. A *Washington Post* article in 2012 quoted Sean Strub, the founder of the influential *POZ* magazine, as saying, "[b]eing positive is vastly more stigmatizing for young men now. People ask, 'What were you doing? Crystal [meth]?'"⁸⁷ Just as the sexual implications of HIV impact the HIV-

79 See Reidpath & Chan, *supra* note 23, at 426–27 (finding that although the stigma associated with HIV fluctuated depending on how it was transmitted, the stigma never disappeared).

80 *Id.*

81 *Federal Trafficking Penalties*, DRUG ENFORCEMENT ADMIN., <http://www.justice.gov/dea/druginfo/ftp3.shtml> (last visited Jan. 6, 2013).

82 *Drug-Associated HIV Transmission Continues in the United States*, CTRS. FOR DISEASE CONTROL AND PREVENTION, <http://www.cdc.gov/hiv/resources/factsheets/idu.htm> (last modified Mar. 8, 2007).

83 See e.g., Richard Knox, *Needle Exchanges Often Overlooked in AIDS Fight*, SHOTS: HEALTH NEWS FROM NPR (July 24, 2012, 11:51 AM), <http://www.npr.org/blogs/health/2012/07/24/157283038/needle-exchanges-often-overlooked-in-aids-fight>; *Needle Exchange Programs Promote Public Safety*, ACLU (May 31, 2006), <http://www.aclu.org/drug-law-reform/needle-exchange-programs-promote-public-safety>.

84 *Needle Exchange and Harm Reduction*, AVERT, <http://www.avert.org/needle-exchange.htm> (last visited Jan. 6, 2013).

85 *Id.*

86 Reidpath & Chan, *supra* note 23, at 425.

87 Dan Zak, *You Don't Know. You Weren't There. You Didn't Live Through It.*, WASH. POST, July 24, 2012, at C9.

positive community at large, so too does its relationship with intravenous drug use.

3. Association with Homosexuality and Minority Groups

HIV is also closely associated with minority groups—particularly gay men, Blacks, and Latinos. Stigma itself is often exaggerated when multiple stigmas layer on top of one another.⁸⁸ Stigma does not exist in a vacuum.⁸⁹ As discussed in greater detail below, gay men experience a great deal of stigma even without HIV. The same is true for both Black and Latino communities. The stigma that a minority group experiences is thus combined with the stigma associated with HIV to create a more complex, ingrained stigma. A gay man with HIV, for instance, will be subject to greater stigma than a heterosexual man with HIV. In other words, the level of stigma that a person feels against an individual is not related entirely to the HIV status. Knowing that an HIV-positive individual is gay or part of a racial minority will contribute significantly to the way an outsider perceives both that person and the disease in general.⁹⁰

Higher rates of HIV in minority communities combine with the preexisting biases against minority groups to increase stigma against people with HIV in general. The incidence of HIV in many minority communities is much higher than in majority communities. Men who have sex with men (“MSM”) made up fifty percent of new HIV infections from 2006 to 2009.⁹¹ In 2010, that percentage rose to sixty-one percent of HIV diagnoses. These percentages are extremely high, especially considering that MSM account for only two percent of the U.S. population.⁹² Though only fourteen percent of the U.S. population, Blacks made up forty-four percent of new HIV infections in 2009.⁹³ Latinos represented sixteen percent of the population in 2009, but made up twenty percent of new HIV infections.⁹⁴ These increased incidence rates are caused by a number of societal factors, such as the paucity of legal protections for the gay community, high incarceration rates among racial minorities, higher poverty rates, insufficient education, and inferior access to health care. Nonetheless,

88 Reidpath & Chan, *supra* note 23, at 425.

89 *Id.*

90 *Id.*

91 *HIV in the United States: An Overview*, CTRS. FOR DISEASE CONTROL & PREVENTION (Aug. 2011), <http://stacks.cdc.gov/view/cdc/11978>.

92 *Id.*

93 *Id.*

94 *Id.*

perceptions about the association between gay men and Black and Latino populations does contribute to the stigma against HIV.

Physicians first recognized HIV in gay male patients in large cities around the United States.⁹⁵ Called a “gay disease” early on, some claim that the connection with the gay community contributed to initial complacency about HIV, prolonging the start of serious HIV research.⁹⁶ Negative perceptions of the gay population translated into their understanding of HIV as well.⁹⁷ There is still a great deal of hostility toward homosexual men and women.⁹⁸ When the disease first came to light, that stigma was even greater. A 1991 study found that roughly two-thirds of the United States thought that homosexuality or homosexual behavior was morally wrong or even sinful.⁹⁹ Same-sex couples cannot marry in most states.¹⁰⁰ There is no national legal structure providing relief for lesbians or gay men if they are discriminated against at work.¹⁰¹ These legal inequalities excuse stigma against the gay community, reinforced by certain religious and “family values” organizations.¹⁰²

That HIV was initially considered to be a disease present exclusively in the homosexual community explains, in part, why popular perception views HIV as connected to homosexuality. However, it is not the only reason. Slightly higher transmission rates between MSM, for instance, make it easier for gay men to pass the disease to one another.¹⁰³ The stigma associated with being homosexual contributes to a lack of access to sexual education programs and condoms.¹⁰⁴ Many

95 HARDEN *supra* note 19, at 15.

96 *Id.* at 79.

97 Reidpath & Chan, *supra* note 23, at 425.

98 *Gay and Bisexual Men's Health: Stigma and Discrimination*, CTRS. FOR DISEASE CONTROL & PREVENTION, <http://www.cdc.gov/msmhealth/stigma-and-discrimination.htm> (last updated Mar. 3, 2011).

99 Herek, *supra* note 18, at 42; Gregory M. Herek, *Stigma, Prejudice, and Violence Against Lesbians and Gay Men*, in *HOMOSEXUALITY: RESEARCH IMPLICATIONS FOR PUBLIC POLICY* 60 (John C. Gonsiorek & James D. Weinrich eds., 1991).

100 *Legal Patchwork*, WALL ST. J., http://online.wsj.com/public/resources/documents/info-SAME_SEX_MAP_0905.html (last visited Sept. 2, 2013).

101 *LGBT Basic Rights and Liberties*, AM. CIV. LIBERTIES UNION, <http://www.aclu.org/lgbt-rights/lgbt-basic-rights-and-liberties> (last visited Aug. 14, 2013).

102 *See, e.g.*, FOCUS ON FAM., <http://www.focusonthefamily.com> (last visited Sept. 2, 2013).

103 Chris Beyrer et al., *Global Epidemiology of HIV Infection in Men who have Sex with Men*, 380 *LANCET* 367, 367 (2012) (“HIV can be transmitted through large MSM networks at great speed.”).

104 *Id.*

sex education programs do not even address homosexuality as a legitimate sexual practice.¹⁰⁵

The same is true for racial and ethnic minorities. Higher rates of HIV in Black and Latino communities stem largely from educational and income disparities.¹⁰⁶ The history of discrimination associated with being Black in the United States, beginning with slavery at the birth of the nation and extending through Jim Crow laws into modern society, contributes to the Black community's lower levels of education and income.¹⁰⁷ Recent waves of immigration and cultural differences create similar barriers for the Latino population.¹⁰⁸ Without access to strong sex education programs, HIV is likely to spread more quickly.¹⁰⁹ Without an understanding of how HIV is transmitted, there is no way to protect oneself against it.¹¹⁰ Low income levels also contribute to higher rates of sex work and drug use, both of which put people at much higher risk for HIV.¹¹¹ High incarceration rates also contribute to the spread of HIV in racial minority groups.¹¹² Prisoners are highly susceptible to HIV transmission due to sexual and physical violence.¹¹³ Because Black and Latino communities are represented in large numbers within prison settings, and the rate of HIV infection is higher in these populations than the general popula-

105 *Sex Education in America: An NPR/Kaiser/Kennedy School Poll*, NPR (Feb. 24, 2004, 12:00 AM), <http://www.npr.org/templates/story/story.php?storyId=1622610>.

106 *HIV Among African Americans*, CTRS. FOR DISEASE CONTROL & PREVENTION,, <http://www.cdc.gov/hiv/risk/raciaethnic/aa/facts/index.html> (last updated May 15, 2013); *HIV Among Latinos*, CTRS. FOR DISEASE CONTROL & PREVENTION, <http://www.cdc.gov/hiv/risk/raciaethnic/hispaniclatinos/facts/index.html> (last updated Apr. 24, 2013).

107 *HIV Among African Americans*, *supra* note 106.

108 *HIV Among Latinos*, *supra* note 106.

109 See Donald H.J. Hermann, *The Development of AIDS Federal Civil Rights Law: Anti-Discrimination Law Protection of Persons Infected with Human Immunodeficiency Virus*, 33 IND. L. REV. 783, 787 (2000) (explaining that current educational efforts are ineffective because they may lead to the involuntary disclosure of HIV-infected status and further discrimination).

110 *HIV & AIDS Stigma and Discrimination*, AVERT, <http://www.avert.org/hiv-aids-stigma.htm#contentTable5> (last visited Jan. 6, 2013).

111 Stefan Baral et al., *Burden of HIV Among Female Sex Workers in Low-Income and Middle-Income Countries: A Systematic Review and Meta-Analysis*, 12 LANCET INFECTIOUS DISEASES 538, 539 (2012); *ASPE Fact Sheet: Youth from Low-Income Families*, ASPE.HHS.GOV (July 2009), <http://aspe.hhs.gov/hsp/09/vulnerableyouth/3/index.shtml>.

112 Nina Harawa & Adaora Adimora, *Incarceration, African Americans, and HIV: Advancing a Research Agenda*, 100 J. NAT'L MED. ASS'N 57 (2008).

113 Elizabeth Kantor, *HIV Transmission and Prevention in Prisons*, HIV INSITE (Apr. 2006), <http://hivinsite.ucsf.edu/InSite?page=kb-07-04-13#S4X>.

tion, this contributes to the spread of the disease as well.¹¹⁴ All of these things also contribute to stigma against both racial minorities.

There are even large racial disparities in antiretroviral therapy (“ART”) adherence, which also contributes to the spread of the disease among those populations.¹¹⁵ There is now significant evidence that adherence to HIV medications not only furthers the health of the HIV-positive individual, but also reduces the spread of the disease.¹¹⁶ Researchers also find that the partners of people with HIV who take ART also reduce their likelihood of contracting the virus.¹¹⁷ However, these medications are prohibitively expensive for many, meaning that these medical advances may do little to reduce the incidence of HIV in low income, minority communities.

C. *The Innocent Victim*

Of course, there are also those with HIV who are widely perceived as “innocent victims” of HIV.¹¹⁸ These victims include blood recipients, children, and emergency responders. But because these populations represent a much smaller part of the HIV-positive community and because fears about HIV transmission persist, their existence is unlikely to reduce stigma significantly, if at all.¹¹⁹ In fact, by labeling them as “victims,” we actually may imply that those in minority groups or those with intravenous drug addictions are the aggressors or perpetrators of the HIV epidemic—a dangerous proposition for reducing HIV-associated stigma. The innocent victims, therefore, are unlikely to counter fears about HIV transmission and, thus, stigma.

However, the victim may actually experience lower levels of stigma. An HIV-positive person who is heterosexual and neither Black nor Latino will not experience the same level of stigma as an HIV-positive person who is also homosexual and Black.¹²⁰ The innocent victim will thus have a very low impact on the stigma against HIV at

114 *Id.*

115 Jane M. Simoni et al., *Racial/Ethnic Disparities in ART Adherence in the United States: Findings From the MACH14 Study*, 60 J. ACQUIRED IMMUNE DEFICIENCY SYNDROMES 466, 466–67 (2012).

116 Seth C. Kalichman et al., *Adherence to Antiretroviral Therapy and HIV Transmission Risks: Implications for Test-and-Treat Approaches to HIV Prevention*, 24 AIDS PATIENT CARE & STDs 271, 271 (2010).

117 *HIV/AIDS*, WORLD HEALTH ORG., <http://www.who.int/mediacentre/factsheets/fs360/en/index.html> (last updated June 2013).

118 HARDEN, *supra* note 19, at 83.

119 *Id.*

120 Reidpath & Chan, *supra* note 23, at 426.

large, though he or she may experience less discrimination on a daily basis.

D. Conclusion

Stigma against people with HIV is still pervasive in the United States. It is one major contributing factor to the discrimination that people with HIV face.

Discrimination against HIV-infected persons has its origins in a complex of fears, phobias, and prejudices. Fear of contagion is the most often expressed concern by those accused of discrimination. Nevertheless, the fact that persons with HIV-infection may be disproportionately discriminated against as compared to members of otherwise discriminated against groups, such as gay men or people of color, is often cited as a basis for the need of legal protection against discrimination.¹²¹

People with HIV may actually face even more severe discrimination than other traditionally marginalized groups in modern society. The history of the disease, the means through which HIV is transmitted, and the populations most affected by it contribute to the persistence of such stigma.

II. CONFIDENTIALITY PROTECTIONS FOR HEALTH-RELATED INFORMATION

Privacy in HIV-related information is important for several reasons. First, the stigma associated with HIV puts individuals diagnosed with the disease at risk for discrimination. The ability to protect that information gives people with HIV a valuable tool for preventing that discrimination. Second, privacy in HIV-related information encourages testing. Again, because of the stigma associated with HIV, many people are reluctant to get tested for the illness in the first place.¹²² Though this fear of testing is not limited to HIV, the stigma exacerbates any reluctance.¹²³ By ensuring that individuals will have privacy in the results of their test, people are more likely to get tested for HIV and begin taking medication, which significantly lowers the likelihood of continued transmission.¹²⁴ Without strong privacy protections, HIV-positive individuals are more likely to spread the disease and experience the sting of discrimination.

¹²¹ Hermann, *supra* note 109, at 787.

¹²² Sean D. Young & Yuda Zhu, *Behavioral Evidence of HIV Testing Stigma*, 16 AIDS & BEHAV. 736, 736 (2012).

¹²³ *Id.*

¹²⁴ Rintamaki et al., *supra* note 17, at 359.

However, HIV is not the only health condition that requires confidentiality. There is stigma associated with many illnesses.¹²⁵ Even without stigma, some people would prefer to keep their health conditions private. The need for health privacy is widely recognized in the United States.¹²⁶ There are privacy protections in place at both the federal and state levels that protect health-related information of all kinds. At the federal level, there are three fundamental sources of confidentiality protections for health-related information: the constitutional right to privacy, HIPAA, and the ADA. State-level protections, largely built upon general federal protections, vary widely.¹²⁷ Though all of these sources provide important confidentiality protections for health-related information—including HIV status—none go far enough to ensure the level of privacy needed to both encourage HIV testing and to provide safety from discrimination. Privacy protections for people with any health-related condition are insufficient to guarantee confidentiality of patients' HIV-related information. They are also insufficient to guarantee the confidentiality of patients' health-related information more broadly.

A. *The Constitutional Right to Privacy*

The constitutional right to privacy is insufficient protection to ensure the confidentiality of HIV-related information. The Supreme Court recognizes a right to privacy embedded in the U.S. Constitution.¹²⁸ There are two types of constitutional privacy rights: the right to make certain kinds of personal decisions and the right to prevent disclosure of personal information—including medical information.¹²⁹ In *Whalen v. Roe*, the Court held that medical records—as personal information—do create a right to privacy.¹³⁰ However, there are exceptions inherent in that right. For instance, the right to privacy as a constitutional constraint on behavior applies only to government action.¹³¹ The constitutional right to privacy does not extend to

125 Fife & Wright, *supra* note 23, at 50.

126 See, e.g., Michael Hiltzik, *Her Case Shows Why Healthcare Privacy Laws Exist*, L.A. TIMES, Jan. 4, 2012, <http://articles.latimes.com/2012/jan/04/business/la-fi-hiltzik-20120104>.

127 Lawrence O. Gostin et al., *The Nationalization of Health Information Privacy Protections*, 8 CONN. INS. L.J. 283, 293–94 (2002); David W. Webber & Lawrence O. Gostin, *Discrimination Based on HIV/AIDS and Other Health Conditions: "Disability" as Defined Under Federal and State Law*, 3 J. HEALTH CARE L. & POL'Y 266, 288 (2000).

128 See, e.g., *Whalen v. Roe*, 429 U.S. 589, 598–600 (1977).

129 *Id.*

130 *Id.* at 602.

131 See *The Civil Rights Cases*, 109 U.S. 3, 11 (1883) (limiting the scope of the Fourteenth Amendment to state action).

disclosures made by private parties.¹³² Further, “disclosures of private medical information to doctors, to hospital personnel, to insurance companies, and to public health agencies are often an essential part of modern medical practice even when the disclosure may reflect unfavorably on the character of the patient.”¹³³ The right to privacy is not absolute.

To determine whether the right to privacy in information has been breached, the Court, in *Nixon v. Administrator of General Services*, held that the claim must be subject to a balancing test.¹³⁴ The Court must balance the private party’s interest in keeping the information private with the public interest in extending access to the information.¹³⁵ The Court, in *Nixon*, made no explicit claims for what counts as an unwarranted disclosure of personal information.¹³⁶ However, relevant considerations include the type of information at issue, the potential harm that would be caused by disclosure, the safeguards in existence to prevent disclosure, and the public’s need for the information.¹³⁷

In the context of HIV disclosure, this balancing act may not be sufficient to protect people with HIV from being exposed in unnecessary circumstances. A frequently litigated area of HIV privacy law is the prison context. There, courts have found that the constitutional right to privacy in HIV-information is insufficient to invalidate disclosures to correctional officers.¹³⁸ In *Doe v. Wigginton*, a Sixth Circuit decision, the court held that the disclosure of an inmate’s HIV status was not in violation of his constitutional right to privacy because it would “force courts to ‘balanc[e] almost every act of government, both state and federal, against its intrusion on a concept so vague, undefinable, and all-encompassing as individual privacy.’”¹³⁹ There, the court found the right to privacy too nebulous to triumph against what it found to be the more concrete interests of the state. However, the Sixth Circuit has also held that prisoners do have a constitu-

132 *See id.*

133 *Whalen*, 429 U.S. at 602.

134 433 U.S. 425, 458 (1977).

135 *Id.*

136 Norman Vieira, *Unwarranted Government Disclosures: Reflections on Privacy Rights, HIV and Ad Hoc Balancing*, 47 WAYNE L. REV. 173, 180 (2001).

137 L. Camille Hebert, *Challenges to Employer Use of HIV Testing as Violation of Constitutional Right to Privacy*, in 2 EMPLOYEE PRIVACY LAW § 11:12 (2012).

138 *Doe v. Wigginton*, 21 F.3d 733, 740 (6th Cir. 1994).

139 *Id.* (quoting *J.P. v. DeSanti*, 653 F.2d 1080, 1090 (6th Cir. 1981)).

tional right to privacy in their HIV status with regard to other prisoners.¹⁴⁰

The Third Circuit has also held that the constitutional right to privacy does extend to HIV status. Again, though, that right is substantially limited by other factors—especially in the prison context.¹⁴¹ Many circuits allow HIV-positive prisoners to be isolated from the general prison population as a means of preventing the spread of HIV, at the cost of revealing prisoners' HIV status to other inmates and putting HIV-positive prisoners at risk of harassment.¹⁴² Though most courts that have addressed the issue do recognize a constitutional right to privacy for HIV-related information, many of those same courts often hold that other interests outweigh the constitutional right to privacy for people with HIV.¹⁴³ This makes the constitutional right to privacy in HIV-related information far from absolute. In a society that places such great stigma on people with HIV, it is unlikely that such prejudices will be entirely avoided in the judicial balancing process.

In Anya's situation, the school disclosed her status as a means of preventing the other little girl from contracting the disease. The fault in that case was that there was no legitimate reason to disclose that information. The blood was on the little girl's finger only. Even the presence of a hangnail was not sufficient to trigger the immunologists' concerns of transmission.¹⁴⁴ The girl would not even need to go through prophylaxis to prevent the exposure from turning into a transmission. No transmissible event occurred, and she had not been exposed to the virus.

However, under the constitutional right to privacy, the school may not be in the wrong for having disclosed Anya's HIV status. There is certainly a good argument for wanting to protect children from transmitting HIV on the playground. Though an HIV-positive immigrant child in rural Pennsylvania may be stigmatized by the disclosure, there is no proof that she would be treated any differently.¹⁴⁵

¹⁴⁰ Moore v. Prevo, 379 F. App'x 425, 427–28 (6th Cir. 2010).

¹⁴¹ Doe v. Delie, 257 F.3d 309, 315 (3d Cir. 2001); Doe v. Se. Pa. Transp. Auth., 72 F.3d 1133, 1138 (3d Cir. 1995).

¹⁴² See, e.g., Harris v. Thigpen, 941 F.2d 1495, 1519 (11th Cir. 1991).

¹⁴³ Hebert, *supra* note 137, § 11:12.

¹⁴⁴ *Pre-Exposure Prophylaxis (PrEP)*, CTRS. FOR DISEASE CONTROL & PREVENTION, <http://www.cdc.gov/hiv/prevention/research/prep/index.html> (last updated Aug. 19, 2013).

¹⁴⁵ It is also worth noting that Anya's non-English-speaking, immigrant status already creates a stigma under which Anya must labor daily. Adding her HIV status to the list will only subject her to a heightened level of stigma, considering the layering discussion above.

Without definitive evidence, it is possible—if not probable—that a court would find more potential harm in a child transmitting HIV than in a child already living with the disease being subject to stigma.

The incomplete nature of the constitutional protections become even more exaggerated when we separate the disclosures: the nurse's disclosure to the principal and the principal's disclosure to the other child's parents. According to the constitutional right to privacy, the principal almost certainly had the right to the HIV-related information. The nurse's interest in ensuring that the little girl did not transmit HIV likely would trump any concerns about the principal subjecting a little girl to discrimination based on her HIV status within the constitutional analysis. Principals are involved in academics, class trips, and punishment. A principal with any HIV-related prejudices might use that against a child in a variety of circumstances. Giving principals access to a student's HIV-related information puts that student at risk of prejudice, stigma, and bullying. However, the nurse's disclosure was in the public interest and the interest of another child. The non-concrete chance that the principal harbors any negative feelings about people with HIV is unlikely to prove more convincing than protecting a child's health. Therefore, it is plausible that a court using this balancing test would find in favor of the school's right to know, rather than the child's right to privacy. This is a major insufficiency in the constitutional right to privacy. Anya's right to privacy should be close to absolute. This would encourage students to be open with schools about their health-related information. It would also allow the students to avoid any possible stigma related to their illnesses.

This is not to suggest that there are no circumstances under which a disclosure might be necessary. For instance, if the two girls had somehow both bled significantly, the other little girl would likely need to be treated for HIV. In that case, the HIV test would be in the public interest. However, more stringent rules around protecting an individual's privacy would ensure that health care professionals are more cautious before disclosing HIV-related information, thus preventing disclosures that may appear to the uninformed eye to be a risk to the public health, but in reality pose no risk at all.

Vague constitutional standards do not guarantee privacy for people with HIV. Courts are not immune to societal stigmas. This case-by-case analysis is not enough to ensure HIV-positive individuals' privacy.

B. HIPAA

HIPAA—which is a federal law providing privacy protections for health-related information—is also insufficient to ensure an HIV patient’s confidentiality. HIPAA is designed

to improve portability and continuity of health insurance coverage in the group and individual markets, to combat waste, fraud, and abuse in health insurance and health care delivery, to promote the use of medical savings accounts, to improve access to long-term care services and coverage, to simplify the administration of health insurance, and for other purposes.¹⁴⁶

Though not initially intended as a health-related information privacy protection, the provisions on privacy were added in response to congressional concerns about the expansion of health information technology.¹⁴⁷ In fact, HIPAA actually delegated responsibility for laying out privacy protections to the Department of Health and Human Services (“HHS”).¹⁴⁸ HHS complied, developing privacy and security rules through administrative notice and comment rulemaking.¹⁴⁹

The privacy rules developed in response to HIPAA allow the Office of Civil Rights (“OCR”) to conduct compliance reviews, either in response to complaints or of its own accord.¹⁵⁰ Since the regulations took effect, OCR has primarily focused on responding to complaints.¹⁵¹ The privacy rules promulgated by HIPAA ensure the privacy of health-related information by preventing disclosure.¹⁵² However, these protections are subject to several exceptions.¹⁵³ For instance, an entity can disclose private health-related information where it is relevant for treatment or payment, with authorization, or for health care operations.¹⁵⁴ Disclosure may also be permitted in the treatment of minors.¹⁵⁵

These disclosures are subject to a “minimum necessary” standard.¹⁵⁶ This provides that the “covered entity must make reasonable efforts to limit protected health information to the minimum neces-

146 Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, pmbll., 110 Stat. 1936 (1997).

147 Michael W. Drumke, *A HIPAA Primer*, 37 AM. BAR ASSOC.: THE BRIEF 1, 1 (2008).

148 *Id.*

149 *Id.*

150 45 C.F.R. §§ 160.306, 160.308 (2012).

151 Drumke, *supra* note 147, at 3.

152 45 C.F.R. § 164.502 (2012).

153 *Id.*

154 Drumke, *supra* note 147, at 4.

155 *Id.*

156 45 C.F.R. § 164.502(b)(1) (2012).

sary to accomplish the intended purpose of the use, disclosure, or request.”¹⁵⁷ However, this “minimum necessary” standard does not apply in all circumstances.¹⁵⁸ HIPAA applies to all persons directly or indirectly providing health care services. It extends to all health care information and records.¹⁵⁹ Again, HIPAA does provide significant protections for health related information. However, the protection is far from absolute. In fact, Congress expressly provided that its protections for the privacy of medical information should not “be construed to invalidate or limit the authority, power, or procedures established under any law providing for . . . public health investigation or intervention.”¹⁶⁰ The Ninth Circuit has read this as a “well-established need for disclosure” under those circumstances.¹⁶¹ Courts also allow HIPAA privacy disclosures in criminal prosecutions—as long as officers get a warrant before gaining access to an individual’s medical records, such confidential information is admissible.¹⁶² Thus, exceptions to HIPAA are interpreted very broadly, allowing for more disclosures than would be immediately apparent on the face of the rule. The regulation itself also acknowledges the possibility of a more stringent state law, suggesting that HHS really did intend for it to be read fairly broadly.¹⁶³

Turning to the disclosures around Anya’s HIV status, Anya probably would not have been able to bring a successful claim under HIPAA either. Any disclosure made to both the principal and the other child’s parents would easily fall into one of the exceptions defined by the regulations. The school would argue that the nurse only disclosed Anya’s HIV status in the service of treatment to ensure that the other child got access to prophylaxis if necessary. Though there could be an argument that the nurse proceeded too quickly—not honoring the mother’s request for time to contact the immunologist—her actions were still in the service of treatment for a child. Because she also seems to have complied with the “minimum necessary” standard by limiting the disclosure to the school principal and the other child’s parents, both of which would have been required to get

¹⁵⁷ *Id.*

¹⁵⁸ *Id.* § 164.502(b)(2).

¹⁵⁹ JAY E. GREINIG & JEFFREY S. KINSLER, HANDBOOK FEDERAL CIVIL DISCOVERY & DISCLOSURE § 18.2 (3d ed. 2010).

¹⁶⁰ 42 U.S.C. § 1320d-7(b) (2011).

¹⁶¹ *Seaton v. Mayberg*, 610 F.3d 530, 541 (9th Cir. 2010).

¹⁶² *United States v. Wilk*, 572 F.3d 1229, 1236 (11th Cir. 2009); *United States v. Bek*, 493 F.3d 790, 802 (7th Cir. 2007).

¹⁶³ *See Drumke*, *supra* note 147, at 3 (discussing HIPAA provisions allowing states to have more stringent privacy protections than those provided by federal law).

the student the prophylaxis treatment, any complaint under HIPAA would likely fail.

C. The ADA

ADA privacy protections are also insufficient for people with HIV. The ADA provides additional privacy protections around health-related information, specifically for people with disabilities.¹⁶⁴ This includes people with HIV, whom courts classify as disabled under the ADA.¹⁶⁵ An infectious disease—tuberculosis—was first found to be a disability in *School Board v. Arline*.¹⁶⁶ The case construed the Rehabilitation Act—a precursor to the ADA—to mean that a teacher with tuberculosis should be considered a “handicapped individual.”¹⁶⁷ Though the case did not address HIV infection specifically, it “played a pivotal role in the development of federal disability law as applied to AIDS and HIV infections because of the communicable nature of HIV.”¹⁶⁸

A little over ten years later, the Court decided *Bragdon v. Abbott*.¹⁶⁹ That case arose from a dentist’s refusal to fill an asymptomatic, HIV-positive woman’s cavity, instead referring her to a local hospital.¹⁷⁰ The woman, Abbott, sued her dentist under the ADA for disparate treatment.¹⁷¹ Ultimately, the Supreme Court determined that HIV is considered a disability under the ADA, which defines disability as “a physical . . . impairment that substantially limits one or more of [an individual’s] major life activities.”¹⁷² The Court held that HIV restricts the ability to reproduce, which it considered to be a “major life activity.”¹⁷³ Because reproduction creates a high likelihood of transmitting HIV, the Court held that the major life activity of reproduction was sufficiently limited by being HIV-positive.¹⁷⁴ However, the Court did not make a blanket holding that HIV would always be considered a disability, instead deciding to reserve that question for another day.¹⁷⁵ Though some circuits have understood *Bragdon* to hold that HIV is a

164 Americans with Disabilities Act of 1990, 42 U.S.C. § 12112(b) (2011).

165 *Bragdon v. Abbott*, 524 U.S. 624, 630–31 (1998).

166 480 U.S. 273, 284 (1987).

167 *Id.* (internal quotation marks omitted).

168 Hermann, *supra* note 109, at 794.

169 *Bragdon*, 524 U.S. at 624.

170 *Id.* at 629.

171 *Id.*

172 42 U.S.C. § 12102(2)(A) (2011).

173 *Bragdon*, 524 U.S. at 639–41.

174 *Id.*

175 *Id.* at 641–42.

per se disability, others have taken a narrower view on the case.¹⁷⁶ These circuits assume that HIV only limits some major life activities, a perspective that would require plaintiffs to plead and prove each instance in which HIV is a limitation.¹⁷⁷

The legislative history associated with the ADA's passage also strongly supports including HIV as a disability within the context of the Act. The HIV-advocacy community played a "powerful role" in enacting the ADA in the first place.¹⁷⁸ Both President George H.W. Bush and Congress apparently assumed that HIV would be included in the definition of a disability.¹⁷⁹

The ADA grants a number of privacy protections to those with disabilities. Assuming that HIV will always be considered a disability under the ADA—which, as discussed above, has yet to be determined by the courts—these protections would extend to people with HIV. The ADA's privacy protections require that any information regarding an individual's disability be treated as a "confidential medical record" and kept confidential.¹⁸⁰ The ADA does have exceptions, however. Supervisors and managers can know about restrictions on an employee's work capabilities in order to provide the necessary accommodations.¹⁸¹ First aid and safety personnel can be notified so that they can be prepared for emergency treatment.¹⁸² Government compliance officials can be provided all relevant health information upon request.¹⁸³

Again, these broad exceptions can lead to serious confidentiality breaches for people with HIV. For instance, a supervisor who is informed of someone's HIV status in order to make accommodations may hold that information against her employee, whether consciously or subconsciously. Many of the same concerns that would suggest that principals should not know about their students' HIV statuses—as in Anya's case—would apply to supervisors as well.¹⁸⁴ It is dangerous for an HIV-positive individual's wellbeing to allow information about such a sensitive subject to be placed in the hands of that super-

176 See, e.g., *Rivera v. Heyman*, 157 F.3d 101, 103 (2d Cir. 1998); *Alsbrook v. City of Maumelle*, 156 F.3d 825, 831 n.5 (8th Cir. 1998); *Deas v. River West, L.P.*, 152 F.3d 471, 478 n.15 (5th Cir. 1998).

177 *Webber & Gostin*, *supra* note 127, at 279.

178 *Id.* at 273.

179 *Id.* at 274.

180 42 U.S.C. § 12112(d)(3)(B) (2011).

181 *Id.* § 12112(d)(3)(B)(i).

182 *Id.* § 12112(d)(3)(B)(ii).

183 *Id.* § 12112(d)(3)(B)(iii).

184 See *supra* Part II.A.

visor, who may be involved in many aspects of an employee's work. Because of the stigma still associated with HIV, people with HIV need more protection than the ADA can offer.

D. Conclusion

The federal laws that provide privacy protections for health-related information are insufficient. Though the constitutional right to privacy, HIPAA, and the ADA play an important role in protecting individuals' privacy broadly, the exceptions make them too easy to manipulate. This puts people with HIV at a risk of stigma and discrimination. However, that risk does not stop with HIV-positive individuals. The insufficiency of privacy protections for health-related information does not only apply to HIV-related information. People with other illnesses, such as cancers or diabetes, are also at great risk of privacy violations.¹⁸⁵ Therefore, more is needed to ensure confidentiality of health-related information in general.

III. HIV LAWS, STIGMA, AND THE NEED FOR PRIVACY

There are laws nationwide designed to provide additional privacy protections for people with HIV. However, these laws are misguided. First, singling out HIV for protection contributes to negative perceptions of the disease. It implies that HIV is a special kind of disease of which one should be ashamed. Treating the disease differently exaggerates existing stigma. Second, HIV-specific laws do not provide protection for people with other illnesses.

A. State Laws that Focus on HIV

Many states have passed laws to provide an added level of confidentiality for people with HIV.¹⁸⁶ There are a number of different types of state laws that provide this additional protection: disability

¹⁸⁵ See Fife & Wright, *supra* note 23, at 50–51 (describing the harms that result from public knowledge that an individual has a disease).

¹⁸⁶ CONN. GEN. STAT. § 19a-583 (2010); DEL. CODE ANN. tit. 16, § 1203(a) (2012); FLA. STAT. § 381.004(2)(d)–(g) (2013); 410 ILL. COMP. STAT. 305/9 (2013); IOWA CODE § 141A.9 (2012); KY. REV. STAT. ANN. § 214.625(5) (West 2010); LA. REV. STAT. ANN. § 40:1300.14 (2010); ME. REV. STAT. tit. 5, § 19203 (2011); MASS. GEN. LAWS ch. 111, § 70F (2012); MONT. CODE ANN. § 50-16-1013 (2009); N.H. REV. STAT. ANN. §§ 141-F:7–8 (2013); N.M. STAT. ANN. § 24-2B-6 (2013); N.Y. PUB. HEALTH LAW § 2782 (McKinney 2011); OR. REV. STAT. §§ 433.045, 433.075 (2012); TEX. HEALTH & SAFETY CODE ANN. § 81.103 (West 2009); VA. CODE ANN. § 32.1-36.1 (1993); W. VA. CODE §§ 16-3C-1, 16-3C-3 (2011); WIS. STAT. § 252.15 (2012); DICKSON, *supra* note 22, at 48.

laws, comprehensive statutes designed to protect private medical information in general, and HIV-specific laws.¹⁸⁷ The disability laws build on the protections available in the ADA.¹⁸⁸ The comprehensive statutes “provide broad protections of health information acquired, collected, used, or disclosed within the state.”¹⁸⁹ HIV-specific laws provide protections for people with HIV explicitly. For instance, some states protect the confidentiality of HIV-related information specifically in the context of testing only.¹⁹⁰ Other states go further, protecting all HIV-related information from confidentiality breaches.¹⁹¹ Many states go as far as requiring a court order before most disclosure.¹⁹²

There are many reasons that states pass such laws. The Report of the Presidential Commission on the Human Immunodeficiency Virus Epidemic stated that

[a]s long as discrimination occurs, and no strong national policy with rapid and effective remedies against discrimination is established, individuals who are infected with HIV will be reluctant to come forward for testing, counseling, and care. This fear of potential discrimination . . . will undermine our efforts to contain the HIV epidemic and will leave HIV-infected individuals isolated and alone.¹⁹³

In other words, states pass HIV-specific laws to encourage HIV testing. States pass HIV-specific laws to encourage people with HIV to get counseling and health care. States pass HIV-specific laws to prevent HIV patients from becoming victims of stigma and discrimination. In doing so, states implicitly acknowledge that available federal protections are insufficient.

187 See Webber & Gostin, *supra* note 127, at 286–303 (surveying state law HIV privacy and nondiscrimination protections).

188 *Id.* at 296–97.

189 Gostin et al., *supra* note 127, at 293–94.

190 DEL. CODE ANN. tit. 16, § 1203(a) (2012); FLA. STAT. § 381.004(2) (2013); 410 ILL. COMP. STAT. 305/9 (2013); KY. REV. STAT. ANN. § 214.625(5) (West 2010); LA. REV. STAT. ANN. § 40:1300.14 (2010); ME. REV. STAT. tit. 5, § 19203 (2011); MASS. GEN. LAWS ch. 111, § 70F (2012); MONT. CODE ANN. § 50-16-1013 (2011); N.H. REV. STAT. ANN. §§ 141-F:7–8 (2013); N.M. STAT. ANN. § 24-2B-6 (2013); N.Y. PUB. HEALTH LAW § 2782 (McKinney 2011); OR. REV. STAT. §§ 433.045, 433.075 (2012); TEX. HEALTH & SAFETY CODE ANN. § 81.103 (West 2009); VA. CODE ANN. § 32.1-36.1 (1993); W. VA. CODE § 16-3C-1 (2011); WIS. STAT. § 252.15 (2012).

191 CONN. GEN. STAT. § 19a-583 (2010); MICH. COMP. LAWS § 333.5131 (2010); MO. REV. STAT. § 191.656 (2002); N.J. STAT. ANN. § 26:5C-7 (West 1990); OHIO REV. CODE ANN. § 3701.243 (West 2000); 35 PA. CONS. STAT. § 7607 (1990).

192 CONN. GEN. STAT. § 19a-583 (2010); IOWA CODE § 141A.9(2)(g) (2012); W. VA. CODE § 16-3C-3(a)(11) (2011).

193 S. REP. NO. 101-116, at 8 (1989) (quoting Report of the Presidential Commission on the Human Immunodeficiency Virus Epidemic 119 (1988)); H.R. REP. NO. 101-485, at 31 (1990).

There are only a few other areas of health-related information that get additional privacy protections in federal and state law. One such example is drug and alcohol rehabilitation programming run by the federal government.¹⁹⁴ These protections ensure anonymity for people with drug or alcohol addictions. Genetic information also gets additional privacy protection in the Genetic Information Non-discrimination Act of 2008 (“GINA”).¹⁹⁵ GINA ensures that any genetic information collected in relation to an individual’s diseases or proclivities for the purpose of research is not recorded with uniquely identifiable information.¹⁹⁶ Some other communicable diseases also get some limited additional privacy protections at the state level.¹⁹⁷ The explicit privacy protections for people with HIV are thus uncommon. It is one of just a few instances that legislators have singled out for additional confidentiality protections.

B. Stigma and the Need for Privacy

Though some state laws targeting people with HIV do provide the needed confidentiality guarantees, they do so at a price: contributing to the stigma associated with the disease. By singling out HIV as a disease in need of additional protection, legislators bring attention to negative perceptions about people with HIV. Treating the HIV-positive community as “different” reinforces the alienating stigma society already forces on people struggling with the disease.

Lawrence O. Gostin argues that some kinds of data are considered “super-confidential . . . leading to inconsistencies and unfairness.”¹⁹⁸ These super-confidential pieces of medical information receive a great deal of attention in legislatures, whereas other types of data get virtually no protection.¹⁹⁹ HIV status is one type of data treated as “super-confidential.”²⁰⁰ The protections provided to HIV specifically often also involve many exceptions. In fact, Gostin argues that the extent of the available exceptions will actually negate additional confidentiality provisions entirely.²⁰¹ Therefore the laws not only single out HIV as a disease in need of special attention, they also do not go far enough to genuinely protect the privacy of people with HIV. Gos-

194 Lawrence O. Gostin, *Health Information Privacy*, 80 CORNELL L. REV. 451, 503 (1995).

195 29 C.F.R. § 1635.9 (2012).

196 *Id.*

197 Gostin et al., *supra* note 127, at 293–94.

198 *Id.* at 294.

199 *Id.*

200 *Id.*

201 *Id.*

tin argues that disease-specific confidentiality statutes create inconsistencies, which both prevent patients from getting the necessary treatment and impede data collection efforts that would serve public health more broadly.²⁰² He writes that “[t]he creation of strict disease-specific standards so much restrains the dissemination of data in some systems that legitimate health goals are undermined, while other categories of data receive insufficient protection.”²⁰³

Furthermore, Gostin argues that the need for disease-specific protections relies on faulty assumptions.²⁰⁴ There are many other health conditions that have similar stigma and sensitivity surrounding them.²⁰⁵ Sexually transmitted diseases, drug and alcohol addictions, some genetic conditions, and mental illnesses all raise similar concerns to HIV. Protecting one of these and not others, according to Gostin, symbolizes a dangerous inconsistency.²⁰⁶ The diseases that are traditionally sensitive may not align with individual patients’ own perceptions.²⁰⁷ For instance, a patient with heart disease or diabetes may feel similarly uncomfortable and private about her illness as someone with HIV.²⁰⁸ Distinguishing between people with HIV and people with other illnesses also causes confusion for those who must actually implement the confidentiality restrictions. The need to treat someone with HIV’s medical records very differently from someone with tuberculosis’s medical records, for instance, creates layers of privacy requirements with which health care providers need to comply. This may make it more likely that a health worker will accidentally breach an HIV patient’s confidentiality—despite state laws designed to provide additional protections.

There are many concerns about treating HIV differently from other diseases—both for people with HIV and for those with other diseases. Laws protecting HIV confidentiality provide for people with HIV protections that people with other diseases do not have. For instance, an HIV-specific law might allow Anya and her family sufficient confidentiality protections to sue the school nurse and principal for improperly disclosing Anya’s HIV status. However, in so doing, Anya might cause the principal, nurse, and school to resent people with HIV specifically. Additional protections for just one disease turn that

202 Gostin, *supra* note 194, at 503.

203 *Id.*

204 *Id.* at 504.

205 *Id.* at 503–04.

206 *Id.*

207 *Id.*

208 *Id.*

disease into one that is more burdensome for school staff and administrators than others, therefore increasing prejudices against people and students with HIV. By requiring students and others to be treated differently because of their HIV statuses, HIV-specific privacy laws force HIV to be viewed differently from other diseases, exaggerating already-existing stigma by acknowledging the need for privacy.

Treating HIV as a disease that needs to be handled differently from others will not reduce stigma in the long run. It will only contribute to it. Until additional comprehensive protections exist that will guarantee privacy in health-related information for people with HIV, however, HIV-specific laws may be a flawed but necessary solution. In the following Part, this Comment proposes a better way to address health-related confidentiality that more comprehensively protects people with disease and illness from stigma and discrimination.

IV. THE FUTURE OF HIV CONFIDENTIALITY

Despite concerns about HIV-specific laws, it is still possible to provide sufficient privacy protections for people with HIV. There are available solutions that do not require people with HIV to be treated any differently from people with any other disease or illness.

First, federal and state privacy protections for health-related information can be strengthened. HIPAA and the ADA could remove some of their exceptions, ensuring broader privacy protections. For instance, the public health exception to HIPAA clearly provides for liberal privacy overrides in the name of public health.²⁰⁹ This broad mandate could be limited through either a greater emphasis on privacy in the law or a more restrictive definition of public health. The ADA exceptions—such as those allowing supervisors and managers to know about employees' disabilities²¹⁰—could also be clarified to reduce the likelihood of unnecessary and potentially stigmatizing disclosures.

Disease-specific lobbies could focus more intently on passing comprehensive privacy reforms, rather than disease-specific ones. Combining the efforts of powerful and well-funded lobbies—such as the breast cancer and HIV lobbies—with those with fewer resources—such as the tuberculosis lobby—would only increase the political influence of health-related privacy efforts as a whole. This could lead

²⁰⁹ See *supra* Part II.B.

²¹⁰ See *supra* Part II.C.

Congress to pass a law explicitly *designed* to provide privacy protections for health-related information in general. These federal laws could include provisions designed to address many of the concerns that the HIV-specific laws were intended to address—such as ensuring sufficient confidentiality to encourage people to get tested—but with a much broader reach. Not only would this take the emphasis off the highly stigmatized HIV, but it would also provide benefits in other contexts, encouraging breast cancer screenings or tests for other sexually transmitted diseases.

Second, the Supreme Court could re-imagine the constitutional right to privacy, reading into the Constitution stronger privacy protections for medical information. The balancing act adopted by the Court already places an emphasis on disclosures in the public interest, but does not define exactly what that means. A broader interpretation of what constitutes the public interest—one that would include the interests of the HIV-positive community—would result in a higher emphasis on confidentiality. For instance, by recognizing the public interest in reducing stigma around HIV and other illnesses, the Court could, within the current constitutional right to privacy, ensure confidentiality for people with HIV.

Third, research around the epidemiology of HIV and its interaction with stigma abounds. This creates great opportunity for reducing HIV-related stigma.²¹¹ As discussed throughout this Comment, there are many diseases that are linked to stigma. Epidemics such as cholera or the plague in previous centuries were similarly connected with low-income groups, multiplying the disease-associated stigma in much the same way that has occurred around HIV.²¹² However, Gregory Herek writes that HIV presents an opportunity that did not exist during those eras.²¹³ Today, there is significantly more data regarding what causes stigma and what its impact can be on public health.²¹⁴ These data can be narrowly tailored to incorporate considerations about stigma into attempts to reduce the spread of HIV and improve public health.²¹⁵ At the same time, more should be done to understand which stigma-reduction programs have been successful so that they can be replicated.²¹⁶ In part, this will mean dissecting the

211 Herek, *supra* note 18, at 1108–09.

212 *See id.* at 1108 (“[T]he AIDS epidemic has many parallels to older epidemics of cholera and plague.” (internal citations omitted)).

213 *Id.* at 1108–09.

214 *Id.*

215 *Id.*

216 Laura C. Nyblade, *Measuring HIV Stigma: Existing Knowledge and Gaps*, 11 PSYCHOL., HEALTH & MED. 335, 335 (2006).

layering inherent in HIV-related stigma to understand the causes and address them more directly.²¹⁷

Finally, there must be a greater emphasis on education about HIV within the United States and throughout the world. One of the largest contributing factors to HIV stigma is the lack of understanding about the disease.²¹⁸ Sexual education programs should be either instituted or expanded so that students get a more thorough understanding of how to mitigate the potential risks of sexual activity. Sexual education programs today emphasize the dangers of HIV in order to encourage the use of condoms and other barriers. However, these programs must take into account the modern realities of the disease. In fact, HIV transmission rates are much lower than sexual education programs suggest.²¹⁹ Sexual education programs should not present HIV as a death sentence. However, this is not enough. HIV education programs must also incorporate methods to reduce stigma around the disease. For instance, *Takalani Sesame* is the South African version of *Sesame Street*, a popular program on public television in the United States. One character on the South African show, a Muppet named Kami, is HIV-positive.²²⁰ Kami, who is named for the Tswana word for acceptance, is a “perky, fun-loving and healthy HIV-positive character with a wealth of information about HIV/AIDS to share with her inquisitive friends. . . . [She] will challenge the stereotype of the HIV-infected sickly child.”²²¹ Such efforts to reduce negative perceptions of people with HIV could make a big impact on reducing the stigma around the disease.²²²

There have been many times throughout history when stigma has attached itself particularly strongly to diseases.²²³ The difference between then and now? Now, we have more insight and information and can genuinely see the impact that stigma can have on public health.²²⁴ It is time to apply that knowledge.

217 *Id.* at 342.

218 Klein, *supra* note 54, at 610.

219 *Confused About HIV Transmission Statistics*, GO ASK ALICE! (Sept. 22, 2006), <http://goaskalice.columbia.edu/confused-about-hiv-transmission-statistics>.

220 Peter Hawthorne, *Positively Sesame Street*, TIME (Sept. 22, 2002), <http://www.time.com/time/magazine/article/0,9171,353521,00.html>.

221 *Id.*

222 *Id.*

223 *See, e.g.*, Herek, *supra* note 18, at 1108.

224 *Id.* at 1108–09.

CONCLUSION

Prior: This disease will be the end of many of us, but not nearly all, and the dead will be commemorated and will struggle on with the living, and we are not going away. We won't die secret deaths anymore. The world only spins forward. We will be citizens. The time has come.

Bye now.

You are fabulous creatures, each and every one.

And I bless you: More Life.

The Great Work Begins.

Tony Kushner, *Angels in America*²²⁵

The year 1990 marked the first performance of Tony Kushner's play, *Angels in America*.²²⁶ The work addresses the HIV epidemic in the late 1980s, looking at individuals touched by HIV from many walks of life.²²⁷ It follows *Prior*, a young gay man, as he is diagnosed with the disease, struggles with it both physically and emotionally, and ultimately accepts it.²²⁸

People with HIV have been stigmatized since the very beginning of the epidemic. However, as an HIV diagnosis becomes increasingly manageable, the need to reduce that stigma becomes more imminent. HIV-specific laws that increase privacy protections for people with HIV do reduce individual instances of discrimination and lead more people to get tested for the disease. However, this is not enough to reduce stigma around HIV. Protecting HIV confidentiality and encouraging HIV testing is undeniably in the public interest. But, by treating HIV differently from other diseases, legislators only perpetuate the public's fears about interacting with HIV-positive individuals. These laws are only temporary solutions to a broader problem. Discrimination around HIV will only be eradicated when stigma around the disease begins to evaporate. Fear of getting tested will not be mitigated until HIV stigma decreases significantly.

As we have seen, the best way to ensure privacy for people with HIV will be to provide comprehensive health-related confidentiality protections so as not to treat HIV as something taboo or worse than

225 TONY KUSHNER, *ANGELS IN AMERICA: A GAY FANTASIA ON NATIONAL THEMES* 280 (2003).

226 *See generally id.*

227 *See generally id.*

228 *See generally id.*

other illnesses. From a public health and perception perspective, changing the way people understand HIV will go a long way toward reducing stigma associated with the disease.

[N]o policy or law can alone combat HIV/AIDS related discrimination. Stigma and discrimination will continue to exist so long as societies as a whole have a poor understanding of HIV and AIDS and the pain and suffering caused by negative attitudes and discriminatory practices. The fear and prejudice that lie at the core of the HIV/AIDS-related discrimination need to be tackled at the community and national levels, with AIDS education playing a crucial role. A more enabling environment needs to be created to increase the visibility of people with HIV/AIDS as a 'normal' part of any society.²²⁹

This is what we need: an understanding that HIV is just another disease. Those suffering from it are no different from anyone else and should not be treated as though they are. Legal change and creative educational efforts can begin to make such a reality.

²²⁹ *HIV & AIDS Stigma and Discrimination*, *supra* note 110.