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**COMPLICATED LIVES: A LOOK INTO THE
EXPERIENCES OF INDIVIDUALS LIVING WITH
HIV, LEGAL IMPEDIMENTS, AND OTHER
SOCIAL DETERMINANTS OF HEALTH**

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Abstract

Those living with HIV continue to have challenges that extend well beyond their medical needs. Public misconceptions surrounding HIV transmission and treatment have resulted in systemic and pervasive discrimination against those living with the disease. Common misconceptions include overly optimistic perceptions of the modern state of medical treatment, leading the uninformed to conclude that people living with HIV are minimally impacted by the disease, and misunderstandings regarding how the disease is transmitted from person-to-person, leading to stigma and social prejudice.

Because of these misconceptions, three professors from the University of Massachusetts Dartmouth formed a community partnership to determine the unmet needs of individuals living with HIV in the Southcoast region of Massachusetts. The team used the social determinants of health as its framework for conducting a community assessment. The goal of the study was to uncover factors preventing individuals living with HIV from attaining optimal health outcomes.

The study addressed the concerns of those living with HIV in Southcoast, Massachusetts. However, the barriers faced by those living with HIV in Southcoast mirror difficulties faced by those in other areas of the country in fundamental ways. This study and others reveal that the social determinants of health influence the quality of life experienced by those living with HIV as much as the condition itself. Out of this study developed the University of Massachusetts School of Law Human Rights at Home Clinic which provides services to low income residents of Southcoast Massachusetts with an interest in serving people living with HIV or AIDS and others experiencing stigma. The implementation of the clinic and its work is not the subject of this article, but its ongoing community activism informs the article's discussion.

Part I describes the study partnerships as well as the study processes. Part II addresses legal and other stressors on those living with HIV that impact many HIV positive individuals locally and across the country. Part III includes a discussion of the study results and the ongoing needs of those living with HIV with a focus on transportation.

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I. Introduction

Sherry was her most-confident self before she was diagnosed with HIV.¹ She was twenty-eight years old and living on her own. Although considered lower-middle class, Sherry was able to support herself independently in a one-bedroom apartment. She was able to save at least thirty dollars each week and was in a romantic relationship in which she felt confidently in. Sherry was offered a job that would put her on a defined career path. The offer, however, was subject to a background check and medical examination.

Sherry lived her entire life on the Southcoast of Massachusetts. She was raised Catholic, but had not practiced in years, much to her parents' disappointment. Her relationship before Doug, her current partner, was with a transsexual woman. Shortly before her diagnosis, Sherry told Doug about her prior partner. Doug responded by throwing a vase into a wall, leaving her apartment, and not returning for a week. After his return, he began monitoring Sherry's whereabouts while expressing his new distrust of her. Now, Sherry does not want to disclose her HIV diagnosis to Doug because she wants him to stay with her. Sherry also does not trust Doug to keep her diagnosis confidential. Additionally, Sherry suspects that Doug is having sex outside of their relationship.

Sherry has never injected drugs, so the diagnosis was shocking. She was tested for HIV because she was symptomatic. Since she was diagnosed, she has been depressed although the doctor assured her that she is likely to live a long life due to highly effective treatment.

Sherry declined the job offer because of the medical examination requirement. She is in fear of being exposed at work because the human resources department has been questioning her recent medical bills. Fearful of prospective layoffs, Sherry worries that if she loses her job, she may have to move in with her parents if Doug won't let her live with him. If Sherry's parents learn of her diagnosis, they will be ashamed. Sherry would like to see a specialist in Boston, but the cost of transportation and co-pays will quickly deplete her savings.

Accordingly, Sherry has made a list of her options; it includes suicide.

¹ This scenario is a composite of information received during the authors' investigation.

Living with HIV has challenges beyond affordable and adequate medical care. While tending to physical health is a priority among those living with HIV, there are also societal factors that are disproportionately burdensome. Opposing cultural norms are based upon stereotypes that thrive in many communities. Among the stereotypes are that a man living with HIV has sex with men, or that anyone living with HIV is a heroin addict; that given health care advances, those living with HIV face no greater health risks than the general population; that HIV can be transmitted in casual non-sexual social encounters. These stereotypes attach themselves to people living with HIV and challenge their lives in explicit and subtle ways.

HIV is both ignored and demonized by the general public; many are under the impression that HIV is no longer a medical concern, while others discriminate against those living with HIV and remain fearful of being infected. The result of such misunderstanding is the ongoing discrimination against individuals diagnosed with HIV.

While it is true that many individuals are able to live long lives due to available HIV treatment, this ability does not mean their lives are necessarily “normal.” Due to the need for continuing medical treatment, the discrimination against individuals diagnosed with HIV, and for many, problems created by poverty, the lives of those living with HIV can be very problematic.

Aware of the concerns of those living with HIV, three professors from the University of Massachusetts Dartmouth (the Team) investigated the needs of those living with HIV in the Southcoast Massachusetts area.² The study focused on the area’s two main cities, Fall River and New Bedford. These cities have struggled economically, particularly since the decline of manufacturing in the area. Many residents have modest resources but most are poor. For various reasons, including an increase in opioid use, both cities have experienced increases in HIV infections in this decade.

The study must be reviewed in its proper context, lest its findings be seen as incomplete. Awareness of the other stressors in the lives of those living with HIV is crucial to comprehending the overt and subtle pressures they face as a part of their daily life. For this reason,

² The Team is comprised of the authors of this article.

three common stressors which are present in the lives of those living with HIV are examined in this article. The first is the presence or threat of violence in intimate relationships where at least one partner is HIV positive. Second, the ever-present threat of arrest due to HIV-positive status. While not all states criminalize sex and other behaviors without disclosing HIV status, criminalization is common, and most jurisdictions have laws that single out those living with HIV.³ Third, is the breach of confidentiality and resulting stigma that remains despite medical advances and limited ways in which the HIV virus can be transmitted. While poverty complicates the lives of impoverished individuals living with HIV, intimate partner abuse, criminalization, and breach of confidentiality impact those of all socio-economic statuses.

II. The Cities of Southcoast Massachusetts

A. Background

National perception could make one believe that HIV prevention and treatment has removed the disease from crisis status.⁴ However, this is not true in many regions of the country, and certainly not true in the cities of New Bedford and Fall River, Massachusetts. New Bedford and Fall River, two diverse and economically challenged cities located in the Southcoast region of Massachusetts, bear a significant burden of the HIV infections in the Commonwealth. People living with HIV/AIDS in New Bedford and Fall River require culturally specific resources, such as sensitivity to individuals' ethnic and religious backgrounds and sexual identities, and access to healthcare to prevent the advancement of the HIV disease and HIV-related co-morbidities. However, more information is needed about what the culturally specific needs are in these communities and how those needs could be met.⁵

³ HIV and STD Criminal Laws CTNS. FOR DISEASE CONTROL & PREVENTION (July, 2019), <https://www.cdc.gov/hiv/policies/law/states/exposure.html>.

⁴ Office of Disease Prevention & Health Promotion, *HIV, HEALTHY PEOPLE 2020*, <https://www.healthypeople.gov/2020/topics-objectives/topic/hiv> (last visited Jan. 12, 2020).

⁵ Caitlin Stover, Margaret Drew et al., *You Can't Get There From Here*, 2 J. OF NURSING & HEALTHCARE (2017) (this introduction, and a portion of the background section, reflect in

1. Profiles of New Bedford and Fall River at the Time of the Study and Since.

The area has a fascinating – yet notorious – history. New Bedford was home to Frederick Douglass for three years when he first escaped slavery in 1838.⁶ It was home to many abolitionists as well as a stop on the Underground Railroad.⁷ New Bedford remains a robust fishing port even long after its representation in Herman Melville’s novel, *Moby Dick*.⁸ Fall River was home to Lizzie Borden, whose house remains one of the area’s tourist attractions.⁹ Both cities offer well-regarded ethnic culinary fare, particularly from the Portuguese culture, with Emeril Lagasse hailing from Fall River.¹⁰ Today, however, most of the formerly-thriving textile mills have shut down leaving the cities to struggle with job scarcity and poverty.

New Bedford and Fall River, cities of comparable population,¹¹ are located south of Boston, fourteen miles from each other. The City of New Bedford is located approximately sixty miles south of Boston and thirty miles east of Providence, Rhode Island.¹² The City of Fall River is located about fifty miles southwest of Boston and twenty miles east of Providence.¹³ There is limited public transportation

part the authors’ prior work regarding the study of services and resources for HIV-Positive Individuals in The Southcoast of Massachusetts).

⁶ New Bedford Historical Society, *Frederick Douglass*, <http://nbhistoricalsociety.org/Important-Figures/frederick-douglass/> (last visited Jan. 12, 2020).

⁷ See Auditi Guha, *New Bedford an Important Stop on the Underground Railroad*, SOUTHCOAST TODAY (Feb 12, 2015), <https://www.southcoasttoday.com/article/20150212/NEWS/150219689>.

⁸ Malerie Yolen-Cohen, *New Bedford, MA: A Working Port with Literary, Culinary, And Historic Appeal*, GETAWAY MAVENS (Dec. 2019) www.getawaymavens.com/visit-new-bedford-ma/.

⁹ Alyson Horrocks, *The Lizzie Borden House Tour the Macabre*, New England Today Travel (Aug. 29, 2019), <https://newengland.com/today/travel/massachusetts/lizzie-borden-house/>.

¹⁰ *Emeril Lagasse*, BIOGRAPHY (Jul. 24, 2019), <https://www.biography.com/personality/emiril-lagasse>.

¹¹ U. S. CENSUS BUREAU, QUICKFACTS: FALL RIVER AND NEW BEDFORD (2019) [hereinafter FALL RIVER AND NEW BEDFORD CENSUS DATA] (According to the National Census, New Bedford’s population is approximately 95,000 people while Fall River is a city of just over 88,500 individuals).

¹² MASS. DEP’T PUB. HEALTH, A PROFILE OF HEALTH AMONG MASSACHUSETTS ADULTS IN SELECTED CITIES, 2008: RESULTS FROM THE BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM (OCTOBER, 2009) [hereinafter 2008 PROFILE].

¹³ *Id.*

linking either Fall River or New Bedford to the state's capital;¹⁴ the public transportation linking one city to the other is inadequate as well.

These communities rank as two of Massachusetts's poorest cities or towns. According to U.S. Census data from 2009 to 2013, the median household income in New Bedford was \$35,999, significantly lower than the state average of \$66,866.¹⁵ More recent data, show the median income has risen to \$43,989¹⁶ as of 2018 but remains far behind the current state median income of \$79,835.¹⁷ Indeed, almost a quarter of New Bedford's population lives below the federal poverty level, which is almost double the state rate.¹⁸ Per capita income in Fall River is similar to that of New Bedford, according to census data.¹⁹ Median household income in Fall River is \$33,211.²⁰ Current, non-census, data indicates the median income has risen by several thousand dollars,²¹ however, Fall River remains far behind the state median income.²² Approximately twenty-three percent of Fall River residents live in poverty.²³

Fall River and New Bedford both face a significantly lower percentage of individuals ages twenty-five or older who are high school graduates, compared to the rest of the state.²⁴ "New Bedford faces a significant dropout rate, resulting in only fifty-five percent of high school students graduating and nearly one-fourth (23%) of students dropping out within four years of beginning high school."²⁵

¹⁴ Stover, *supra* note 5, at 3.

¹⁵ FALL RIVER AND NEW BEDFORD CENSUS DATA, *supra* note 11.

¹⁶ *Id.*

¹⁷ *Id.*

¹⁸ FALL RIVER AND NEW BEDFORD CENSUS DATA, *supra* note 11. (23.5% v. 11.9% respectively).

¹⁹ *Id.* (The per capita income in New Bedford during the twelve months preceding the study was \$21,056 v. \$35,763. In Fall River, per capita income is \$21,257).

²⁰ *Id.*

²¹ CITY-DATA, Fall River, Massachusetts, <http://www.city-data.com/city/Fall-River-Massachusetts.html#b> (lists current median income at \$43,235).

²² *Id.* (the 2016 median income for Massachusetts was \$75,297)

²³ *Id.* (23.3 % of Fall River residents live in poverty).

²⁴ FALL RIVER AND NEW BEDFORD CENSUS DATA, *supra* note 11. (70.3% Fall River; 70.5% New Bedford; 89.4% Massachusetts total).

²⁵ Michel Beradino, *Latinos in Massachusetts Public Schools: Fall River*, GASTÓN INSTITUTE PUBLICATIONS (2013), http://scholarworks.umb.edu/gaston_pubs/183/.

In Fall River, the data is not as dismal but remains bleak.²⁶ To the extent that at risk youth are more vulnerable to opioid use, Fall River and New Bedford have significant at-risk young population.

According to 2010 census data, New Bedford is more racially and ethnically diverse than Massachusetts overall, while Fall River is less diverse.²⁷ The presumption is that influx of various ethnicities creates much of the diversity, as the African American population of Fall River and New Bedford was low at the time of the study.^{28,29} By 2019, the percentage had declined for both cities.³⁰ Still, the data indicates that throughout this past decade, New Bedford's population is more racially and ethnically diverse than Fall River's.³¹ Unlike other areas of the country, such as the Southern U.S., where African Americans account for a significant increase in HIV diagnosis,³² the Southcoast area with its small population had increases in HIV diagnosis with no

²⁶ *Id.* (Only 69% of students graduate and 18% drop out within four years of beginning high school, far below the state graduation rate (85%) and far above the state dropout rate (7%)).

²⁷ *Id.* (In New Bedford 74.5% v. 80.4% identifying as white and in Fall River 87% identify as white.)

²⁸ FALL RIVER AND NEW BEDFORD CENSUS DATA, *supra* note 11. (African American population of Fall River was 3.9% at the time of the study).

²⁹ *Id.* (The African American population of New Bedford was 8.6 % at the time of the study).

³⁰ Population Demographics for Fall River, Massachusetts in 2019, 2018, SUBURBAN STATS, <https://suburbanstats.org/population/massachusetts/how-many-people-live-in-fall-river> (Fall River's African American population dropped to 3%); *Current New Bedford, Massachusetts Population, Demographics and stats in 2019, 2018*, SUBURBAN STATS, <https://suburbanstats.org/population/massachusetts/how-many-people-live-in-new-bedford> (last visited July 30, 2019) (The African American population of New Bedford dropped to 6%).

³¹ *Id.* (New Bedford has almost double the percentage of people who identify as Hispanic or Latino than Massachusetts overall (16.7% v. 9.6%), and more than double the percentage of people who identify as multi-racial (defined as two or more races) than Massachusetts overall (5.7% v. 2.6%); *See also* WALLETHUB, *Most Diverse Cities in the U.S.*, <https://wallethub.com/edu/most-diverse-cities/12690/#size> (Fall River has a significantly lower percentage of residents who identify as Black or African-American than Massachusetts overall (3.9% v. 6.4%), and a much lower percentage of Hispanics or Latinos than New Bedford (7.4% v. 16.7%)).

³² Madeline Y. Sutton et al., *Social Determinants of HIV Disparities in the Southern United States and in Counties with Historically Black Colleges and Universities* (2012-2014) <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0170714>; *see generally* HIV and African Americans, CNTR. FOR DISEASE CONTROL AND PREVENTION, <https://www.cdc.gov/hiv/group/raciaethnic/africanamericans/index.html> (Last visited Jan. 12, 2020).

significant correlation to race, other than significantly higher rates of addiction among Caucasians.³³

There is significant health disparities between residents of the Southcoast area and Massachusetts residents around the state. In a comprehensive 2008 survey by Massachusetts' Department of Health and Human Services (HHS), HHS found that adults in Fall River are significantly "more likely to report fair or poor health than adults living in Massachusetts overall."³⁴ The report also found Fall River residents are "more likely to report that they could not see a doctor due to [medical] cost during the past twelve months than adults in Massachusetts overall."³⁵ Accordingly, between 2000 and 2008,³⁶ the rate of adults tested in Fall River for HIV decreased.³⁷ Adults residing within the coverage area of the Greater New Bedford Community Health Network were almost twice as likely to report having no health insurance coverage compared to Massachusetts residents in general.³⁸ This is reflected in the most recent census data.³⁹ Unmistakably, residents of these two communities face exceptional challenges in accessing healthcare services⁴⁰ and it was this data which alerted the Team of the necessity to examine healthcare access for marginalized members of the two cities.

³³ *HIV/AIDS Epidemiologic Profile Detailed Data Tables, 9–12*, MASSACHUSETTS DEP'T. OF PUBLIC HEALTH, BUREAU OF INFECTIOUS DISEASE AND LABORATORY SCIENCES (2019). See also *2018 Massachusetts HIV/AIDS Epidemiologic Profile Detailed Data Tables and Technical Notes: The Massachusetts HIV/AIDS Epidemic at a Glance, 7–9, 20*, MASSACHUSETTS DEP'T. OF PUB. HEALTH, BUREAU OF INFECTIOUS DISEASE AND LABORATORY SCIENCES (2018).

³⁴ *2008 Profile*, *supra* note 9, at 15. (23% v 12%).

³⁵ *Id.* (10% v 6%).

³⁶ *Id.* Adults defined as between ages eighteen and sixty-four.

³⁷ *Id.*

³⁸ *Id.* at 17 (Adults living in New Bedford were more likely to report not having health insurance (11%) than were adults living in Massachusetts overall (3%.)

³⁹ FALL RIVER AND NEW BEDFORD CENSUS DATA, *supra* note 11. (6.6% Fall River; 8.1% New Bedford; 4.3% Massachusetts overall).

⁴⁰ Timeline: History of Health Reform in the U.S., THE HENRY J. KAISER FAMILY FOUNDATION <https://kaiserfamilyfoundation.files.wordpress.com/2011/03/5-02-13-history-of-health-reform.pdf> (last visited Jan. 13, 2020). (We recognize that statistics of the population who are uninsured may seem low when compared with other regions. Massachusetts implemented "universal" health care in 2006 while other states were not required to implement universally available care until 2014.); See generally Richard Cauchi, State Actions to Address Health Insurance Exchanges, NAT'L. CONFERENCE OF STATE LEGISLATURES (Aug. 13, 2015).

2. HIV/AIDS in New Bedford and Fall River

The Massachusetts Department of Health and Human Services, Office of HIV/AIDS refers to Fall River and New Bedford as two areas of “significant concern” in the fight against HIV in the Commonwealth.⁴¹

From 2009 to 2011, New Bedford annually reported a higher average HIV diagnosis rate per 100,000 residents than the Massachusetts total.⁴² By the end of 2012, the city averaged twice the HIV/AIDS prevalence rate than the Massachusetts total.⁴³ Of these statistics, minorities in New Bedford bear a significant burden. From 2009-2011, non-white individuals accounted for fifty percent of new infections in New Bedford, however, as of December 31, 2012, over fifty percent of people living with HIV/AIDS were non-white.⁴⁴

Infections attributed to men having sex with men (MSM) comprise of a significant percentage of HIV infections in New Bedford.⁴⁵ HIV infections traceable to injection drug use (IDU) are also pervasive in New Bedford; from 2009 to 2011, seventeen percent of new infections were attributed to injection drug use (IDU), giving the city the second highest percentage of HIV infections attributed to intravenous drug use in the Commonwealth.⁴⁶ As of December 31, 2012, it was reported that forty-one percent of people living with HIV in New Bedford were exposed to the HIV virus through injection drug use;⁴⁷ the highest percentage of people living with HIV in the Commonwealth whose infections were attributed to IDU,⁴⁸

⁴¹ *SouthcoastHealth 2016 Community Needs Assessment*, UMASS DARTMOUTH PUB. POLICY CENTER (2016), <https://www.southcoast.org/wp-content/uploads/2019/05/South-Coast-CHNA-2016-Final.pdf> (last visited July 30, 2019).

⁴² *Regional HIV/AIDS Epidemiologic Profile of New Bedford, Massachusetts: 2013*, MASS. DEP'T PUB. HEALTH, at 2 (2013), <http://www.mass.gov/eohhs/docs/dph/aids/2013-profiles/city-new-bedford.pdf> (hereinafter NEW BEDFORD EPIDEMIOLOGIC PROFILE) (12.6, n=12; 10.3, n=664.7) (This data is based on a June, 2015 release and is the most recent information available at the time of this writing).

⁴³ *Id.* (488.1, n=464; 277.5, n=18,170).

⁴⁴ *Id.* White (non-Hispanic) individuals comprise 50 percent of new HIV infections.

⁴⁵ *Id.* (36%).

⁴⁶ *Id.* at 4 (n=6).

⁴⁷ NEW BEDFORD EPIDEMIOLOGIC PROFILE, *supra* note 33, at 4.

⁴⁸ *Id.*

surpassing three other diverse and economically challenged cities in the Commonwealth: Springfield,⁴⁹ Worcester,⁵⁰ and Lawrence.⁵¹

From 2009 to 2011, Fall River reported the highest percentage of HIV rate through injection drug use at twenty-two percent, and New Bedford reported the third highest at seventeen percent.⁵² From 2010 to 2012, Fall River had the state's second-highest rate of HIV infection in people between the ages of thirteen to twenty-four at twenty-five percent.⁵³ In Fall River, the data indicated a dramatic increase in the number of infections among men who have sex with men at fifty percent, affording the city one of the highest rates of infection among MSM in the state.⁵⁴

While some improvement has been recorded, data from 2015 places New Bedford and Fall River on the list of the top 15 cities and towns in Massachusetts for rates of new infection and number of residents living with HIV/AIDS.⁵⁵

B. Additional Population Diversity

The cities are home to substantial immigrant communities, of which, home those whom have valid legal status and those whom remain undocumented. Historically, the dominant immigrant

⁴⁹ Regional HIV/AIDS Epidemiologic Profile of Springfield, Massachusetts: 2013, MASS. DEP'T OF PUB. HEALTH 4 (2013), <http://www.mass.gov/eohhs/docs/dph/aids/2013-profiles/city-springfield.pdf> (As of 2013, As of the date of this study, the only city/town in Massachusetts reporting a higher rate of exposure to HIV through IDU is the City of Springfield, which reported that 18 percent of new infections from 2009-2011 resulted from exposure through IDU).

⁵⁰ *Regional HIV/AIDS Epidemiologic Profile of Worcester, Massachusetts: 2013*, MASS. DEP'T PUB. HEALTH, 4 (2013), <http://www.mass.gov/eohhs/docs/dph/aids/2013-profiles/city-worcester.pdf>.

⁵¹ *Regional HIV/AIDS Epidemiologic Profile of Lawrence, Massachusetts: 2013*, MASS. DEP'T PUB. HEALTH 4 (2013) at 4, <http://www.mass.gov/eohhs/docs/dph/aids/2013-profiles/city-lawrence.pdf> (25%, n=105).

⁵² *Massachusetts HIV/AIDS Epidemiologic Profile Men Who Have Sex with Men*, MASS. DEP'T OF PUB. HEALTH, <https://www.mass.gov/lists/hivaids-epidemiologic-profiles> (last visited Aug. 5, 2019).

⁵³ *Id.*

⁵⁴ *Id.*

⁵⁵ Commonwealth of Massachusetts Department of Public Health, *Massachusetts HIV/AIDS Epidemiologic Profile*, Table 1. <https://www.mass.gov/files/documents/2018/03/15/geographic-distribution.docx>. (Additional data has been released on the number and rates of new infections. For 2013-2015, New Bedford ranked number 8 and Fall River number 11).

population in these areas has been Portuguese.⁵⁶ Portuguese immigrants began arriving in significant numbers in the late 19th century.^{57, 58} Immigrants arrived from mainland Portugal, and in significant numbers from its territories of Madeira, Cape Verde and Azores. New Bedford claims the largest Portuguese population outside of the home country; and annually New Bedford hosts the largest Portuguese feast in the world.⁵⁹ Given the large immigrant population, the area is known as “Little Portugal.”⁶⁰ With an increasing Cape Verdean population, New Bedford held in July 2019 a Cape Verdean Recognition parade.⁶¹

In recent years the cities have seen influxes of individuals from a variety of other nations, including Haiti and Guatemala.⁶² Brazilians have started making their way to Fall River and New Bedford. There is a significant Hmong population as well,⁶³ with many immigrants not speaking English. There is a significant Spanish speaking

⁵⁶ Benjamin Bailey, *History and Description of Portuguese Immigration and the East Providence/SE New England Portuguese Community*, THE SELECTED WORKS OF BENJAMIN BAILEY (2000) (http://works.bepress.com/benjamin_bailey/63).

⁵⁷ *Id* at 1.

⁵⁸ Lisa Maya Knauer, *The Maya of New Bedford: Genesis and Evolution of a Community, 1980-2010*, 39 HISTORICAL JOURNAL OF MASSACHUSETTS, 170, 197 (2011) (While many long-time New Bedford residents voiced concern about the Central Americans, they are not the only newcomers. There is a sizeable (and also largely undocumented) Brazilian immigrant population in southeastern Massachusetts).

⁵⁹ *Who We Are*, NEW BEDFORD DAY OF PORTUGAL, <http://www.nb-dayofportugal.com/festival> (last visited Sept. 8, 2015) (Today, New Bedford has the largest percentage of Portuguese population in the United States—more than 59% of the population of New Bedford claims Portuguese ancestry); *See also Feast History*, Feast of the Blessed Sacrament, <http://feastoftheblessedsacramentcom.ning.com/feast-history>.

⁶⁰ Ric Oliveira, *Azoreans Celebrate a Successful Quest*, SOUTHCOAST TODAY (Jan. 10, 2011), <http://www.SouthCoasttoday.com/article/19960225/News/302259995>.

⁶¹ *Photos: Cape Verdean Recognition Parade, New Bedford 2019*, SOUTHCOAST TODAY (July 6, 2019), <https://www.southcoasttoday.com/photogallery/NB/20190706/NEWS/706009998/PH/1>.

⁶² Simon Rios, *Harrowing Journey Ends in New Bedford for Guatemalan Teen*, SOUTHCOAST TODAY (Jul. 13, 2014), <http://www.southcoasttoday.com/article/20140713/NEWS/407130303>. *See also Jack Spillane: Haitian Emigres Hope Island Residents Can Create Stable Future*, SOUTHCOAST TODAY (Jan. 17, 2010), <http://www.southcoasttoday.com/article/20100117/NEWS/1170348/101061/ARCHIVE>.

⁶³ *The State of the Hmong American Community 2013*, U.S. CENSUS REPORT (2013), <http://aapidata.com/wp-content/uploads/2017/04/State-of-the-Hmong-American-Community-2013.pdf>.

population among immigrants and non-immigrants.⁶⁴ The report noted in 2013 that Latinos were increasing in population within the New Bedford public schools, compared with the shrinking white and black populations.⁶⁵ A 2018 newspaper account reported increases in people of color in Fall River, and Puerto Rican residents as well.⁶⁶ Not surprisingly, both groups reported facing bias from some local residents, a situation not unique to the Southcoast.⁶⁷ Dealing with bias adds additional stress to the population of those living with HIV. The African-American population, in particular, is disproportionately at-risk for the HIV infection,⁶⁸ as well as Puerto Rican communities.⁶⁹ Undocumented immigrants face additional difficulties in accessing treatment, particularly since receipt of public benefits, such a state provided healthcare, is now an impediment to receiving legal status.⁷⁰

Given the significant Spanish speaking and Portuguese populations, it is not surprising that Catholicism⁷¹ has a strong presence in the New Bedford and Fall River area, particularly when considered in conjunction with a significant area population of those whose heritage is Irish.⁷² Fall River is the center of the Catholic

⁶⁴ Phillip Granberry et al., *Latinos in Massachusetts Selected Areas: New Bedford*, GASTÓN INSTITUTE PUBLICATIONS, Paper 173 (2001) (The area is home to a growing Puerto Rican community, as well).

⁶⁵ Beradino, *supra* note 25, at 3.

⁶⁶ Marc Monroe Dion, *The Immigrant Experience: Fall River*, SOUTHCOAST TODAY, (June 18, 2018). <https://www.southcoasttoday.com/news/20180618/immigrant-experience-fall-river>.

⁶⁷ *Id.*

⁶⁸ *HIV and African Americans*, CNTRS. FOR DISEASE CONTROL AND PREVENTION (Sep. 9, 2019), <https://www.cdc.gov/hiv/group/raciaethnic/africanamericans/index.html>.

⁶⁹ Kristen Mahle Gray et al., *Diagnoses and Prevalence of HIV Infection Among Hispanics or Latinos — United States, 2008–2013*, 64 MORBIDITY AND MORTALITY WEEKLY REPORT (Oct. 9, 2015), <https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6439a2.htm>.

⁷⁰ Franco Ordonez, *Trump Administration To Deny Green Cards To Immigrants Receiving Public Benefits*, NPR (Aug. 12, 2019), <https://www.npr.org/2019/08/12/750577638/trump-administration-to-deny-green-cards-to-immigrants-who-use-public-benefits>.

⁷¹ *Religion Statistics for New Bedford City*, CITY-DATA, (Jan. 14, 2020) <http://www.city-data.com/city/New-Bedford-Massachusetts.html>; Matt Apuzzo, *AIDS Cases on the Rise Among Women*, SOUTH COAST TODAY (Jan. 12, 2011), <https://www.southcoasttoday.com/article/20020821/News/308219995>.

⁷² See Jack Spillane, *City's Irish Boast Proud, Storied History*, SOUTHCOAST TODAY (Jan. 12, 2011), <https://www.southcoasttoday.com/article/20020316/news/303169997>.

diocese in which it is located.⁷³ Other religious affiliations are evidenced in the area, including Baptist, Jewish, and Presbyterian. Faith based organizations play an important role in serving the Southcoast poor,⁷⁴ enhancing the need to consider faith affiliations when providing culturally specific services.

The immigrant population in New Bedford accounts for a large portion of its work force. Due to the loss of manufacturing work in the area, the community is facing a significant economic decline.⁷⁵ In addition to economic decline and rising medical costs, the culture in New Bedford discourages the disclosure of a family member battling addiction, or an HIV infection, making it very difficult for individuals living with HIV to seek appropriate help.⁷⁶

C. The Commercial Fishing Industry

One industry surviving the economic downturn in New Bedford is commercial fishing.⁷⁷ Commercial fishermen make up a significant portion of the cities' workforce.⁷⁸ New Bedford is known as a world-class fishing region; its port maintains its position as the largest U.S. fishing port.⁷⁹ Interestingly, the fishing industry contributes to the

⁷³ *Diocesan Map*, DIOCESE OF FALL RIVER (last visited July 30, 2019), <http://www.fallriverdiocese.org/dfir-today/>.

⁷⁴ E.g. Debra Ryan, *Mobile Ministries Feeds the Poor*, SOUTHCOAST TODAY (Oct. 13, 2018), <https://www.southcoasttoday.com/entertainmentlife/20181013/mobile-ministries-feeds-poor>.

⁷⁵ See Robert E. Weir, *WORKERS IN AMERICA: A HISTORICAL ENCYCLOPEDIA*, 536 (ABC-CLIO, 2013).

⁷⁶ Angela Wangari Walter et al., *Preventing Opioid Use Disorders Among Fishing Industry Workers*, 15 INT. J. ENVIRON. RES. PUBLIC HEALTH, 648, 654 (2018).

⁷⁷ See John Dyer, *Scallops: Giving New Bedford Fishermen a Welcome Break*, BOSTON GLOBE (Dec. 1, 2013), <https://www.bostonglobe.com/business/2013/12/01/scallops-bringing-decent-living-new-bedford-fishermen/P9WxPWhm05vYN5xaBSZY8I/story.html>.

⁷⁸ *Executive Summary- Harbor Study: New Bedford, Massachusetts*, NEW BEDFORD HARBOR DEVELOPMENT COMMISSION (2005), <http://www.portofnewbedford.org/documents/New%20Bedford%20Harbor%20Study%20-%20Executive%20Summary%2005-01-09.pdf>

(The New Bedford port economy today is quite diverse, with a mix of commercial and recreational use. Fishing and seafood processing are by far the dominant employers and their presence defines much of the harbor's character).

⁷⁹ *NOAA Report Finds 2013 U.S. Seafood Landings and Value Increased From 2012*, NAT'L. OCEANIC AND ATMOSPHERIC ADMIN (Oct. 29, 2014), <https://www.noaa.gov/media-release/noaa-report-finds-2013-us-seafood-landings-and-value-increased-over-2012>. See also, Bonner supra note 8.

area's drug epidemic.⁸⁰ The industry demands long periods of time away from family; fishermen with and without children, experience problems with IDU.⁸¹ Upon return to port, the fishermen are paid significant wages from the trip.⁸² This large influx of money lends itself to the excessive consumption of drugs, particularly for those with pre-existing addictions.⁸³ Heroin use is reported to be an area of concern in coastal communities and in particular in the fishing industry.⁸⁴ Additionally, evidence shows the use of heroin among fishermen often has an intergenerational component.⁸⁵ The workers can be away from port for weeks, if not months, at a time.⁸⁶ Children of those in the industry can be left without adequate supervision for long periods of time, contributing to their substance misuse.⁸⁷

In March 2016, federal agents made four arrests for opiates when they raided eleven boats at the New Bedford waterfront.⁸⁸ Six of

⁸⁰ See NATIONAL DRUG ASSESSMENT CENTER, *Heroin Use in the Northeast: A Regional Drug Threat Assessment* (Jan. 15, 2020), <https://www.justice.gov/archive/ndic/pubs5/5787/5787p.pdf>. (federal, state, and local law enforcement officials, particularly in Maine, Massachusetts, New Hampshire, and Rhode Island report that heroin and other opiate abuse by crew members aboard commercial fishing vessels is increasing. Federal and local law enforcement officials in Massachusetts report that approximately 175 of the 200 fishing vessels in the Gloucester fleet (approximately 36 miles northeast of Boston) are operated by captains or crews who abuse heroin. Injection is the primary method of administration for most of these abusers, and many had fathers and grandfathers who also worked aboard commercial fishing vessels and abused heroin. Law enforcement officials in these areas attribute the high number of accidents and injuries in this industry, at least in part, to individuals performing their duties while under the influence of heroin or other opiates).

⁸¹ Ric Oliveira, *Fishing's Deadly Dark Side*, SOUTHCOST TODAY (Mar. 12, 2007), <http://www.southcoasttoday.com/article/19960714/News/70312047>.

⁸² *Id.* at 9. (Wages for as much as \$4,500 is not unusual).

⁸³ *Id.*

⁸⁴ Katharine Q. Seelye, *Massachusetts Chief's Tack in Drug War: Steer Addicts to Rehab, Not Jail*, N.Y. TIMES (Jan. 24, 2016), <https://www.nytimes.com/2016/01/25/us/massachusetts-chiefs-tack-in-drug-war-steer-addicts-to-rehab-not-jail.html> (The addiction difficulties for Southcoast fishermen and their families are comparable to those experienced by the population of Gloucester, MA, a fishing port north of Boston. Readers may be familiar with the actions of the Gloucester police chief, Leonard Campanello, who created a policy that prioritizes treatment over arrest).

⁸⁵ Walter et.al., *supra* note 76.

⁸⁶ Robert Barboza, *A Day in the Life of a Scallop Boat Captain*, SOUTHCOST TODAY (Jan. 20, 2017), <https://www.southcoasttoday.com/special/20170120/day-in-life-of-scallop-boat-captain/>.

⁸⁷ Walter et.al., *supra*, note 76.

⁸⁸ Mike Lawrence, *Drug Testing a Toucy Issue on New Bedford's Waterfront*, SOUTHCOST TODAY (Apr. 8, 2016), <http://www.southcoasttoday.com/news/20160403/drug-testing-toucy-issue-on-new-bedfords-waterfront>.

those boats, all outbound, had heroin on board.⁸⁹ But criminal arrests do not necessarily help the addicted.⁹⁰ One captain and former user suggested mandatory testing for all members of the crews.⁹¹

Efforts are being made to assist those fishermen who are addicted. Academics from UMass Lowell, have studied the industry with a goal of determining the extent of the problem, as well as exploring tools to help reduce the problem.⁹² A subsequent report by the UMass Lowell researchers notes that fishermen and women have grueling work lives. They often work excessive hours (14.6 or more hours per day) in physically difficult conditions leading to musculoskeletal disorders (MSDs) and chronic pain.⁹³ Those with chronic pain may be prescribed opiates which are associated with depression, leading to addiction and dependency.⁹⁴

While some fishing captains were initially resistant, simple and helpful steps promoted to the fishing industry by the Fishing Partnership are making inroads. For example, one recommendation is for each boat to be stocked with Narcan,⁹⁵ a drug that counteracts the dangerous symptoms of overdose. The Fishermen's Partnership Support Services (FPSS) works with fisherman all over New England, promoting Narcan and defibrillator training within the

⁸⁹ Brian MacQuarrie, *State's Fishing Fleet Confronts An Opioid*, BOSTON GLOBE (April 17, 2017), <https://www.bostonglobe.com/metro/2017/04/17/state-fishing-fleet-confronts-opioid-problem/X41GzDtelTMOoHm4FVe8L/story.html>.; See also *Addiction in the Fishing Industry*, CLINICAL SERVICES OF RHODE ISLAND, <https://clinicalservicesri.com/addiction-in-the-fishing-industry/>. (Last Visited Jan. 12, 2020).

⁹⁰ *Id.* (There was a drug related death on the water in March, 2017. "This is a mayday call for the fishing industry," said J.J. Bartlett, president of Fishing Partnership Support Services, a nonprofit agency in Massachusetts that addresses health and safety issues. "Ambulances don't go where fishermen fish)."

⁹¹ Gray, *supra* note 69.

⁹² Walter, *supra* note 76, at 654.

⁹³ Walter, *supra* note 76, at 653.

⁹⁴ Angela Wangari Walter et al., Preventing Opioid Use Disorders Among Fishing Industry Workers, 15 INT'L J. ENVTL. RESEARCH PUB. HEALTH 648, 653 (2018) ("...commercial fishing industry workers with MSDs, chronic pain, or traumatic injury who are using prescribed opioids are at high risk for developing an opioid use disorder").

⁹⁵ Narcan is the marketing name for Naloxone.

industry.⁹⁶ Comparable training has been held in other Massachusetts fishing ports.⁹⁷

The diversity in communities provides cities with cultural richness. The same diversity creates barriers for those living with HIV. Language, ethnic and cultural customs, social status and poverty all contribute to conditions that can delay or prevent good health outcomes. Sensitive to the range of possibilities that create barriers to optimal health, the investigative team saw an opportunity to assess the population's immediate unmet needs, as well as an opportunity to develop a long-term vision for providing sustained assistance to the target population by way of interdisciplinary services.

And of course, one reason why opioid addiction is a critical health issue is the transmission of sexually transmitted diseases.⁹⁸

D. Additional Substance Abuse Data in the General Southcoast Population.

Opioid use on the Southcoast is in no way limited to the fishing industry. As the University of Massachusetts at Lowell, one researcher reported:

Substance use disorders were known of in all groups by race, age, socioeconomic position, neighborhoods, and profession. Among all participants, there was the perception that everyone in the community knows someone who has or had a substance use disorder. This suggests that substance use disorders have impacted community members across the life span.⁹⁹

⁹⁶ Following one New Bedford meeting, 40 boat captains left a Narcan training with the antidote to be stored on their fishing boats. Another training addresses proper defibrillator use. Mike Lawrence, *Narcan Entering Safety, Health Plans for Services Supporting New Bedford's Fishing Industry*, SOUTHCOAST TODAY (Mar. 17, 2016), <https://www.southcoasttoday.com/news/20160317/narcan-entering-safety-health-plans-for-services-supporting-new-bedfords-fishing-industry>.

⁹⁷ *Id.*

⁹⁸ UMASS DARTMOUTH PUBLIC POLICY CENTER SOUTHCOAST URBAN INDICATORS PROJECT, SUBSTANCE ABUSE <http://southcoastindicators.org/health/substance-abuse/>.

⁹⁹ Walter, *supra* note 76, at 651.

In New Bedford, there is limited acceptance of substance abuse as a disorder or disease.¹⁰⁰ In turn creating a lack of healthcare options and a barrier to treatment. Only 59% of fishing industry crew members have health insurance, and for those who struggle with addiction and have no significant income, health insurance options are even more limited.¹⁰¹

Data involving Fall River, Massachusetts is equally concerning regarding opioid use. By 2010, heroin overtook alcohol as the most common addiction among the city's population.¹⁰² In 2017 and 2018, Fall River faced fifty-five resident deaths during both years due to opioid use.¹⁰³ New Bedford reported forty-five resident deaths in 2017, and reported fifty-four in 2018.¹⁰⁴ By contrast, in Boston, a city of over 690,000¹⁰⁵ (which is at least 7 times larger than New Bedford or Fall River), only 187 deaths were reported in 2017.¹⁰⁶ That number is only three times that reported by the Southcoast cities.

Fall River has been battling the opioid crisis for many years. The city residents are perplexed as to why Fall River, plagued for decades by opioid use, has not received the help available now opioid addiction has spread to young members of middle-class societies.¹⁰⁷ Some speculate that when opioid addiction was seen as a poor person's problem, help was scarce.¹⁰⁸ However, when the

¹⁰⁰ Walter, *supra* note 76, at 652.

¹⁰¹ *Id.*

¹⁰² UMASS DARTMOUTH, SUBSTANCE ABUSE (finding that 51% of reporters were addicted to opioids and explaining, "because opioid abuse is particularly prevalent in Fall River, it and the deaths resulting from it are also measured. ((Opioids include illegal narcotics like heroin as well as prescription painkillers like oxycodone and codeine"))).

¹⁰³ MASS. DEP'T PUB. HEALTH, NUMBER OF OPIOID-RELATED OVERDOSE DEATHS, ALL INTENTS BY CITY/TOWN 2014-2018 (Aug. 2019) [hereinafter *Opioid-Related Overdose Deaths*], <https://www.mass.gov/files/documents/2019/08/21/Opioid-related-Overdose-Deaths-by-City-Town-August-2019.pdf>.

¹⁰⁴ *Id.* at 11.

¹⁰⁵ Some estimates differ between approximately 695,000 and 699,000 as of 2019. Compare *Population of Boston 2019*, U.S. POPULATION 2019, <https://uspopulation2019.com/population-of-boston-2019.html> (last visited Aug. 5, 2019), see also *Boston, Massachusetts Population*, WORLD POPULATION REVIEW, <http://worldpopulationreview.com/us-cities/boston-population/> (last visited Oct. 12, 2019).

¹⁰⁶ *Opioid-Related Overdose Deaths*, at 2.

¹⁰⁷ Brian MacQuarrie, *Fall River Gets Assistance to Confront an Old Foe: Heroin*, BOSTON GLOBE (Feb. 21, 2016) <https://www.bostonglobe.com/metro/2016/02/21/fall-river-confronts-old-foe-heroin/ZthYcAb8kWAL5EJLNeypO/story.html>.

¹⁰⁸ *Id.*

government began recognizing the extent of the problem and reconciling it in 2016, Fall River and all of Bristol County were already designated High Intensity Drug Trafficking Areas, which permitted federal agents to track the source of incoming drugs.¹⁰⁹ Despite the government effort, finding the source of incoming drugs is not the same as meeting the community's treatment needs.

III. Composition of the Study

A. Building Community Capacity Through Community Partnership.

The team developed a relationship with a network of community health workers (CHW).¹¹⁰ The team engaged with these members to inform the team of particular needs of their patients who are living with HIV. The CHW also provided community links to vendors of HIV services.

The team secured funding for the project, most of which was used to conduct trainings for community health workers.¹¹¹ Starting the project with funding of a community partner gave credibility to the team. In describing what she calls “insider-outsider tensions, author Meredith Minkler notes, “For although a major aim of such research is to benefit the local community, the outside researchers typically stand to gain the most from such collaborations, bringing in grants, getting new publications, and so forth.”¹¹²

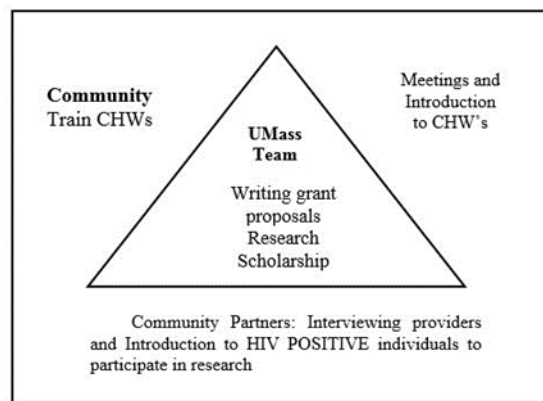
¹⁰⁹ *Id.*

¹¹⁰ Community Health Workers (CHWs) are trusted members of the community who, by utilizing their knowledge and respected position in the community, served as a liaison, link, or intermediary between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery. *See generally* WORLD HEALTH ORGANIZATION, COMMUNITY HEALTH WORKERS: WHAT DO WE KNOW ABOUT THEM? (Jan. 2007), https://www.who.int/hrh/documents/community_health_workers_brief.pdf.

¹¹¹ Focusing on enhancing the community partnership, the team developed a proposal to the University of Massachusetts President's Office that would both fund Community Health Worker (CHW) trainings, as well as fund the addition of two new community health workers. Funding for conducting individual research with those living with HIV was included. The funding for recording and transcription services was vital to the research aspect of the project. The proposal was funded. The total grant was \$32,500.00, with approximately \$25,000.00 allocated to CHW training and the remainder primarily allocated to the academic team's research expenses.

¹¹² Meredith Minkler, *Community Based Research Partnerships: Challenges and Opportunities*, 82 J. URB. HEALTH (SUPP. 2) ii3, ii9 (2005).

Funding of CHW training limited the opportunity for skepticism to develop within the community. Because of the training offered, fewer community members perceived that yet another team of academic researchers would invade the community to gather data without producing any concrete benefit to the targeted population or their advocates. “Partnerships are very valuable because the collaborative process brings different kinds of people and organizations together, making it possible for them to accomplish much more than they can on their own.”¹¹³



Two partnerships were formed as part of the study. The initial partnership was formed exclusively with the academic team. The goals of that partnership were research and scholarship, as well as the development of advocacy strategies to reach better health outcomes. Such advocacy strategies included policies to improve the lives of those living with HIV. The second partnership was one between the team and community health care workers and advocates.¹¹⁴ This

¹¹³ *Partnership Self-Assessment Tool*, CENTER FOR THE ADVANCEMENT OF COLLABORATIVE STRATEGIES IN HEALTH, http://www.peecworks.org/PEEC/PEEC_Inst/01795CC4-001D0211.58/Partnership%20Assessment%20tool.pdf [http://webcache.googleusercontent.com/search?q=cache:http://www.peecworks.org/PEEC/PEEC_Inst/01795CC4-001D0211.58/Partnership%20Assessment%20tool.pdf].

¹¹⁴ Communities possess various capacities, skills, and resources, which are identified during the community assessment process. A collaborative partnership consists of reciprocal sharing of skills among community partners, which provides a learning opportunity for all involved in the project. For example, the personal knowledge of HIV-positive individuals and

partnership is represented in the square of the image above. The second partnership was symbiotic. The academic team provided the broader partnership with funding for CHW training,¹¹⁵ and in exchange the academic team was given access to the targeted population to conduct needs research.

Meanwhile, the Massachusetts Governor and Attorney General declared the opioid crisis a priority for their administrations. The Governor's recommendations included the "integration of Mental Health, Primary Care, and Opioid Treatment." Since the HIV new infection rate is linked to opioid use,¹¹⁶ particularly needle sharing,¹¹⁷ the team's research was timely, as HIV prevention must be part of comprehensive opioid treatment.¹¹⁸

their providers in New Bedford and Fall River informed the academic partners and gave a contextual understanding of the physical, social, and healthcare environment. Academic partners relied on the health workers and advocates to access HIV-positive individuals for one-on-one interviews. Participant interviews informed the understanding of community resources that are in need of development. Additional knowledge that was gained related to the form of skill building in problem definition, assessment, intervention development, implementation, and evaluation. All of these skills strengthened community capacity by recognizing and reforming weaknesses and reinforcing existing strengths.

¹¹⁵ CHWs contribute to community capacity by increasing health knowledge and self-sufficiency through a range of activities such as outreach, community education, informal counseling, social support, and advocacy. As a method of building community capacity and providing a mechanism of impact for the cities of New Bedford and Fall River, the project team funded a three-pronged training, which included the lessons: "Community Health Worker Trainer," "Community Health Worker Core Competency Training," and "Community Health Worker Supervisor." Previously these trainings were not offered in the Southcoast region. CHWs were otherwise required to travel a minimum of one hour by car to receive the trainings. The trainings are also expensive. By bringing the training program to the Southcoast region and targeting the culturally diverse communities of New Bedford and Fall River, the likelihood of increasing and maintaining a sustainable trained workforce was enhanced, as those trained became qualified to train future cohorts of CHWs, ultimately resulting in improved health outcomes for the region.

¹¹⁶ See *Opioid Epidemic is Increasing Rates of Some Infectious Diseases*, NAT'L INST. HEALTH (Apr. 3, 2019), <https://www.nih.gov/news-events/opioid-epidemic-increasing-rates-some-infectious-diseases>.

¹¹⁷ *Massachusetts Opioid Summary*, NAT'L INST. ON DRUG ABUSE (Mar. 2019), <https://www.drugabuse.gov/opioid-summaries-by-state/massachusetts-opioid-summary> (Of the new HIV cases in 2016, 710 occurred in Massachusetts. Among males, 16.1 percent of new HIV cases were attributed to IDU or male-to-male contact and IDU. Among females, 20.3 percent of new HIV cases were attributed to IDU).

¹¹⁸ WORLD HEALTH ORG., POLICY BRIEF: CONSOLIDATED GUIDELINES ON HIV PREVENTION, DIAGNOSIS, TREATMENT AND CARE FOR KEY POPULATIONS 4 (2017), <https://apps.who.int/iris/bitstream/handle/10665/258967/WHO-HIV-2017.05-eng.pdf> (All people from key populations who are dependent on opioids should be offered and have access to opioid substitution therapy in keeping with WHO guidance).

B. Developing Community Capacity

The need to provide culturally specific resources is wide ranging. Whether this means recognizing sexual differences, poverty, or language barriers, community providers must have the capacity to be available to address individual client concerns. Client-centered care has been an effective approach to ensuring HIV health care regularity.¹¹⁹ Capacity requires health care systems to meet clients where they are and address the most immediate needs of patients. Case managers work within this framework, and case management often is one of the identified needs of those living with HIV.¹²⁰

Identifying which patient needs must be met in order to ensure consistent health care requires patient/provider communication, as well as provider ability to assist in resolving the identified barrier. Social determinants of health impact whether the patient will be able to access care. Social determinants of health are part of community-based health care and often address issues ranging from systemic problems such as housing to individual needs such as assistance in applying for benefits.

C. Assessing the Social Determinants of Health

Given the range of diversity in the two Southcoast cities, HIV-positive individuals in Fall River and New Bedford require both culturally specific resources and access to healthcare in order to prevent advancement of HIV disease and HIV-related co-morbidities. However, more information is needed about what the culturally specific needs are in these communities and how those needs can be met. Therefore, a community assessment guided by collecting social determinants of health (SDH) data was necessary. SDH are conditions in the environment that affect a wide range of risk factors, as well as health, functioning, and quality-of-life outcomes.¹²¹ A community assessment guided by the SDH will identify the gaps in

¹¹⁹ Marcia Andersen et al., *Retaining Women in HIV Medical Care*, 18 J. ASS'N NURSES AIDS CARE, May/June 2007, at 33, 34 (Jun. 2007).

¹²⁰ *Id.* at 33.

¹²¹ See generally Paula Braveman & Laura Gottlieb, *The Social Determinants of Health: It's Time to Consider the Causes of the Causes*, 129 PUB. HEALTH REP. (SUPP. 2) 19 (2014).

resources and services within the HIV-positive community in New Bedford and Fall River.

In 2010, the Department of Health and Human Services announced a federal initiative, *Healthy People 2020*,¹²² publicizing “new 10 year goals and objectives for health promotion and disease prevention.”¹²³ The government made three recommendations to prevent HIV-related exacerbations and mortality: (a) establish linkages to and continued engagement in treatment; (b) increase the availability of ongoing HIV intervention; and (c) provide prevention services for the partners of people living with HIV.¹²⁴

Social determinants are classified within the triad of social environment (e.g., discrimination, socioeconomic status), physical environment (e.g., place of residence, crowded conditions), and health services (e.g., access to and quality of care, insurance status).¹²⁵ In order to understand the specific socio-physical and health service conditions within a community it is important to conduct a comprehensive community assessment. When this assessment is guided by a social determinants framework, resulting action and intervention will directly affect the social conditions influencing HIV-positive individuals.

An interdisciplinary approach,¹²⁶ led by community-engaged professionals, can mobilize community members and community organizations into a partnership that will enhance the community’s capacity for managing HIV infection. For example, law both acts as a pathway for social determinants that impact HIV and helps to establish or change these social determinants. Housing and socioeconomic status are two major social determinants linked to both improved HIV infection outcomes and adherence to

¹²² See *2020 Topics and Objectives – Objectives A-Z*, HEALTHY PEOPLE 2020, <http://www.healthypeople.gov/2020/topicsobjectives2020/default> (last visited Sept. 8, 2015).

¹²³ *HHS Announces the Nation’s New Health Promotion and Disease Prevention Agenda*, U.S. DEPT. HEALTH & HUMAN SERV. (Dec. 2, 2010) http://www.healthypeople.gov/sites/default/files/DefaultPressRelease_1.pdf.

¹²⁴ *HIV*, HEALTHY PEOPLE 2020, <http://www.healthypeople.gov/2020/topics-objectives/topic/hiv> (last visited Sept. 8, 2015).

¹²⁵ For a discussion of social and physical environment factors see *Id.* at 20-22.

¹²⁶ Although HIV is often considered a healthcare provider-focused disease, management of the infection crosses numerous disciplines with various skillsets.

treatment.¹²⁷ Therefore, a legal perspective on the SDH when assessing HIV-positive communities will yield a discipline-specific plan of action, or compliment another discipline's plan for addressing the barriers or filling the gaps in resources. For example, should the needs assessment show that substandard housing is a common determinant on the Southcoast, then law students could assist an individual in taking action against a negligent landlord, as well as provide assistance in locating healthy housing.

IV. Contemporaneous Legal and Other Stressors Experienced by Those Living With HIV

Since the introduction of effective medical interventions in treating HIV, the legal needs of those living with HIV have changed. The Team anticipated their research might unveil legal needs consistent with those living with chronic illness, poverty, and stigma. Legal services can address both short-term and long-term client needs. The good news is that certainty of death from an HIV diagnosis is no longer the norm. This eliminates the urgency that was attached to the provision of legal services concerning guardianship and estate planning during the 1980s and 1990s. Less good news is that while HIV now presents a reduced need for dramatic interventions, legal and social voids are still as chronic as the condition.

To bring additional context to the challenges faced by those living with HIV/AIDS, the following section explores some of the barriers common to the target population. The discussed barriers are a glimpse into some of the social health determinants that universally influence health outcomes and the general quality of life of those living with HIV/AIDS, regardless of the individual's income level.

The below-described circumstances were presented to the team in various ways, although not all of the described difficulties were the primary concerns of those interviewed. The general population may misconceive that with medical advances, those living with HIV/AIDS experience no significant challenges outside those experienced by the

¹²⁷ Matthew E. Falagas et al., *Socioeconomic Status (SES) as a Determinant of Adherence to Treatment in HIV Infected Patients: A Systematic Review of the Literature*, 5 *RETROVIOLOGY*, 13 (Feb. 2008).

general population. Because of this misconception, and in order to more thoroughly understand the complex lives of those living with HIV/AIDS, we will discuss of some of the barriers faced by the target population.

A. Intimate Partner Abuse

At least half of the women living with HIV/AIDS report have been in abusive intimate relationships.¹²⁸ The vast majority of abusive intimate relationships are hereosexual.¹²⁹ Men and women in homosexual relationships report intimate partner abuse at about the same rate as heterosexual women,¹³⁰ although men in same-sex relationships report higher rates of abuse when they are living with HIV/AIDS.¹³¹ Transgender women report the highest rate of abuse of all, whether or not they are living with HIV-AIDS.¹³² A 2014 report by AIDS United¹³³ found that 55% of U.S. women living with HIV experience intimate partner violence, while 61% report having

¹²⁸ CENTERS FOR DISEASE CONTROL AND PREVENTION, INTERSECTION OF INTIMATE PARTNER VIOLENCE AND HIV IN WOMEN 2 (Feb. 2014) [hereinafter *Intersection of Intimate Partner Violence*], (“HIV-positive women in the United States experience IPV at rates that are higher than for the general population. Across a number of studies, the rate of IPV among HIV-positive women (55%) was double the national rate, and the rates of childhood sexual abuse (39%) and childhood physical abuse (42%) were more than double the national rate”).

¹²⁹ Leonard D. Pertnoy, *Same Violence, Same Sex, Different Standard: An Examination of Same-Sex Domestic Violence and the Use of Expert Testimony on Battered Woman’s Syndrome in Same-Sex Domestic Violence Cases*, 24 ST. THOMAS L. REV. 544, 545 (2011-2012).

¹³⁰ Susan C. Turrell, *A Descriptive Analysis of Same-Sex Relationship’s Violence for a Diverse Sample*, 15 J.FAM. VIOLENCE 281, 288 (2000) (“[t]his study confirmed that same-sex relationship violence is a significant problem for a sizable part of the gay/lesbian/bisexual/transgendered (g/l/b/t) community within the limitations of the sampling methods. It further indicates that g/l/b/t people experience physical and sexual violence at similar frequencies to heterosexual people”).

¹³¹ See generally Shruti Ramachandran, Michael A. Yonas, Anthony J. Silvestre, & Jessica G. Burke, AIDS CARE, 22(12) NIH-PA 1536, (Dec. 2010) (originally titled *Intimate Partner Violence among HIV Positive Persons in an Urban Clinic* at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3005966/pdf/nihms231257.pdf>); See also, Pertnoy supra note 129 at 554 and 568.

¹³² Leigh Goodmark, *Transgender People, Intimate Partner Abuse, and the Legal System*, 48 HARV. C.R.-C.L. L. REV. 51, 61-62 (2013) (“Transgender women are particularly likely to be marked for violence. The 2011 NCAVP survey found that transgender women made up 40% of murder victims in the survey, but constituted only 10% of the overall sample Surveys of the transgender community have found that 98% of violence in the transgender community was targeted at transgender women”).

¹³³ See generally AIDS UNITED, <https://www.aidsunited.org/> (last visited Oct. 12, 2019). (Aids United is one of the premier HIV/AIDS national advocacy groups in the United States).

been sexually abused, and 30% suffer from post-traumatic stress disorder.¹³⁴ According to the Center for Disease Control and Prevention¹³⁵ (CDC), women who experience intimate partner abuse report high rates of childhood sexual abuse (39%) and childhood physical abuse (42%).¹³⁶ Intimate partner violence itself is a risk for HIV infection given, among other factors, the lack of condom negotiation that the abused partner has in the relationship.¹³⁷ “[B]attered women have described sexually abusive and controlling acts such as verbal sexual degradation, refusal to use condoms, or refusal to use contraception. These issues might partly explain links between intimate partner violence and sexually-transmitted diseases, HIV, and unintended pregnancy”¹³⁸ In physically abusive relationships, female intimate partner survivors report sexual abuse at a rate of 40-45%.¹³⁹ Forced sex can result in various ongoing physical ailments for those experiencing sexual abuse in intimate relationships.¹⁴⁰

Because abusive partners prey on vulnerabilities, the ways in which HIV or AIDS can manifest in an abusive relationship are numerous.¹⁴¹ “Qualitative data from in depth interviews show how abuse interacts with complex social, psychological, and cultural factors involved in decisions and actions to prevent pregnancy or

¹³⁴ AIDS UNITED, THE INTERSECTION OF WOMEN, VIOLENCE, TRAUMA, AND HIV, <https://www.aidsunited.org/resources/the-intersection-of-women-violence-and-hiv?docid=51>.

¹³⁵ See generally *Violence Prevention*, CTR. DISEASE CONTROL & PREVENTION, <https://www.cdc.gov/violenceprevention/datasources/nisvs/summaryreports.html> (summary and special reports on National Intimate Partner and Sexual Violence). See also CTR. DISEASE CONTROL & PREVENTION, THE NATIONAL INTIMATE PARTNER AND SEXUAL VIOLENCE SURVEY (Apr. 2017), <https://www.cdc.gov/violenceprevention/pdf/NISVS-StateReportBook.pdf>.

¹³⁶ *Intersection of Intimate Partner Violence*, *supra* note 128, at 2.

¹²⁹ Jane Stover, *Stories Absent from the Courtroom: Responding to Domestic Violence in The Context of HIV and AIDS*, 87 N. CAROLINA L. REV. 1157, 1176 (2009).

¹³⁸ Jacquelyn C. Campbell, *Health Consequences of Intimate Partner Violence*, 359 LANCET 1331, 1332 (2002).

¹³⁹ *Id.*

¹⁴⁰ *Id.* (“The combination of physical and sexual abuse that characterises the experience of at least 40–45% of battered women puts these women at an even higher risk for health problems than women only physically assaulted”).

¹⁴¹ See generally EVAN STARK, COERCIVE CONTROL: HOW MEN ENTRAP WOMEN IN PERSONAL LIFE (2007), for a detailed review of the calculated tactics used by abusive men to gain control over their partners by deprivation, intimidation, shaming, and identifying the areas in a woman’s life that he can target to gain power.

sexually-transmitted diseases, including HIV and AIDS and the difficulty of negotiation of use of condoms or contraception in violent relationships”¹⁴² The diagnosis of the targeted partner brings new vulnerabilities to the target who is living with HIV/AIDS, supplying the abusive partner with additional devices with which to manipulate the target and hold the target captive.

The targeted partner must consider the risks of disclosing or not disclosing HIV-positive status to the abusive partner.¹⁴³ Disclosure can result in severe physical and emotional abuse, particularly if the abusive partner is not HIV-positive. “Some researchers have suggested that a diagnosis of HIV infection may trigger violence at the time of disclosure to significant social relationships.”¹⁴⁴ An earlier study supports this notion, finding that HIV-seropositive status is often a cause of violent episodes from abusive partners. The study found that “[o]verall, 20.5% of the women, 11.5% of the men who reported having sex with men, and 7.5% of the heterosexual men reported physical harm since diagnosis, of whom nearly half reported HIV-seropositive status as a cause of violent episodes.”¹⁴⁵

HIV-positive participants in the Southcoast study also reported intimate partner abuse, with one participant stating that the abuse was “[p]hysical mental, whatever way. Last time I was in the hospital; my ribs, two black eyes. Well I went to the emergency room.”¹⁴⁶ . This was affirmed by one HIV positive Southcoast study participant in a gay relationship. “I had been in a bad abusive relationship when you are gay and a relationship is abusive because the, as your partner says, ‘You’re a guy. Just suck it up.’”¹⁴⁷

¹⁴² See generally *id.*

¹⁴³ Privacy rights versus mandatory reporting are of much concern. See, e.g., Mary D. Fan, *Sex, Privacy and Public Health in A Casual Encounters Culture*, 45 U.C. DAVIS L. REV. 531 (2011). (Privacy is not the main focus of Fan’s article, but the article does explore privacy and mandatory disclosure in specific contexts, such as criminalization).

¹⁴⁴ Sally Zierler, DrPH, MPH, MEd, William E. Cunningham, MD, MPH, Ron Andersen, PhD, Martin F. Shapiro, MD, PhD, Sam A. Bozzette, MD, PhD, Terry Nakazono, BS, Sally Morton, PhD, Stephen Crystal, PhD, Michael Stein, MD, Barbara Turner, MD, MEd, and Patti St. Clair, BS *Violence Victimization After HIV Infection in a US Probability Sample of Adult Patients in Primary Care*, 90 AM. J. OF PUB. HEALTH 208, 208 (Feb. 2000).

¹⁴⁵ *Id.* at 211.

¹⁴⁶ Participant 107, (transcript on file with authors).

¹⁴⁷ Participant 121, (transcript on file with authors).

In some cases, the onset of physical violence in a relationship may coincide with the diagnosis.¹⁴⁸ The abuse can continue for years after the disclosure.¹⁴⁹ In addition to posing immediate risk of physical harm, violence lowers the immune system, which is a critical treatment interference for those who are HIV positive.¹⁵⁰ Those experiencing abuse in intimate relationships may already be suffering from depression.¹⁵¹ The existence of depression and the resulting lowered immune system has physical consequences that place a person who experiences abuse at higher risk of being infected with HIV;¹⁵² depression can result in the thinning of the vaginal and anal mucus membranes, and the body's ability to resist absorption of the infection is lowered.¹⁵³

Use of alcohol or drugs, a common coping mechanism for abused individuals,¹⁵⁴ contributes to a lowered immune system as well.¹⁵⁵

¹⁴⁸ See generally AIDS UNITED, *supra*, note 134.

¹⁴⁹ See *Intersection of Intimate Partner Violence*, *supra* note 128.

¹⁵⁰ See generally Pertnoy, *supra* at note 129. See also HUMANSERVICES EDU, <https://www.humanservicesedu.org/domestic-violence.html> (last visited Jan. 12, 2020).

¹⁵¹ Giulia Ferrari, Roxane Agnew-Davies et al. *Domestic violence and Mental Health: a Cross-Sectional Survey of Women Seeking Help from Domestic Violence Support Services*, GLOBAL HEALTH ACTION, 1, 2 (2016) ("IPV is associated with depression, anxiety, posttraumatic stress disorder (PTSD), and substance abuse in the general population and among women consulting in primary care. There is evidence for a bidirectional effect (i.e. that women experiencing abuse are at greater risk of mental health conditions and that having a mental health condition makes one more vulnerable to abuse").

¹⁵² Campbell, *supra* note 138 at 1332 (Earlier studies raised the connection between intimate partner abuse and lowered immune system. "Suppression of the immune system as a result of stress, mental-health disorders such as depression, or both is again another reasonable but untested causal hypothesis").

¹⁵³ *Id.* ("Possible mechanisms of increased risk include the shame and stress reported with forced sex manifesting as especially high levels of stress and depression known to depress the immune system; vaginal, anal, and urethral trauma from forced sex (direct force or lack of lubrication) leading to increased transmission of microorganisms through direct transmission into the bloodstream or back flow of bacteria in the urethra").

¹⁵⁴ Debra Kaysen, Tiara M. Dillworth et al., *Domestic Violence and Alcohol Use: Trauma-related Symptoms and Motives for Drinking*, 32 ADDICTIVE BEHAVIORS 1272, 1274, (2007). (Describes relationship between traumatic experiences and alcohol consumption); See also *Addiction as a Coping Mechanism and Healthy Alternatives*, AM. ADDICTION CTR., <https://americanaddictioncenters.org/>.

¹⁵⁵ *Id.*; See also, US DEP'T OF VETERANS AFFAIRS, DRUGS AND ALCOHOL: EFFECTS ON YOUR IMMUNE SYSTEM (Apr. 29, 2019) ("Drinking too much alcohol can weaken your immune system. A weaker immune system will have a harder time fighting off common infections (such as a cold), as well as HIV-related infections. A weaker immune system also increases the chance that you will experience more side effects from your HIV medications;" Found at, <https://www.hiv.va.gov/patient/daily/alcohol-drugs/immune-system.asp>.

“Significant associations have also been found between IPV and altered red blood cell and decreased T-cell function, and the relationships between stress and depression.”¹⁵⁶

The diagnosis may provide the abusive partner with information that tightens the abuser’s grip because of the target’s fear of disclosure to family, friends, landlords and employers.¹⁵⁷ A participant reported that upon learning of her HIV positive status, her abusive partner told her children, including her younger child who had not known.¹⁵⁸

HIV-positive partners risk severe physical violence upon disclosure. In a review of intimate partner violence and intersections with medicine and medical professionals, the author notes:

Disclosure of a woman’s HIV status to her intimate partner and/or attempts to prevent HIV transmission to or from a woman’s intimate partner also may increase the risk of intimate partner violence. An individual’s notification to his or her sexual partners of his or her positive HIV status has been encouraged in order to protect partners from possible infection, to inform partners who may have been exposed so that they can seek HIV testing and any necessary medical care, and to bring those at risk of contracting or transmitting HIV infection into the public health system for appropriate behavioral counseling. However, the promotion of condom use has been linked to an increased risk of violence against women. In at least two cases, women have been shot following their disclosure of their HIV status to their sexual partners.¹⁵⁹

¹⁵⁶ *Supra* note 124, at 3.

¹⁵⁷ See *Violence as a Result of HIV Status Disclosure*, NAT’L Resource CTR. on Domestic Violence, <https://vawnet.org/sc/violence-result-hiv-status-disclosure>. (States that require partner notification of an HIV diagnosis can place an abused diagnosed partner at increased risk of harm. Some states have an exception for domestic violence survivors while others may have anonymous reporting, where the diagnosed partner is not identified).

¹⁵⁸ Participant 107, (transcript on file with authors).

¹⁵⁹ San Loue, *Intimate Partner Violence Bridging the Gap Between Law and Science*, 21 J. LEGAL MED. 1, 4, 2000.

Yet, withholding critical information of diagnosis deprives the intimate partner of making informed decisions on lifestyle choices, such as whether to use preventative measures during sex or for the non-infected partner to use preventative medication.¹⁶⁰

To the abused partner, disclosing the diagnosis to the abusive partner can carry heightened risk of abuse.¹⁶¹ For those living in states that prosecute those having sex without disclosing positive HIV status, criminal consequences are possible.¹⁶² More on this particular risk is addressed later.

While non-disclosure can be a self-protective measure for the targeted partner, non-disclosure can be used by the abusive partner as a way to further deprive the target of their autonomy. Non-disclosure can be a favored tool of the abusive partner who seeks to deprive the targeted partner of choice around preventative measures.¹⁶³ When asked which partner was diagnosed first, one participant said “I believe he was. Because he – yeah. . . But he never said nothing to me.”¹⁶⁴ Thus, the infected partner’s fear of the non-infected partner leaving the relationship following disclosure may contribute to a decision not to disclose as well.¹⁶⁵

¹⁶⁰ See, Jason Potter Burda, *Prep and our Youth: Implications in Law and Policy*, 30 COLUM. J. GENDER & L. 295, 302 (2016). (“Truvada®, an antiretroviral medication originally approved to treat HIV, is the first drug to receive FDA approval for use by HIV-negative individuals to actually prevent infection. The prophylactic use of an antiretroviral such as Truvada is a pharmacological prevention method called “HIV pre-exposure prophylaxis” (or “PrEP”). With an efficacy of over ninety percent when used as prescribed, Truvada as PrEP has been embraced by the public health community, and implementation is under way across the United States. Truvada as PrEP is currently indicated for adult use only, but it may also be prescribed off-label to at-risk youth”).

¹⁶¹ Stover, *supra* note 129, at 1161 (2009).

¹⁶² CTR. FOR DISEASE CONTROL & PREVENTION, HIV AND STD CRIMINAL LAWS (2019) (19 states have specific disclosure laws for HIV, but every state regulates, in some form, the transmission of HIV).

¹⁶³ Office For the Prevention of Domestic Violence, *Information for Professionals*, N.Y. ST., <https://opdv.ny.gov/professionals/health/hivavids.html> (last visited Jan. 14, 2020) (list of how an HIV diagnosis can impact the abused partner).

¹⁶⁴ Participant 113, (transcript on file with authors).

¹⁶⁵ See Nat’l Coal. Against Domestic Violence, *WHY DO VICTIMS STAY?*, NCADV.ORG, <https://ncadv.org/why-do-victims-stay> (last visited Jan. 14, 2020) (abusive partners tend to resort to extreme, often violent, measures when they believe the other partner is leaving or planning to leave); see U.S. DEP’T. OF JUSTICE, EXTENT, NATURE, AND CONSEQUENCES OF INTIMATE PARTNER VIOLENCE: FINDINGS FROM THE NATIONAL VIOLENCE AGAINST WOMEN SURVEY (2000) (“[o]ne study found in interviews with men who have killed their wives that either threats of separation by their partner or actual separations were most often the precipitating events that lead to the murder”); Maria Scheffer Lindgren & Barbro Renck, *Intimate Partner Violence and*

Likewise, coercion may be a result of abusive control of treatment and medication. For example, when both parties are living with HIV, the abusive partner may appropriate medication prescribed for the other partner if the target is the only one receiving treatment. The abusive partner may resist disclosure, even to medical professionals, which necessitates their finding medical treatment through another source, typically the abused intimate partner.¹⁶⁶

Sometimes the abused partner may be the only member of the couple receiving or requiring treatment for HIV. In those instances, the abusive partner may withhold the partner's medication as a means of assuring that they do what the abusive partner demands.¹⁶⁷ Coercion plays out in different ways. Threats to disclose the abused partner's medical diagnosis to employers and failure to pay health insurance premiums are but two of the coercive techniques that abusive partners employ to force the partner living with HIV to refrain from actions they would otherwise take or engage in. One participant reported that her boyfriend insisted that she attend anger management classes. She enrolled "to shut him up" but never attended.¹⁶⁸

As with any disability that is misunderstood in the general population, and to which stigma attaches, the partner's fear of disclosure provides the manipulative partner with a powerful tool with which to maintain control over the intimate partner.

In abusive MSM relationships, an HIV diagnosis heightens the risk for the abused partner who may not have disclosed his same sex status to family or the wider community.¹⁶⁹ The additional stigma that attaches to a feared and misunderstood medical condition expands the control of the abusive partner and the terror of a non-abusive partner living with the condition who has unwittingly relinquished control over the information by revealing the condition to the partner. Certain marginalized populations are at heightened risk for violence prior to HIV diagnosis. Transgender women, immigrants, and people of color

the Leaving Process: Interviews with Abused Women, 3 Int'l J. of Qualitative Stud. On Well-Being & Health 113, 115-16 (2009).

¹⁶⁶ Stover, *supra* note 129, at 1173.

¹⁶⁷ *Id.*

¹⁶⁸ Participant 107, (transcript on file with authors).

¹⁶⁹ Satoko Harada, *Additional Barriers to Breaking the Silence: Issues to Consider When Representing a Victim of Same-Sex Domestic Violence*, 41 U. BALT. L. F. 150, 159 (2011).

historically are less likely to receive assistance from actors in the civil and criminal justice systems.¹⁷⁰ When members of those communities are also HIV positive, stereotypes that the infected individual engages in sex work, or is promiscuous can diminish the individual's credibility as well as cultural concern for the survivor's wellness. Other differences, such as race, can result in lack of support and lack of advocacy on the survivor's behalf.¹⁷¹

Intimate partner abuse can be characterized by the abusive partner's insecurity surrounding where they fit into sexual cultural norms, accompanied by a rigid view of gender roles. While other factors, such as childhood experiences,¹⁷² influence why one partner does harm to another partner, sexual confusion or unexpressed sexual differences often accompanies intimate partner abuse. Sex, sexuality, and gender are not generally fluid in relationships that involve abuse.¹⁷³ Those who challenge gender norms are not only at higher risk for abuse generally, but for lack of respectful treatment when they encounter bureaucratic players.¹⁷⁴

Notions of gender and "femaleness" minimize the perceived need for services for those who are abused, as defined by bureaucratic institutions. The stereotype of who is a victim further separates sexual minorities from inclusion in the stereotypes of the "worthy victim."¹⁷⁵

¹⁷⁰ Kylar W. Broadus, *The Criminal Justice System and Trans People*, 18 TEMP. POL. & C.R. L. REV. 561, 561 (2009) ("[t]he criminal justice system, like many other top-down social institutions, has been used to segregate and disenfranchise the less fortunate of our citizens. The obvious divides are along race and class lines, but there are many hidden divisions, such as gender identity.")

¹⁷¹ Geneva Brown, *Ain't I a Victim - The Intersectionality of Race, Class, and Gender in Domestic Violence and the Courtroom*, 19 CARDOZO J. L. & GENDER 147, 165-66 (2012) ("[b]attered women who are not white, passive, or straight, will have difficulty being configured into the battered woman standard. Compounding the predicament for poor, battered African American women is a court system that historically has been a barrier for equal treatment in the administration of justice for African Americans").

¹⁷² See, e.g., Ctrs. For Disease Control & Prevention, *Adverse Childhood Experiences*, CDC.GOV, <https://www.cdc.gov/violenceprevention/childabuseandneglect/acestudy/index.html> (last visited Jan. 14, 2020).

¹⁷³ See generally, Harada, *supra* note 169.

¹⁷⁴ *Id.* at 156.

¹⁷⁵ Leigh Goodmark, *When is a Battered Woman Not a Battered Woman? When She Fights Back*, 20 YALE J. L. & FEMINISM 75, 77 (2008) (the stereotypical "worthy victim" is white, middle class, well-behaved and passive).

The certainty with which law enforcement and justice systems define “worthy” behavior and “worthy actors” based upon traditional gender norms contributes to the criminalization of HIV.¹⁷⁶

B. Criminalization

“HIV criminalization” refers to the use of criminal law to penalize alleged, perceived or potential HIV exposure; alleged nondisclosure of a known HIV-positive status prior to sexual contact (including acts that do not risk HIV transmission); or nonintentional HIV transmission. Sentencing under HIV criminal law sometimes involves decades in prison or required sex offender registration, often in instances where no HIV transmission occurred or was even possible.”¹⁷⁷

Non-disclosure of HIV/AIDS status is a criminal offense in many U.S. jurisdictions.¹⁷⁸ According to the Center for Disease Control and Prevention, twenty-six states have laws specifically targeting non-disclosure of HIV to a sexual partner as a criminal offense.¹⁷⁹ Some states require disclosure to needle sharing partners as well.¹⁸⁰ Other states include HIV/AIDS status as a sentencing enhancement attached to other crimes such as sexual assault.¹⁸¹

The laws reflect hyper-reaction to sex-based behavior and conditions that threaten notions of male heteronormative sexuality as well as fear of infection. The laws were implemented at a time when

¹⁷⁶ Adelle Morrison, *Queering Domestic Violence: to Straighten Out Criminal Law: What Might Happen When Queer Theory and Practice Meet Criminal Law's Conventional Responses to Domestic Violence*, 13 S. CAL. REV. L. & WOMEN'S STUD. 81, 154 (2003); see also, Barbara Bradley Hagerty, *An Epidemic of Disbelief*, THE ATLANTIC (July 22, 2019), <https://www.theatlantic.com/magazine/archive/2019/08/an-epidemic-of-disbelief/592807/>.

¹⁷⁷ *HIV Criminalization: A Challenge to Public Health and Ending Aids*, AIDS UNITED, https://www.aidsunited.org/data,/files/Site_18/2014AidsUnited-FactSheet-HIVCriminalization.pdf (last visited Jan. 14, 2020).

¹⁷⁸ See Arshy Mann, *Two Toronto-area men charged for HIV non-disclosure*, XTRA (Aug. 22, 2016), <https://www.dailyxtra.com/two-toronto-area-men-charged-for-hiv-non-disclosure-71776>.

¹⁷⁹ Ctrs. For Disease Control & Prevention, *HIV and STD Criminal Laws*, CDC.GOV (Jul 1, 2019), <https://www.cdc.gov/hiv/policies/law/states/exposure.html>.

¹⁸⁰ *Id.*

¹⁸¹ *Id.*

HIV/AIDS were largely considered to be a gay man's problem.¹⁸² Historically gay sex has been a threat to the dominant model of straight male sexuality. Enveloping gay sex within the hyper-masculine criminal justice system was a predictable response of the straight male legislators and other actors responding to their own homophobia.¹⁸³ As with many laws that seek to address social and health issues through criminal statutes, the focus on health care and health science becomes secondary.

In 2015, the Sero Project conducted a nationwide survey to determine the extent of stigma against those living with HIV with a particular focus on criminalization.¹⁸⁴ Among the findings, 78% of those surveyed felt that non-disclosure was a legal matter for the courts. When the laws were explained to the participants, 7% said that there should not be separate laws that treat people living with HIV differently and 93% state that these laws should be modernized.¹⁸⁵ The implication is that with HIV specific education, even those who favor disclosure law believe that scientific advances warrant revision of the criminalization laws. Yet the laws persist.

Among the criminalized behaviors is failure to disclose to HIV status to sex partners,¹⁸⁶ medical personnel and needle sharers.¹⁸⁷ High-risk behaviors that are criminalized range from prostitution to a variety of sex acts, such as anal and vaginal sex. Some states criminalize oral sex, spitting, biting, blood donation, organ, and tissue donation. Others include sharing sex objects.¹⁸⁸ Some states permit defenses and require the prosecution to prove non-disclosure in addition to proving the sex act and that one partner was HIV positive.

¹⁸² See *Lawrence v. Texas*, 539 U.S. 558 (2003); see also *Bowers v. Hardwick*, 478 U.S. 186 (1986).

¹⁸³ See Siobhán Elizabeth Stade Murillo, *Twenty-First Century Regression: The Disparate Impact of HIV Transmission Laws on Gay Men*, 30 EMORY INT'L L. REV. 623, 626 (2016) (“[a]s the link between AIDS and homosexuality became increasingly apparent, so too did vulgar prejudices towards gay men.” “The public’s response to the disease led to increased attacks on homosexuals, 35 and gay men became frequent victims of violence).

¹⁸⁴ Rosita Thomas, *HIV Criminalization, Attitudes and Opinions of the American Public*, THE HENNE GROUP (Jun 29, 2016), <http://www.seroproject.com/wp-content/uploads/2017/04/HIV-Criminalization-Presentation-Webinar-June-29-2016.pdf>.

¹⁸⁵ *Id.*

¹⁸⁶ FLA. STAT. ANN. § 775.0877 (West 2016); S.C. CODE ANN. § 44-29-145 (1976).

¹⁸⁷ V.I. CODE ANN. tit. 14 § 888 (2005); S.C. CODE ANN. § 44-29-145 (1976).

¹⁸⁸ Sergio Hernandez, *State-by-State: HIV Laws*, PROPUBLICA (Dec. 1, 2013), <https://projects.propublica.org/tables/penalties.html>.

Following conviction, sentencing of an HIV-related offense ranges from up three years¹⁸⁹ to life in prison.¹⁹⁰ In one case, a man was sentenced to 25 years in jail for a one-time encounter with a sex partner who was not informed of his HIV status.¹⁹¹ This sentence was imposed despite the fact that the HIV positive status partner was on antiretroviral therapy and used a condom.¹⁹²

Criminalization is problematic because state HIV laws often originate in fear but fail to reflect science. For example, there is no credible evidence that HIV/AIDS can be transmitted through spitting.¹⁹³ The same is true for oral sex, yet at least two states have specific criminal laws prohibiting non-disclosure for oral sex.¹⁹⁴ As one author notes, “close reflection demonstrates that a purportedly clear set of criminal laws rarely reflects the complexity of sexual interaction.”¹⁹⁵

Sadly, abused partners who are HIV positive cannot be certain that safety will be addressed by the courts when the abuser is not HIV positive. In one case, the partner of an HIV-positive woman was arrested for domestic violence. He retaliated by claiming that the woman never disclosed her HIV status. The abused partner testified

¹⁸⁹ *Indiana man who withheld HIV status gets longer sentence*, S. BEND TRIB. (Nov. 27, 2017), https://www.southbendtribune.com/news/publicsafety/indiana-man-who-withheld-hiv-status-gets-longer-sentence/article_0844f094-d399-11e7-975a-bb0e661a7f25.html (a northern Indiana man received a 3-year prison sentence for having sex with several women without disclosing his HIV positive status).

¹⁹⁰ *Id.*

¹⁹¹ *See* *Lawrence v. Texas*, 539 U.S. 558 (2003); *see also* *Bowers v. Hardwick*, 478 U.S. 186 (1986).

¹⁹² Sandra Young, *Imprisoned Over HIV: One Man's Story*, CNN HEALTH (Nov. 9, 2012), <https://www.cnn.com/2012/08/02/health/criminalizing-hiv/index.html> (the sentence was later reduced to time served plus five years of supervised probation).

¹⁹³ Ctr. for HIV Law & Policy, *Spit Does Not Transmit: Fact Sheet for Law Enforcement Professionals on the Risk of HIV Transmission in the Line of Duty*, HIVLAWANDPOLICY.ORG, https://www.hivlawandpolicy.org/sites/default/files/Spit%20Does%20Not%20Transmit_0.pdf.

¹⁹⁴ *Commonwealth v. Cordoba*, 902 A.2d 1280 (2009) (evidence was sufficient to show that the defendant's decision to engage in oral sex without disclosing HIV diagnosis constituted a gross deviation from standard of conduct that a reasonable person would observe and satisfied the criteria for reckless conduct); *State v. Mubita*, 188 P.3d 867, 925 (2008) (holding that oral sex was sufficient to support a conviction for transferring body fluid which may contain the human immunodeficiency virus.)

¹⁹⁵ Aziza Ahmed & Beri Hull, *Sex and HIV Disclosure*, A.B.A. (Apr. 1, 2011), https://www.americanbar.org/groups/crsj/publications/human_rights_magazine_home/human_rights_vol38_2011/human_rights_spring2011/sex_and_hiv_disclosure/.

that she had disclosed her status to the partner several years earlier.¹⁹⁶ The court focused entirely on the man's exposure to (even though the man tested negative for HIV) and sentenced the woman to jail for one year for sexual assault resulting from her non-disclosure of HIV status.¹⁹⁷ Similarly, the prosecution of sex workers for engaging in sex while HIV-positive falls heavily upon those who are already marginalized.¹⁹⁸

The burden of disclosure removes responsibility from the non-infected sex partner to inquire as to HIV status and take appropriate precautions. Since the criminal justice system uses a framework that labels involved parties as either perpetrators or victims, acknowledging an affirmative responsibility of those engaging in sexual conduct is ignored. Without this framework, the prosecution would lose its "perfect victim" theory and would demand that law enforcement address the multi-dimensions of sexual encounters and the complexities of the human beings involved.

HIV specific laws, as well as cultural perceptions of those living with HIV, can influence not only the ability to travel safely, but an individual's likelihood of being tested.¹⁹⁹ Even when HIV specific laws are not enforced, their existence is a reminder of the stigma that attaches to the diagnosis and that alone can lead to significant mental health responses as well as test avoidance.

More innovative and benevolent solutions are needed because current HIV criminalization laws do not promote increased disclosure or risk reduction. The psychological impacts of these laws on PLHIV are profound and many laws only reinforce and propagate stigma and frequent incidents of discrimination directed against PLHIV. These laws paradoxically undermine efforts to make individuals aware of

¹⁹⁶ Women's testimony, particularly that of abused women, is discounted in court proceedings. See Deborah Epstein & Lisa A. Goodman, *Discounting Women: Doubting Domestic Violence Survivors' Credibility and Dismissing Their Experiences*, 167 U. PENN. L. REV. 399 (2019).

¹⁹⁷ Ahmed, *supra* note 195.

¹⁹⁸ *Id.*

¹⁹⁹ See, e.g., FLA. STAT. ANN. § 796.08(5) (2016).

their HIV-seropositive status, disclose to partners, and/or seek testing and treatment for HIV.²⁰⁰

Perhaps the most well-known case is that of Michael L. Johnson of Missouri. He was sentenced to thirty years confinement after being found guilty of failing to disclose his HIV status to sexual partners.²⁰¹ None of the partners were infected.²⁰² An appeals court found that his trial was fundamentally unfair due to the failure of the prosecution to disclose evidence until the morning of trial.²⁰³ Additionally, the court found that Johnson's sentence was inappropriately long, noting that it was harsher than that for second degree murder.²⁰⁴ "His case, which encompasses a half-dozen years of court appearances, unflattering headlines and stints in solitary confinement, has galvanized advocates working to update laws that they say further stigmatize and unfairly penalize people with H.I.V."²⁰⁵ Johnson decided to accept a deal where he was immediately released but will be on parole for ten years.²⁰⁶

Johnson's case attracted HIV advocates because of accusations of racial bias in addition to HIV criminalization. Johnson, a former college athlete, is black and was portrayed as a monster. Four of his accusers are white.²⁰⁷ The overlay of images of the black man sexually abusing whites was part of the media discourse.²⁰⁸ Mr. Johnson is also among the thousands of African American individuals who are disproportionately charged throughout the criminal justice

²⁰⁰ Timothy Heckman, *How psychology can contribute to reforming HIV criminalization laws*, AM. PSYCHOL. ASS'N (Mar. 2017), <https://www.apa.org/pi/aids/resources/exchange/2017/03/reforming-hiv-laws>.

²⁰¹ Emily S. Rueb, *He Emerged From Prison a Potent Symbol of H.I.V. Criminalization*, N.Y. TIMES (July 14, 2019), <https://www.nytimes.com/2019/07/14/us/michael-johnson-hiv-prison.html>.

²⁰² *Id.*

²⁰³ *Id.*

²⁰⁴ *Id.*

²⁰⁵ *Id.*

²⁰⁶ *Id.*

²⁰⁷ *Id.*

²⁰⁸ Steven Thrasher, *How College Wrestling Star "Tiger Mandingo" Became An HIV Scapegoat*, BUZZFEED (July 7, 2014), <https://www.buzzfeed.com/steventhrasher/how-college-wrestling-star-tiger-mandingo-became-an-hiv-scap>.

system each year.²⁰⁹ Not surprisingly, those most frequently prosecuted under HIV disclosure statutes are African American.²¹⁰ While white HIV-positive individuals may be arrested, they less likely to be prosecuted.²¹¹

Each time an individual living with HIV is prosecuted for non-disclosure of status, the stigma that envelopes those living with HIV is strengthened. If the goal of these laws is deterrence, then the laws fail to accomplish this goal.

“Contrary to the expectations of commentators, courts, and legislatures, public health experts have been doubtful about the deterrent effect of criminalization. These experts point out that the fear of criminal punishment is not likely to affect sexual decisions because sexuality is highly complex and involves many different feelings and desires. Public health experts note that historically, lawregulating sexual behavior, such as sodomy statutes, have not effectively deterred such behavior.”²¹²

Studies support the observations that criminalization does not deter high risk behaviors.²¹³

C. Stigma and Confidentially

Presently, HIV/AIDS is not curable. However, the current state of treatment can result in suppressing the condition so that those living with HIV are not obviously symptomatic.²¹⁴ One participant in the study stated, “but basically if you get out there and you take care of

²⁰⁹ Timothy Williams, *Black People Are Charged at a Higher Rate Than Whites. What if Prosecutors Didn't Know Their Race?*, N.Y. TIMES (June 12, 2019), <https://www.nytimes.com/2019/06/12/us/prosecutor-race-blind-charging.html?module=inline>.

²¹⁰ AMIRA HASENBUSH, AYAKO MIYASHITA & BIANCA WILSON, HIV CRIMINALIZATION IN CALIFORNIA: PENAL IMPLICATIONS FOR PEOPLE LIVING WITH HIV/AIDS 1, 3 (2015) (a study by the Williams Institute regarding penal implications for people living with HIV found that African Americans are disproportionately impacted by HIV criminalization laws).

²¹¹ *Id.* (“[w]hite men were significantly more likely to be released and not charged”).

²¹² Sun G. Lee, *Criminal Law and HIV Testing: Empirical Analysis of How At-Risk Individuals Respond to the Law*, 14 YALE J. HEALTH POL'Y L. & ETHICS 194, 214 (2015).

²¹³ *Id.*

²¹⁴ Ctrs. For Disease Control & Prevention, *HIV Treatment*, CDC.GOV (Oct. 17, 2019), <https://www.cdc.gov/hiv/basics/livingwithhiv/treatment.html>.

yourself, the only way someone is going to look at you and say, oh, she's positive is if you come out and say it."²¹⁵ As previously mentioned, medical advances can suppress viral loads to zero.²¹⁶ However, this result is remission, not cure. Given the many stereotypes enveloping those living with HIV and the lingering fear of contraction, confidentiality of diagnosis is imperative.

Discovery and disclosure of HIV status is sometimes compulsory. Several jurisdictions require HIV testing upon arrest on prostitution charges, others upon conviction.²¹⁷ Once this testing is complete, disclosure of HIV status is not likely to remain confidential in the face of bureaucratic goals of warning sex partners and the inclination of criminal systems to engage in information sharing with other parts of the criminal justice system.²¹⁸ Florida offers voluntary testing for those arrested for prostitution.²¹⁹ In other jurisdictions, victims may request that the defendant be tested. Treatment is not necessarily offered for those who test positive; once found by the state to be HIV positive, sex workers then become targets for arrest for not disclosing the condition to sex partners.²²⁰

Mandatory disclosures of HIV status is part of some states' schemes when positive test results are given to a patient. This is different from disclosure prior to a sexual encounter. Mandatory disclosure requires that an individual with positive status give notice to prior sexual partners who could have been exposed.²²¹ This policy can discourage testing. For example, youth are among those most vulnerable yet are the least protected. Many young people are discouraged from seeking help with HIV prevention and treatment because of mandatory disclosure laws. As co-author Potter has noted, "one critical step toward achieving this end involves incentivizing at-

²¹⁵ Participant 113, (transcript on file with authors).

²¹⁶ Nat'l Inst. of Allergies & Infectious Diseases, *10 Things to Know About HIV Suppression*, NIAD (Nov. 14, 2017), <https://www.niaid.nih.gov/news-events/10-things-know-about-hiv-suppression>; See FLA. STAT. ANN. § 796.08(5) (2016).

²¹⁷ See FLA. STAT. ANN. § 796.08(5) (2016).

²¹⁸ CTR. FOR HIV LAW & POLICY, *HIV CRIMINALIZATION IN THE UNITED STATES: A SOURCEBOOK ON STATE AND FEDERAL HIV CRIMINAL LAW AND PRACTICE* 97 (3rd ed. 2017).

²¹⁹

²²⁰ *Id.*; see also HEATHER G. MILLER, CHARLES F. TURNER & LINCOLN E. MOSES, *AIDS: THE SECOND DECADE* 279 (1990).

²²¹ See generally, CTR. FOR HIV LAW & POLICY, *supra* note 218.

risk youth to seek care by safeguarding the confidentiality of that care.”²²²

Confidentiality is presumed in the medical world. The legal obligation of confidentiality applies to physicians and other medical personnel as well as those with access to medical information, such as insurers. Patients believe they have control over the medical information that is disseminated.²²³ Strict protections are in place under the Health Insurance Portability Act (HIPAA).²²⁴ Non-disclosure of confidential information is ideal; for those living with HIV, fear of disclosure is constant.

Those interviewed as part of the study discussed the ways in which their diagnosis was revealed. The most common was a hospital or clinic nurse or other worker. One participant recalled:

“There was a new receptionist and she was asking me questions about my insurance and that. And I told her I had Ryan White. And the area where people sat and waited was right there. And after I was done with her, I went and sat down and there was a gentleman sitting there. He got up and moved his seat.”²²⁵

This type of stigma within a medical setting is not unique. One study noted: “Attempting to avoid disclosure in the waiting room, laboratory, and pharmacy created additional obstacles for these participants and discouraged regular clinic attendance.”²²⁶ Another Southcoast study participant encountered disclosure at a local hospital pain clinic. Within earshot of those in the waiting room, a hospital worker loudly asked about the participants medications

²²² Jason Potter, *Prep and Our Youth: Implications on Law and Policy*, 30 COLUM. J. GENDER & L. 295, 357 (2015).

²²³ Katherin Bindey, *Your Health Data Is Not As Safe As You Think*, THE WALL STREET J. (Nov. 22, 2019), <https://www.wsj.com/articles/your-health-data-isnt-as-safe-as-you-think-11574418606>.

²²⁴ Health Insurance Portability and Accountability Act of 1996, Pub. L. 104–191, 110 Stat. 1936 (1996).

²²⁵ Participant 112, (transcript on file with authors).

²²⁶ Baligh Yehia et al., *Barriers and facilitators to patient retention in HIV care*, 15 BMC INFECTIOUS DISEASES 1, 3 (2015).

stating, “and the Complera.²²⁷ What is the Complera for? Do you have HIV?”²²⁸

The stigma can evidence itself within the medical professional itself. More than one participant reported that a specialist refused to treat them for unrelated medical concerns once the HIV status was disclosed. “I sat in his office for two hours and once I disclosed the doctor didn’t want to treat me.”²²⁹

HIV disclosure to an intimate partner can have frightening consequences. HIV-positive status can be used in custody disputes as an argument why the infected parent should not be awarded custody.²³⁰ Disclosure to family, friends, and co-workers can put the infected partner at risk both from losing important social contacts as well as a source of income.

Of course, disclosure of any medical condition has consequences. One woman who “worked in the field, she actually disclosed someone else’s status because her friend was gonna date this person.”²³¹ What is unusual about disclosure of a positive HIV status is that the misunderstandings around infection and how the infection is acquired remain rampant. If someone was not a target of social stigma prior to diagnosis, stigma is likely to be experienced post-diagnosis. The impact of stigma varies according to how much social capital the person living with HIV enjoys, but few escape some level of stigma.²³² Unlike some other life-threatening conditions, HIV carries blame with it, and a resulting shame. Those diagnosed with HIV will be judged to have been at a minimum sexually careless, but more likely promiscuous. Black women, in particular, are often

²²⁷ U.S. Dep’t of Health & Human Servs., *EMTRICITABINE / RILPIVIRINE / TENOFOVIR DISOPROXIL FUMARATE*, AIDSINFO (Nov. 11, 2019), <https://aidsinfo.nih.gov/drugs/441/complera/0/patient>.

²²⁸ Participant 104, (transcript on file with authors).

²²⁹ Participant 107, (transcript on file with authors).

²³⁰ Elicia Lee, *Difficult Custody Decisions Being Complicated by HIV*, N.Y. TIMES (Mar. 4, 1995), <https://www.nytimes.com/1995/03/04/nyregion/difficult-custody-decisions-being-complicated-by-aids.html>.

²³¹ Participant 106, (transcript on file with authors).

²³² Gwendolyn Barnhart, *The Stigma of HIV/AIDS*, *Am. Psychol. Ass’n*, (Dec. 2014), <https://www.apa.org/pi/about/newsletter/2014/12/hiv-aids>.

presumed not only to be promiscuous but to be sex workers.²³³ The same is assumed of young men, particularly young gay men.

In an ideal world, no judgment would exist as to how someone contracts HIV, but the U.S. is obsessed with sex and sexual behavior which most often evidences itself through judgment of others' sexual standards and behaviors.²³⁴ Uninfluenced by science-based evidence, the stigma continues to be a barrier for those living with HIV.

A sampling of cases evidences the extent of stigma and the resulting discrimination against those living with HIV include the following:²³⁵

- Military policy denying those living with HIV from enlistment, deployment or commissioning as an officer. The inability to be deployed usually results in discharge.²³⁶
- A man was denied a haircut in a Los Angeles barbershop due to the customer's HIV status.²³⁷
- Disclosure of HIV status due to a corporation's data breach impacted dozens of lower income people living with HIV.²³⁸
- A doctor's breach of confidentiality when he disclosed a patient's HIV status to a co-employee of the patient without the patient's permission.²³⁹
- A patient being denied treatment by a dentist because of the patient's disclosed HIV status.²⁴⁰ One study participant reported having to sue a dentist within the past three years because the dentist refused to treat him.²⁴¹

²³³ Monica Melton, *Sex, Lies and Stereotypes: HIV Positive Black Women's Perspectives on HIV Stigma and the Need for Public Policy as HIV Prevention and Interventions*, 18 RACE, GENDER & CLASS 295, 298, 300 (2011).

²³⁴ For example, American politics is currently embroiled in controversies surrounding LGBTQ+ rights, abortion, birth control, and other sex-related issues.

²³⁵ *Search results for "HIV Cases,"* LAMDA LEGAL, <https://www.lambdalegal.org/in-court/cases/all?keyword=&issue=11450®ion=All>.

²³⁶ *See generally* Harrison v. Shanahan, 2019 WL 2216474 (E.D. Va. May 22, 2019).

²³⁷ *See generally* Complaint, Briteramos v. King of Cuts, No. 2:18-CV-06400 (C.D. Ca. July 25, 2018).

²³⁸ Doe v. A. J. Boggs & Co., 2019 WL 1517567 (E.D. Cal. 2019).

²³⁹ Doe v. Dep't of Veterans Affairs, 519 F.3d 456 (8th Cir. 2008).

²⁴⁰ *See generally* Doust v. Dornfeld, No. MID-L-6905/02 (N.J. Super. Ct. May 13, 2003).

²⁴¹ Participant 107, (transcript on file with authors).

- An employee fired from his job when his HIV status was disclosed.²⁴²
- One participant reported losing clients because someone told them that the participant is HIV positive.²⁴³
- Another reported his girlfriend being placed on leave after a co-worker saw her at the hospital and learned the girlfriend is HIV positive. “Because you put your history out there, these are consequences. Now you’re getting treated like you are a f——g walking disease.”²⁴⁴
- A prisoner experienced administrative segregation and other disproportionate punishments compared with non-HIV positive prisoners.²⁴⁵

All of these and more are issues still encountered by HIV positive people despite prior successful litigation.

The stigma experienced by those living with HIV persists when public HIV education is limited. Several participants referenced the need for community education. “It’s been so long, and I’ve been dealing with this, I forget that young people coming up aren’t aware of different things like [HIV].”²⁴⁶ “[People need] a little bit more knowledge about HIV and how it is transmitted, things of that nature.”²⁴⁷ “People aren’t educated about this [HIV].”²⁴⁸

Multiple participants stated that they believe people generally are not culturally competent about LGBTQ+ issues. One stated, “I am just surprised at the number of unaware of what is happening right here.”²⁴⁹ Another stated, “There is still a lot stigma. People just do not want to interact with people who are infected.”²⁵⁰ Another stated, “People are not educated about this [how the virus is transmitted]. There is a lot of fear and there is a lot of anxiety. People don’t want to be judged (as HIV-positive) because they are in a relationship with

²⁴² See generally *Hickman v. Donna Curry Investments, LLC*, No. CV-S 06-0127-JCM (D. Nev. Dec. 20, 2006).

²⁴³ Participant 106, (transcript on file with authors).

²⁴⁴ Participant 404, (transcript on file with authors).

²⁴⁵ *Dorn v. Michigan Dep’t of Corrections*, 2017 WL 2436997 (W.D. Mich. 2017).

²⁴⁶ Participant 103, (transcript on file with authors).

²⁴⁷ Participant 105, (transcript on file with authors).

²⁴⁸ Participant 106, (transcript on file with authors).

²⁴⁹ Participant 105, (transcript on file with authors).

²⁵⁰ Participant 106, (transcript on file with authors).

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someone who is.” “When I told other people they completely backed away from me.”²⁵¹ “Most of the stigma I found is within the medical profession.”²⁵²

Despite medical and legal successes, discrimination touches most major aspects of life for someone living with HIV. One participant reported having her son taken away from her shortly after giving birth claiming that the woman could not care for her son due to her HIV status. Upon receiving a copy of the social service record, the participant discovered that the worker had written that the son was HIV positive when he was not.²⁵³ The health consequences of stigma are serious. Those concerned about stigma are less likely to receive consistent care.²⁵⁴

V. Research Outcomes and Analysis

A. Research Outcomes

1. Housing

During the beginning of the AIDS epidemic housing was identified as a critical need for diagnosed individuals. Landlords became less willing to rent to those living with the illness who were symptomatic; the resulting loss of income for someone weakened by the illness only compounded the problem.²⁵⁵

Since the 1990's, housing has been federally recognized as a particular problem for those living with AIDS. In 1992 Congress enacted the Housing Opportunity for People With Aids

²⁵¹ Participant 109, (transcript on file with authors).

²⁵² Participant 404, (transcript on file with authors).

²⁵³ Participant 404, (transcript on file with authors).

²⁵⁴ “Other research has suggested that stigma can be an impediment to consistent health care-seeking behavior due to lack of disclosure of HIV and/or MSM status to social network members which can result in hidden and often substandard care-seeking behaviors.” Amy Rock Wohl et al., *Barriers and Unmet Need for Supportive Services for HIV Patients in Care in Los Angeles County, California*, 25 AIDS PATIENT CARE & STDs 525, 529 (2011).

²⁵⁵ AIDS AND HOUSING, 2004 SUPPLEMENT, SEC. 6:02

(HOPWA).²⁵⁶The Ryan White CARE Act provided housing opportunities, as well.²⁵⁷

Although fewer patients are now symptomatic, discrimination is still prevalent. Landlords are still influenced by homophobia, racial discrimination, and fear of contraction by others. These biases contribute to landlords denying housing requests from those living with HIV. Similarly, the level of financial resources and source of income for those living with HIV can pose a barrier, even if the patients are financially able to obtain housing on the open market.

Source of income discrimination has also been identified as a continuing problem. Armen Merjian, Legal Director of the New York based HIV Law Project and Senior Staff Attorney for HousingWorks, Inc. noted that:

“Source of income discrimination is as rampant in New York as it is blatant. Given that tens of thousands of folks living with HIV/AIDS in New York depend upon subsidies and vouchers for their housing, this is hugely consequential for our community. To take but one example, one client utilizing a housing subsidy from HIV/AIDS Services Administration (“HASA”) sought the assistance of a real estate agency only to find that they repeatedly steered him to the very worst, vermin-infested apartments (an all-too-typical experience for those with public subsidies). He noticed, however, that there were lovely apartments advertised in the agency’s window, all within the range of his subsidy, and asked if he could view those apartments. ‘Sorry,’ the realtor responded. ‘Some of our apartments are for HASA clients and some are for regular people.’”²⁵⁸

²⁵⁶ See IND. HOUS. & CMTY. DEV. AUTH., HOUSING OPPORTUNITIES FOR PERSONS WITH AIDS (HOPWA): AWARD MANUAL 3 (2018); see also *Housing Opportunities for Persons With AIDS*, HUD EXCHANGE, <https://www.hudexchange.info/programs/hopwa/> (last visited Aug. 8, 2019).

²⁵⁷ Ryan White Comprehensive AIDS Resources Emergency Act of 1990, Pub. L. No. 101-381, 104 Stat. 576, (1990); see also *Ryan White Program*, DOORWAYS, <https://www.doorwayshousing.org/resources/ryan-white-program/> (last visited Oct. 12, 2019).

²⁵⁸ E-mail from Armen Merjian, Legal Director of HIV Law Project and Senior Staff Attorney, HousingWorks, Inc., to Margaret B. Drew (Aug. 8, 2019, 11:14 EST) (on file with author).

Southcoast study participants also identified housing as a barrier to maintaining good health. One of the Southcoast study participants described transportation and housing as the two greatest needs of those living with HIV in the area; “I’m in a much better place than most people. But [the greater needs] would be transportation and housing.”²⁵⁹ Another participant was grateful to simply find housing in a garage attached to his landlord’s house.²⁶⁰

Unstable housing continues to be a barrier to healthcare beyond treating HIV/AIDS itself. Lack of housing or having only transient housing is associated with increased depression rates.²⁶¹ The burden of homelessness due to poverty disproportionately falls on African Americans and Latinos.²⁶²

2. Transportation

The Southcoast study revealed that accessible and affordable transportation is the predominant need for those living with HIV in the Southcoast of Massachusetts; transportation can be a barrier to treatment for many chronic diseases.²⁶³ However, HIV/AIDS can present unique difficulties due to the limited number of physicians specializing in the field, in turn, often requiring frequent, and sometimes lengthy, travel. This study’s outcome is consistent with outcomes found in prior studies regarding the needs of those living with HIV. In a 2015 study of Philadelphia, PA, transportation was found among the reasons why those living with HIV might have inconsistent treatment histories.²⁶⁴ Transportation was fourth among

²⁵⁹ Participant 106, (transcript on file with authors).

²⁶⁰ Participant 404, (transcript on file with authors).

²⁶¹ Suzanne Dowlick Grieb, Melissa Davey-Rothwell & Carl Latkin, *Housing stability, residential transience, and HIV testing among low-income urban African Americans*, 25 AIDS EDUC PREV. 430, 437 (2013).

²⁶² The Henry J. Kaiser Family Found., *Poverty Rate by Race/Ethnicity*, KFF.ORG, <https://www.kff.org/other/state-indicator/poverty-rate-by-raceethnicity/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D> (last visited Aug. 8, 2019).

²⁶³ See Semina Syed, Ben Gerber & Lisa Sharp, *Traveling Towards Disease: Transportation Barriers to Health Care Access*, 38 J. COMMUNITY HEALTH 976, 976 (2013).

²⁶⁴ Yehia, *supra* note 226, at 4 (“Patients who were not retained in care more often (high tertile) discussed transportation-related challenges relative to other barriers, as compared to retained patients where transportation-related challenges were in the medium tertile”).

the needs identified; “specific issues included the inability to afford bus/subway passes or carfare, unreliable shuttle van services, and the impact of inclement weather on public transportation and bike riding. Some participants also mentioned heavy traffic and the cost and availability of parking as barriers.”²⁶⁵ Transportation as a barrier to care was reported highest among those having difficulty maintaining consistent care.²⁶⁶

A separate study was conducted in Los Angeles County in 2011.²⁶⁷ That study inquired into the types of services needed by participants during the preceding twelve months. Transportation was the fourth ranked unmet need, only after the need for dental services, case management, and mental health counseling.²⁶⁸ Among the reasons for transportation difficulty was inability to pay.²⁶⁹ The Southcoast study obtained a similar result except that transportation was ranked as the number one need.

Accordingly, rural communities face more transportation barriers.²⁷⁰ A study conducted with rural women in California found transportation as the second most identified barrier to receiving healthcare; the first being inability to make appointments due to poor health.²⁷¹ Patients reported the most problematic health barriers included taking public transportation or relying on someone else to drive them. Recognizing that transportation is a barrier to HIV healthcare in rural areas has been recognized for many years.²⁷² One of the earliest studies of healthcare barriers in Wisconsin noted that rural residents were far more likely to place transportation difficulty

²⁶⁵ *Id.* at 4.

²⁶⁶ *Id.* at 1.

²⁶⁷ Wohl, *supra* note 254, at 529.

²⁶⁸ *Id.* at 527 (“[a]ssistance finding dental services (39%), HIV case management (34%), mental health counseling (30%) and transportation support (23%) were the services most commonly needed by participants”).

²⁶⁹ *Id.* at 530.

²⁷⁰ Christiane Brems et al., *Barriers to healthcare as reported by rural and urban interprofessional providers*, 20 J. INTERPROFESSIONAL CARE 105, 114 (2006) (traveling to provide HIV related services in rural areas was identified as a barrier for providers, as well).

²⁷¹ Clea C. Sanquist et al., *Rural HIV-infected women’s access to medical care: ongoing needs in California*, 23 AIDS CARE 792 (2011) (“[t]he most commonly cited barriers to accessing care included physical health problems that prevented travel to care (32.8%), lack of transportation (31.2%)”).

²⁷² *Id.* at 794.

as a health care barrier given the long distances they needed to travel to access health care services.²⁷³ More recently, a Washington state study placed transportation as one of the most significant barriers to receiving health care and anti-retroviral therapy (ART).²⁷⁴

B. Findings

Furthermore, housing and transportation were also identified as significant barriers in receiving healthcare for those participating in the Southcoast study. Transportation being identified as the most prominent issue in the Southcoast is significant because this result is less expected in urban areas than rural areas. Urban HIV studies generally place transportation as a difficulty, but not the primary need.²⁷⁵ In this regard, the Southcoast study results are more like the results of studies conducted with people living with HIV in rural America.²⁷⁶

A reason for transportation being the number one need in rural areas is attributed to the availability of resources as well as poverty. This is the case in Fall River and New Bedford. We know that “reduction of HIV in the population as a whole is contingent on delivering timely and consistent medical care to infected persons in hard-to-reach communities.”²⁷⁷ Accordingly, “transportation vulnerability includes two key components: 1) transportation

²⁷³ Timothy Heckman et al., *Barriers to care among persons living with HIV/AIDS in urban and rural areas*, 10 AIDS CARE 365 (1998).

²⁷⁴ Julia Dombrowski, *Barriers to HIV Care and Treatment Among Participants in A Public Health HIV Re-Linkage Program*, 29 AIDS PATIENT CARE & STDs 279, 280-81 (2019).

²⁷⁵ At first glance a Detroit study seems comparable to the Southcoast study as Detroit, Fall River and New Bedford share higher than average rates of poverty. However, the Detroit study began with the hypothesis that if women were provided regular and free transportation to their medical appointments, greater medical compliance would result. That hypothesis was supported for women who did not have mental health concerns or substance abuse. The participants were not surveyed with open ended questions as to what their greatest needs were. Marsha Anderson, et al., *Retaining Women in HIV Medical Care*, 18 J. ASSOC. OF NURSES IN AIDS CARE 3, 13 (2007).

²⁷⁶ Likewise, a 2016 Georgia study focused on transportation as a barrier to consistent HIV treatment. Transportation availability was assessed per county and correlated with the ability of those living with HIV to access consistent treatment. Neela D. Goswami et al., *Understanding Local Spatial Variation along the Care Continuum: The Potential Impact of Transportation Vulnerability on HIV Linkage to Care and Viral Suppression in High-Poverty Areas, Atlanta, Georgia*, 72 J. ACQUIRED IMMUNE DEFICIENCY SYNDROMES 65, 66 (2016).

²⁷⁷ *Id.* at 66.

availability, the presence of transportation resources in a geographic area, and 2) accommodation, the linkage between healthcare and transportation systems.”²⁷⁸ Thus, “lack of access to services due to transportation difficulties, travel distances, and healthcare costs were reported overwhelmingly more by rural than urban providers.”²⁷⁹

Boston has an extensive public transportation system but some might be surprised to know the transportation systems in smaller Massachusetts cities are not as comprehensive. Transportation consists primarily of bus service with some service by van for those who qualify. The local transportation administration is hampered by the same funding concerns that plague Fall River and New Bedford public administrations. Both poverty and lack of transportation availability are the leading causes of the difficulties facing Southcoast study participants, which one participant described as “weird.”²⁸⁰ Another stated, “[t]his city is terrible to live in without transportation.”²⁸¹ Another succinctly said, “[t]ransportation is a big issue.”²⁸²

For many, difficulties arise because of scheduling. Bus service is limited in some areas; at the time of the study, evening bus service was not available at all. Some improvements have been made; for example, limited evening service is now available. However, even with expanded schedules, service can still be difficult to navigate. The road on which one of the medical facilities is located, does not have marked bus stops and requires riders to flag down the bus. One study participant complained that, “one day I may have an appointment at 2[p.m.] and the next day at 8[a.m]. I was going for physical therapy. Now I go for pain management and all the appointments are at a different time and you can’t tell the bus to pick you up.”²⁸³ Although many participants in the Southcoast study reported having a case manager, the inability to coordinate health care appointments and providers complicates access to healthcare. For this reason, case

²⁷⁸ *Id.*

²⁷⁹ Brems et al., *supra* note 270, at 114.

²⁸⁰ Participant 105, (transcript on file with authors).

²⁸¹ Participant 106, (transcript on file with authors).

²⁸² Participant 117, (transcript on file with authors).

²⁸³ Participant 116, (transcript on file with authors).

management and transportation have been top concerns and priorities of those living with HIV.²⁸⁴

Those with disabilities and limited income may qualify for a discounted bus pass. The discount card permits riders to pay less than half of the standard fare.²⁸⁵ Even with the discounted rate, some riders struggle to pay the fare while others find that they cannot attend medical appointments after five or six p.m. because the buses stop running; “five o’clock and they (the buses) stop and you don’t see another bus.”²⁸⁶

Community providers agree; one stated that, “[t]ransportation is, and has always been an issue. Many individuals do not [have] transportation at all and require assistance. Aside from public transportation, many individuals try to obtain transportation from transportation assistance, however many of the companies require two-days advanced notice for pick up. Often there are delays due to insurance company (approval), which results in the individual not being able to secure a ride and appointments are missed.”²⁸⁷

Another provider noted that, “[e]ven though there is bus transportation to bring individuals to and from doctor’s appointments, it is not open to everyone and so many individuals face the difficulty of being able to get \$1.75 to be able to take the bus.”²⁸⁸

For many, the cost of purchasing and maintaining a vehicle is prohibitive. For others, the cost of maintaining a vehicle means devoting a significant portion of his or her monthly income to the vehicle. One participant echoed a familiar sentiment, “you live down here? You need a vehicle. And if you get 800 bucks a month to actually get a vehicle on the road, and insure it, and maintenance and everything else is almost impossible. And just for medical appointments alone. I’m all over the place doing medical stuff. . . There is no way I would be able to get there without my own vehicle. I mean, it’s just tough.”²⁸⁹

²⁸⁴ Anderson et al., *supra* note 275, at 34.

²⁸⁵ Se. Reg’l Transp. Auth., *Access Pass / Reduced Fare Card*, SRTABUS, <http://www.srtabus.com/access-passes> (last visited Jan. 12, 2020).

²⁸⁶ Participant 119, (transcript on file with authors).

²⁸⁷ Stover, *supra* note 5, at 3.

²⁸⁸ *Id.*

²⁸⁹ Participant 106, (transcript on file with authors).

VI. Conclusion

An analysis of the results of the Southcoast study dispels any doubt that transportation is a significant barrier maintaining consistent medical care in urban areas as it is in rural communities. Along with other barriers, transportation inadequacies are more likely to occur in smaller, poorer cities with limited transportation options. Legal, medical, and other service providers must be cognizant of poverty as a limitation on providing direct services to his or her clients. Some major cities have adequate or thriving public transportation systems, but for smaller urban but densely-populated areas, the existence of a public transportation system does not always equate to sufficient access to regular healthcare treatment. The Southcoast study participants prove that even those with sufficient income to live healthy lifestyles, may face insufficient resources to own or maintain a vehicle. This results in imperative transportation needs in a location where the transit system has difficulty accommodating many patient needs.

Before documenting clients as non-compliant, or in the case of legal services – uncooperative – providers must consider the difficult lives of those living with HIV. In addition to the complication or inability to access transportation, patients may be combating intimate partner violence, social stigma, inability to secure safe housing, and/or even criminal proceedings based on their HIV status. When these stressors are experienced in conjunction with a transportation deficit the results are exponential.

Medical and legal providers must take more of a role in providing accommodations for those who have unreliable transportation services. Lawyers, particularly those who provide pro bono services, might consider a variation of the case management system provided by many HIV medical providers. Providing alternative methods of communication, such as video or telephone conferencing may lessen transportation barriers for clients. Addressing client transportation needs well in advance of when a client's physical presence is required will reduce stress for both the client and the lawyer. Lawyers must be flexible in scheduling with those for whom transportation poses a financial hardship. Finding an alternative meeting space for clients

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who may be able to walk to a neighborhood library, for example, will help in maintaining consistent communication with them. Creative and non-traditional solutions are needed when serving marginalized communities, particularly those living at the intersection of poverty and serious medical conditions. Transportation equity in all communities is a laudatory goal. Until that goal is achieved, cultural competency demands that providers think beyond their traditional responsibilities when serving our most vulnerable populations. This includes assisting with adequate transportation needs.