# Chapter 9: Sex Work and the HIV Continuum of Care

# **Introduction**

This chapter explores the experiences of sex workers within the HIV continuum of care (CoC) that is made up of HIV education, prevention, and treatment in the United States. Sex workers have long been framed as vectors of disease within the United States and this chapter looks to provide and understand alternative narratives of disease, disease prevention, and wellness among sex workers. This project explores the experiences of the HIV CoC specific to sex workers and situates these experiences in a historical context. This research examines how and why these experiences diverge from those of the general public and explores, how the HIV CoC could be more sex worker-friendly and what operating within a rights-based framework would look like for the HIV CoC. Carried out through the community-based research the remainder of this book focuses on, this project also highlights the importance of research that is developed by sex workers and informed by their understanding of the nuances of the sex industry and decades of experience in organizing to promote better conditions for sex workers. Through this human rights-based approach, this research explores how the HIV CoC can serve to alleviate or prevent discrimination faced in other sectors of a sex worker's life. Major topics of this chapter include:

- 1. *Divergent experiences and discrimination:* Analysis found that sex workers experience preventative, screening, and educational services within the HIV CoC differently than the general public. Findings include that sex workers', are hesitant to disclose their occupation (58% have never disclosed), face discrimination when their occupation is disclosed, field inappropriate questions or advances due to their work, and find assumptions about their health behaviors being made.
- 2. *Effective care for Sex workers:* This research found many concrete ways HIV care could serve sex workers more effectively. Findings include: publicizing acceptance of sex workers, treating sex workers with the same respect as other patients, not making assumptions about the health risks of sex work, and sex worker-specific training. To improve the experiences of sex workers within the HIV CoC, it is critical to reconsider and avoid assumptions about the needs of sex workers and acknowledge how their work is separate from the discrimination they face outside

of healthcare due to restrictive policy and widespread stigma. This study finds that alleviating social isolation is key to maintaining health. The nature of this research as a community-based project also speaks to the importance of grassroots organizing among sex workers to create support networks among a population that is often isolated socially from each other and the public.

3. Conclusions and Implementing Rights-Based Healthcare for Sex workers: Sex workers have been identified as a key population in HIV/AIDS research and care but current measures do not effectively reach and care for this population. Understanding the distinctions between healthcare that treats sex workers as vectors of disease as opposed to patients whose rights should be upheld is critical in reconsidering how the HIV CoC could better care for sex workers. Changes within the structure of HIV services and the way in which providers interact with sex workers could allow sex workers to maintain HIV- negative status and improve their health more broadly. Acknowledging and working to remove stigma within HIV care could serve to provide an example of how other sectors should be framing their work that addresses sex workers; through a right-based approach in which sex workers are listened to and supported as any other population would be.

In the United States, moral condemnation and strict policing have long accompanied working in the sex industry.<sup>i</sup>The belief that sex workers are responsible for the outbreak and spread of numerous sexually transmitted infections has furthered this judgment and punishment throughout US history. Within the realm of public health, the first widespread research on syphilis and gonorrhea during the Progressive Era designated sex workers as a "social evil" and dangerous vectors of disease. <sup>ii</sup> This perception of sex workers as a primary cause of STIs does not remain intact today in the way it existed in the Progressive Era but has influenced the development of modern healthcare practices. The emergence of HIV in the US in the 1980s brought about another wave of concern that sex workers as primary vectors of transmission.<sup>iii</sup> In the decades since sex workers have been identified as a key population experiencing a disproportionate incidence of HIV and focused upon in HIV research and care.<sup>iv</sup>

The relationship between sex work and HIV remains of great interest in the United States but is often studied in isolation from other areas of the lives of sex workers. Subjects such as the pervasive stigma surrounding sex work and the criminal status of many parts of the sex industry remain less central to mainstream discussions of the sex industry than the subject of HIV among sex workers. For many decades, rights-based groups founded by and for sex workers have pushed back on this myopic view of HIV as independent from the conditions of sex workers within the US. Sex workers' rights advocates view health as a right that can only be upheld along with the rights to fair labor conditions, housing, education, and freedom from violence and stigma.<sup>v</sup> This approach also emphasizes the importance of understanding how discrimination and violence along the lines of race, class, gender, sexuality, disability, and immigration status compound the difficulties sex workers face in maintaining their human rights. This rights-based approach situates HIV within a much broader context than public health; however, the conclusions of work focused on solely HIV and sex work are similar. Positive outcomes regarding HIV among sex workers can only be achieved through support inside and outside of healthcare.<sup>vi</sup>

This chapter looks to understand the experiences of sex workers across the United States within the HIV continuum of care (CoC), which is the educational, preventative, and treatment programming surrounding HIV. Through a multi-methodological analysis, this research looks to explore what the experiences of sex workers within the HIV CoC are and how these experiences relate to the historical and current view of sex workers in policy and public perception. <sup>vii</sup> The multi-methodological design of this study not only fills in the gaps in the analysis that may appear between methods but also examines areas of disagreement or agreement between fields and what this dissonance signifies. This examination of the experiences of sex workers within the HIV continuum of care grants an understanding of how existing healthcare structures serve or fail this key population. Situating these experiences in the broader context of sex workers' rights creates ways in which the HIV CoC could more effectively and compassionately care for sex workers and address discrimination faced in other areas of a sex worker's life.

### Primary Areas of Research

The primary areas of inquiry were developed for this research a priori based on a literature review and during the course of data analysis using grounded theory. Qualitative analysis using grounded theory involves reading through and beginning to code the data as a way to formulate primary areas of research. <sup>viii</sup> In this way, the data itself guides the major questions being asked and areas of inquiry in this project in order to avoid assumptions, biases, and expected outcomes in the primary questions being investigated. The three main questions include:

- 1. How sex workers experience the HIV CoC in the United States.
  - a. Why these experiences occur and the influence of morality, lack of training, disclosure, income verification, and nature of sex work.
  - b. How the narrative of sex workers as vectors of disease plays into treatment. Ways in which this narrative still exists and is true or untrue. How this impacts the quality of care sex workers receive.
  - c. Potential positive and negative impacts and ways in which this dynamic creates a complete or incomplete picture of patient health.
  - d. Disclosure of sex workers' status in clinical encounters.
- 2. How the HIV CoC serve sex workers better through a rights-based approach, what would this look like, and what the implications of these changes would be?
  - a. What sex workers want from the HIV continuum of care, on its own, and as it relates to other healthcare.
  - b. What sex workers think sex worker-friendly care looks like.

- c. How sex worker's needs are different than other groups and how these differences should be addressed.
- d. Possibility of providing HIV services within a rights-based approach.
- e. How a right-based approach is different from the current existing approach. Whether or not the conclusions are similar.
- f. How current clinical/public health workers could function within a right-based framework and what forms of policy and/or public perception change would be necessary.
- g. If rights-based, whether or not the HIV continuum of care and sex worker-friendly healthcare, in general, could serve as a site to Remedy discrimination in other sectors OR Influence stigma in and out of medicine and serve to prevent and remedy discrimination.

Current public health literature and healthcare guidelines address sex workers as a patient population in need of care; however, much of the interest in sex workers is founded upon the history of moral disapproval and the idea of sex workers as vectors of disease.<sup>ix</sup> Language in HIV research has largely shifted away from designating sex workers as vectors of disease, but this study looks to see if this notion remains in the clinical encounter and HIV programming. Through hearing directly from the respondents of this survey is it possible to fully understand the realities of whether or not healthcare continues to regard sex workers as vectors of disease. This qualitative analysis also allows for the experiences of sex workers within healthcare to be understood as multi-faceted and impacted not only by stigma and policing specific to sex workers but also the stigma, policing, and violence born out of racism, classism, transphobia, homophobia, ableism, and anti-immigrant sentiments.

### <u>The HIV Continuum of Care in the United States</u>

As this project focuses on the experiences of Sex workers within the HIV CoC within the United States, it is first necessary to understand what the HIV CoC encompasses. This term refers to a loosely organized network of services and programming related to HIV rather than to a well-defined and structured system. The Center for Disease Control defines the CoC as four primary steps: diagnosis and screening, linking to care, received and retained in care, and viral suppression so that the levels of virus in the blood remained at a level that would make infecting other people unlikely.<sup>x</sup> Within this project and other recent publications, this continuum of care also includes preventive services for HIV negative populations.<sup>xi</sup> These preventative services include education surrounding HIV, harm reduction efforts (needle exchanges, condom distribution, PrEP), and viral suppression as prevention of further infections. In this way, the HIV CoC does not impact only HIV positive populations; HIV negative populations may become very involved in the CoC through screening and preventative measures.

#### Research on Sex Workers and HIV

Given the far-reaching impacts of HIV and HIV prevention efforts, research on topics surrounding HIV occurs in almost every academic field and over thirty years of literature now exists on HIV. Research on HIV/AIDS does not fall within the HIV CoC but will also be discussed throughout this project because research on HIV is fundamental in developing the HIV CoC that exists today. Research also plays a critical role in shaping how different populations are perceived through the conclusions that are made about these populations and their relationship to HIV incidence and transmission. HIV research constructs the framework through which these populations are regarded and cared for in clinical encounters in addition to outside of healthcare settings. This project will examine primarily HIV research that is carried out through a public health and medical sciences framework. Research operating within a public health framework is population-based and emphasizes collective responsibility for health, health protection, and disease prevention. Tools used within public health are varied but may incorporate social science, biological, or clinical methodologies. Within public health research, sex workers have been defined as a key population that experiences disproportionate rates of HIV infection. Other key populations reported by the WHO include men who have sex with men (MSM), injection drug users (IDUs), transgender women (TW), and people in prisons and other enclosed settings.<sup>xii</sup> Sex worker's designation as a key population allows for research on sex workers and HIV to be prioritized, and a large volume of literature on sex workers and HIV has been written in the past 20 years. From January 2000 to December 2018 along, 776,000 publications can be found on the search engine Google Scholar and 4,313 publications on PubMed that address sex workers and HIV. This research studies the incidence of HIV among sex workers, behaviors that cause HIV infection in sex workers, how sex workers spread HIV, and the effectiveness of HIV interventions with sex workers.

In recent years, research on sex workers and HIV has remained a priority among HIV research. These recent publications arrive at very different conclusions than publications from twenty and thirty years ago that largely concluded that sex workers remain a threat to the general public as HIV carriers. <sup>xiii</sup> These recent publications, and reviews of these publications, find that sex workers engage in health behaviors that are largely similar and in many cases more cautious than the general public. <sup>xiv</sup> Many of these studies find that behaviors that make sex workers more susceptible to contracting or spreading HIV are often brought about by economic constraints such as being pressured into having unprotected sex for more money by clients.<sup>xv xvi</sup> Additionally, these publications highlight that there are many structural barriers sex workers face in accessing the same quality HIV care that other populations utilize to prevent or treat HIV. x<sup>vii</sup>, In addition, many of these papers find that stigma, violence, and legal persecution of sex workers contribute to poor HIV outcomes among sex workers and that in order to improve HIV outcomes, other fundamental rights of sex workers must be upheld. <sup>xviii xix xx xxi</sup> In this way, current public health literature arrives at a similar conclusion to much of the work being carried out in the realm of the sex workers rights movements: that in order for HIV incidence to decrease among sex workers, their rights in all areas of life must be upheld.

### Key Populations and PEPFAR's Anti-Prostitution Pledge

This study follows more than thirty years of publications referenced above that examine the relationship between sex workers and HIV/AIDS. <sup>xxii</sup> Throughout this complex history, the way in which sex workers have been defined and regarded within the field of public health has remained dynamic. Prior to the emergence of HIV, biomedical publications were largely concerned with sex workers in relation to sexually transmitted infections such as syphilis and gonorrhea and regarded sex workers as vectors of disease. <sup>xxiii</sup> While described as a "vector for transmission" in earlier HIV publications, sex workers are now defined as a key population within the field of HIV. The designation of key population means that the group experiences a disproportionate incidence of HIV.<sup>xxiv</sup> Many recent studies have supported this designation, with sex workers being shown to experience a rate of HIV infection 15 times that of the general US population: 12% HIV infection among sex workers as opposed to 0.7 – 0.9% among the general population.<sup>xxv</sup> As a key population, additional support is given to programming and research focusing on sex workers by federal governments and international organizations such as the UN and the WHO.<sup>xxvi</sup> Despite the intention of caring for sex workers as a key population, two key events from the past 20 years suggest that current HIV interventions are working through a framework that is not effective in caring for the health of sex workers and continues to view sex workers as dangerous vectors of disease instead of a population worthy of care and inclusion in HIV efforts.

The US President's Emergency Plan for AIDS Relief (PEPFAR) was signed into law 2003 to provide financial support for HIV/AIDS programs across the globe, with a focus on Africa. xxvii PEPFAR allocated funding for HIV education, prevention, and treatment programs, and in order to receive PEPFAR funding, low and middle-income nations had to agree to a series of conditions. One of these conditions is an anti-prostitution pledge (APP) that requires nations receiving PEPFAR funding to pledge to instate and adhere to laws criminalizing sex work. xxviii The PEPFAR guidelines explain that the program is "opposed to prostitution and sex trafficking because of the psychological and physical risks they pose for women, men and children." xxix Supporters of this pledge declared that criminalizing sex work was critical to "solving" the HIV/AIDS crisis, under the belief that sex work is exploitative and sex workers harbor and spread the virus.<sup>xxx</sup> Since the creation of PEPFAR, a UN report on discussing sex work and HIV has been published. HIV and the Law: Risks, Rights, and Health concludes that decriminalizing sex work worldwide would improve health outcomes across the board and calls for sex work to be decriminalized. xxxi PEPFAR policies have been brought to court, and in June 2011 a US appeals court ruled that the pledge violated the US Constitution. As a result, the government cannot enforce the pledge against US-based members of InterAction and the Global Health Council. xxxii, However, the APP remains in place for organizations outside the US, and the few US organizations not protected by the lawsuit. xxxiii Pushing the criminalization of sex work via this pledge cuts sex workers off from critical HIV care and other supports systems in their lives. Healthcare providers, researchers, and activists worldwide criticized this policy for endangering sex workers worldwide. <sup>xxxiv</sup> This policy also imposes the US belief of sex work as morally reprehensible and criminal in regions where it was not previously regarded as such.xxxv

Many nations such as Cambodia and Bangladesh tightened anti-prostitution laws in response to this relief plan in order to maintain funding for HIV services that previously supported sex workers. <sup>XXXVI</sup> Other nations, such as Brazil, refused the \$40 million of funding in protest of the anti-prostitution pledge. <sup>XXXVII</sup> Brazilian authorities declared that this requirement undermines the country's efforts to fight HIV/AIDS, which have traditionally included policies written based upon the recommendations of sex workers. This clear messaging made the

PEPFAR program aware of the contributions of sex workers and how they have been critical in developing comprehensive HIV programming in Brazil, and that explicitly opposing prostitution would not only make the lives of sex workers more difficult but would also alienate a key ally in developing HIV care. This message was clear and public but did not result in any changes to the policy, and the PEPFAR conditions include the anti-prostitution pledge to this day.

# Exclusion from the 19th International AIDS Conference and The Sex Workers Freedom Festival

Nine years after PEPFAR was put into place, another key event in the relationship between the field of HIV in the US and sex workers' rights took place. In 2012, the 19th International AIDS Conference was held in Washington, D.C. to celebrate the Obama administration's repeal of the travel ban on HIV positive individuals. xxxviii This revised policy allowed HIV positive individuals to enter the country for the first time in 22 years. However, the travel ban on sex workers and injection drug users entering the United States remained, and no open sex workers were able to enter the country to attend the conference. Hundreds of sex workers had planned on attending and presenting at the conference, as they had contributed to efforts worldwide to address HIV.<sup>xxix</sup> In reaction to the travel ban and continued alienation of sex workers within HIV programming through US policy, the Sex Workers Freedom Festival was organized in Kolkata, India. A gathering of over 550 representatives from sex workers rights organizations from 41 countries, this festival coincided exactly with the 19<sup>th</sup> International AIDS Conference (working with the 9.5 hour time difference). Attendees of the Sex Workers Freedom Festival presented their findings and workshopped with sex workers carrying out similar work in other environments. By the end of the festival, the attendees had outlined a statement in which they demanded freedoms for Sex workers. The seven freedoms for sex workers included: vl

- 1. Freedom of movement and to migrate.
- 2. Freedom to access quality health services.
- 3. Freedom to work and choose an occupation.
- 4. Freedom to associate and unionize.
- 5. Freedom to be protected by the law.
- 6. Freedom from abuse and violence.

#### 7. Freedom from stigma and discrimination.

These freedoms align with many of the conclusions reached the International AIDS Conference in the United States: in order for the HIV crisis to be solved, human rights in other areas of life must be upheld. <sup>xli</sup> Even in the presence of similar findings, and ultimately the same desire for individuals and communities to live healthy lives, a disconnect remains between the HIV field in the US and sex workers, as shown by these two events and others. This study looks to understand the realities of navigating the HIV CoC as a sex worker in the United States and how these realities came to be. Through exploring how and why the HIV CoC in the United States cares for sex workers in the way that is done, it is possible to imagine how the HIV CoC could more effectively and compassionately treat sex workers. Examining the work and demands of the sex workers' rights movement can provide additional insight into how HIV among sex workers can be more justly addressed.

# Part I: Understanding How Sex Workers Experience the HIV Continuum of Care

The results of the qualitative and quantitative analysis indicate that sex workers experience the HIV continuum of care in the United States differently than people that have never worked in the sex industry. This research looks to situate the experiences described by respondents in a historical context in order to understand why these experiences happen and how existing HIV structures and perceptions of sex workers came to be.

## Sex Workers and Moral Prophylaxis during the Progressive Era

The United States has a long history of regarding sex work as an immoral activity that leads to sickness not only for the sex worker but also for society as a whole. <sup>xlii</sup> During the Progressive Era, the period in the United States between 1898 and 1917, many developments took place in the field of public health amid broader social, political, and industrial change. Following the Spanish-American War, the US emerged as a great power and vast changes occurred in communications, transportation, immigration, migration, gender roles, family structure, class structure, work patterns, business methods, education, intellectual life, religion, the professions, technology, science, and medicine. <sup>xliii</sup> The scope and feel of people's lives and relationships rapidly transformed and in many ways the events of era set the agenda for the rest of the 20th century. Public health practices became more institutionalized during this era and in 1905 The American Society of Sanitary and Moral Prophylaxis was founded to promote sex education and study the "sanitary, moral, and administrative" ways in which prostitution could be eliminated." <sup>xliv</sup> This organization looked to eliminate syphilis and gonorrhea and was based on the notion that venereal disease is retribution for sexual immorality and that social evils must be removed in order for "the race" to flourish. "The race" refers to the white middle and upper class and the efforts of the social hygiene movement of the Progressive Era was founded upon protecting "the race." <sup>xlv</sup> The social hygiene movement focused on abolishing vice industries, such as prostitution, gambling, and alcohol, throughout the country. Prior to 1915, prostitution was illegal only in streets and tenements in cities such as NYC, and there were many loopholes that allowed women to practice prostitution even in these locations. <sup>xlvi</sup> However in 1914, the NYC legislature passed the Herrick Injunction and Abatement Law removing legal loopholes and making prostitution illegal in all parts of the city. <sup>xlvii</sup> Many brothels closed in the following years, police involvement in prostitution steeply decreased, and newly enacted laws were strictly enforced.  $^{\mbox{\tiny xlviii}}$ 

Medical and moral framings continued to exist in conjunction; the prostitute remained stuck in the paradigm of being viewed as both the helpless victim in need of saving and the sexually deviant locus of disease. Laws constructed during the Progressive Era had an immediate impact on the practice of prostitution, and laws created during this era, such as the Mann Act, remain in place today. The extent to which sex workers are still seen as vectors of disease today is more difficult to measure and identify than any policy or law. This perception of sex workers can be found in clinical interactions mentioned by respondents as well as in public health research. Terms such as "vectors for transmission" and "vector of disease" continue to appear in how sex workers are regarded.<sup>XLIX1</sup>This perception frames the sex work as dangerous and malicious, furthering the notion that sex workers are morally inferior and only deserving of care due to their threat to the rest of the population.

### The Relationship Between Sex Workers and Healthcare Providers

This chapter focuses on the experiences of HIV-negative sex workers because of the 706 respondents that disclosed their HIV status, only 4 reported being HIV positive while 686 reported being HIV negative and 16 did not know their HIV serostatus. For this reason, the results of this study focus on the experiences of sex workers that are not HIV positive or not aware of their serostatus and not on sex workers that are HIV positive, as a sample of 4 respondents is too small to draw any conclusions.

The respondents reported being involved in a range of different occupations within the sex industry and the majority of respondents had worked in more than one area of the sex industry throughout their careers. The majority of respondents, 83%, are currently working in the sex industry while 17% have formerly worked within the sex industry. The results of the quantitative, qualitative, document and ethnographic participant observation analysis focus on how these HIV negative sex workers interact with more upstream interventions and programming within the HIV continuum of care, such as education, screening, outreach, specialized sexual health clinical encounters, and other prophylactic measures. In brief, this analysis found that not only did HIV negative sex workers have many complex interactions with HIV services, but that many aspects of these interactions were shaped by their involvement in the sex industry.

In reporting their histories within the HIV continuum of care, respondents discussed

many aspects of hesitation surrounding disclosing their involvement in the sex industry to their providers. In a variety of settings (walk-in clinics, PCPs, screening events), **58.3% of respondents reported that they did not disclose their involvement in the sex industry to their providers and 41.7% of respondents did disclose their status as sex workers.** This aligns with the results of community-based research among transgender sex workers; the majority of sex workers choose not to disclose their involvement in the sex industry.<sup>li</sup> Respondents cited many reasons for choosing not to disclose their status as sex workers, the most frequent being:

- 1) Fear of receiving judgment from providers,
- 2) Fear of receiving lower quality treatment from providers
- 3) The belief that their status as sex workers was unrelated to their health concerns.

Many respondents also stated that they disclose that they are a sex worker to some healthcare providers, but not others. As stated by respondents ages 23 and 40, 29, and 31 respectively, on whether or not sex worker status was disclosed and the quality of care they received:

Yes and no. At the end of the day, I don't want to be subjected to other's opinions on my work and possibly be subject to discrimination so I keep it to myself.

No, the times I choose to not disclose my job, the doctors have been nicer and much less awkward.

PP once treated me poorly after I disclosed being a sex worker. I'm hesitant to attract that type of attention in a clinic setting.

A few practitioners were passively disapproving, their effect changed after I disclosed

Lower quality care after disclosure includes judgmental comments, harsher tone and language, and uncomfortable questions for the sex worker seeking care. Many respondents also reported hesitation to disclose for fear that their provider would attribute medical concerns of the patient to sex work when the respondent believed the concern was unrelated to this work. Sex workers surveyed noted that it would be helpful to be able to provide physicians and other healthcare workers with a more complete view of their life and occupation, but that in many circumstances it was not worth the risk of altered, inferior treatment after disclosure.

#### Disclosure and Legal Repercussions

Another frequently reported reason for not disclosing sex worker status was the fear of facing legal repercussions, primarily having one's children taken away, after being reported as a sex worker by medical providers. A respondent age 30 states:

However, I would never tell them I am a sex worker for fear that they would report me. They are my children's doctor too. We fear being exposed as sex workers and the state trying to take our children.

As shown by many reports on the status of sex workers in the US, fear of legal consequences influences decisions in all areas of life. Due to the criminal status of sex work, disclosing involvement in the sex industry, particularly escorting and street-based work can lead to direct legal repercussions. The legal prosecution sex workers fear includes arrest or fines for them personally and also being found unfit parents an having their children taken away. Respondents discussed being unsure of how their healthcare providers will or are obligated to report them, and this uncertainty brings about an even greater unwillingness to disclose. Respondents who disclosed their status described that they only do so in settings they feel they will not be judged or reported. Gauging what the reaction of the provider will be was described as an unreliable task, except for in the cases that providers advertise that they are sex worker-friendly. A respondent, age 31, clearly articulated what must be in place in a healthcare setting in order to disclose:

One, in particular, was great, but that was specifically because I sought a therapist who was sex-positive and who worked with people in the sex industries. Unless a therapist identifies as sex-positive and declares on his/her website that they work with sex worker populations, there is no way that I would volunteer that information now. There is too little understanding of it, and I would be judged.

Respondents who did disclose their status chose to do so in order to give their healthcare provider a more complete picture of their lives. As with any other occupation, they wanted to be able to share with their provider the details of their life so that their provider could understand them and their health needs better. Even when health concerns were unrelated to sex work, respondents noted that being able to disclose their status could lead to stronger relationships with their providers and overall improved healthcare than if they didn't disclose.

# Income Verification

Another frequently cited area of disclosure is income verification, which is an initial step in receiving treatment at many sites. Due to the criminal status of sex work, many respondents reported that they are unable to report their income for fear of being reported as a sex worker and prosecuted, so they are unable to verify their income to receive comprehensive HIV services. In settings where HIV care is free or subsidized, income verification did not cause the same tension is in other settings. However, the inability to verify income contributed to overall tension and reluctance in seeking and maintaining regular healthcare.

#### Discrimination Against Sex Workers in Healthcare

In discussing their hesitation to disclose to their provider, many respondents cited a fear of being shamed, judged, pitied, infantilized, and treated disrespectfully by providers. This experience was brought up again and again and healthcare providers' judgment appeared in many ways during healthcare encounters. Forms of judgment respondents perceived during clinical encounters include rudeness and dismissiveness after sex worker is mentioned. Respondents ages 27, 40, and 53 respectively also had clinical experiences that included:

Mannerisms and demeanor portrayed as disgust or disdain for our profession. Asking inappropriate questions or noting things in my charts that had nothing to do with the visit like over-use of make up or dressed in sweats but wearing make-up. Asking if I was homeless, asking how much drugs I did. Treat[ing] me like a child or a broken person.

These forms of discrimination against sex workers regarding how they are treated within healthcare are born out of the stigma against sex workers discussed by the sex workers rights movement. The presence and nature of stigma against sex workers is more difficult to measure than discrimination against sex workers, as stigma is a negative stereotype or perception and discrimination is the behavior that results from this negative stereotype. Discrimination can be more easily measured within healthcare and quantified in examples such as the ones shown above. However, this discrimination is born out of stigma that may be more widespread or take different forms than what is measurable through tracking stigma in clinical encounters. Respondents also reported providers making many assumptions about the patient, rather than asking for clarification after hearing about involvement in the sex industry. Such assumptions include assuming that the patient was being abused, coerced, or forced, that the patient did not practice safe sex, that the patient had substance abuse issues, and that the patient did not understand their own health needs. In this way, discrimination also appears as healthcare providers failing to take thorough medical histories and making unfounded assumptions about patients because they work in the sex industry.

### Moralism and HIV Care

Respondents noted that moral judgments on the part of providers often occurred after disclosure. One respondent 40, states, "Don't let your personal idea of morality get in the way. Just because it looks ugly to you does not mean what we do is bad and we need to stop." In this response and many others, morality appears in how providers conceptualize and react to patients' involvement in the sex industry. Modern sexually transmitted infection (STI) interventions are born out of this notion that STIs are retribution for sexual deviance. While sexual immorality is now framed very differently than when this society is founded, respondents note that the notion of sex work as immoral remains within healthcare. Whether or not morality is explicitly stated as an issue within clinical encounters, respondents describe how they are consistently aware of their providers' sense of morality. Respondents report feeling valued less and perceiving that providers think they are displaying harmful and shameful behavior after the disclosure of their status as sex workers.

Another concept discussed by respondents that is founded in the history of sexual immorality discussed earlier is the notion that sex workers are vectors of disease, primarily STIs such as HIV. Respondents report feeling as if they are being treated as vectors of disease within healthcare settings, and one respondent 34, writes a sentiment echoed by many other respondents, "We are not vectors of disease. The exchange of money does not make our work more of a public health risk than non-sex- workers who have multiple partners."

#### Sex Workers and HIV Prophylaxis

### Condom Use Among Sex Workers

In opposition to this image of the sex worker as a vector of disease, many respondents

reported a number of prophylactic measures to avoid contracting or spreading STIs. Prophylactic measures such as condom use, PrEP use, screening of partners, and early detection of STI strategies such as frequent screening were discussed in the survey.

Condom Use While Working		614	86.4
	Never	58	9.45
	Rarely	28	4.46
	Sometimes	50	8.14
	Most Often	119	19.38
	Always	358	58.31
	No Access to Safe-Sex Materials	1	0.16
Condom Use While Not Working		680	95.7
	Never	138	20.29
	Rarely	109	16.03
	Sometimes	145	21.31
	Most Often	159	23.38
	Always	128	18.82
	No Access to Safe-Sex Materials	1	0.15

Table 1: Condom Use Among Sex Workers Surveyed

While working, the majority of respondents used condoms while working, although this question surveyed sex workers across different types of sex work, and many respondents are not providing services in which condoms could be applicable [Table 1]. While not working, a lower percentage of respondents used condoms but the majority of respondents used condoms always, most of the time, or some of the time.

This percentage of sex workers that use condoms both while working and not working is higher than the national average. In 2017 the CDC reported that 14.8% of women and 19.0% of men aged 15–44 used a condom "every time" and 23.8% of women and 33.7% of men aged 15–44 used a condom at last sexual intercourse in the past 12 months.<sup>lii</sup> In this way, the instance

of condom use at all times while working among sex workers in more than three times the national average, and while not working is similar to the national average among men and greater than the national average among women. Condom use some of the time is also greater among sex workers than the general population.

There are many reasons sex workers may use condoms more frequently than the general population such as economic stability being contingent upon good sexual health, increased awareness of topics in sexual health through discussions within the sex industry, and many others. Publications by sex workers describe how they often serve as sex educators for their clients and that the criminalization of both sex work and HIV transmission necessitates that sex workers are additionally precautious and open about their sexual health practices. In exploring this dynamic Cyd Nova, a sex worker and harm reduction activist writes: <sup>liii</sup>

Sex workers never doubt that we can be thrown in jail for diseases transmitted or not. Because the sex we have is paid for, it becomes available to the scrutiny of all. The transaction is assumed to be dangerous from the beginning, leaving us in constant jeopardy of being accused of being a vector of disease, with the only salvation of laying in the arms of being a "good whore." The laws that target sex workers for HIV go beyond incarcerating individuals. They reinforce a story that we are dangerous, need to be managed, medicated, legislated, and our bodies rendered safe to the so-called general public.

This pressure to be a "good whore" may contribute to the many safe sex practices that sex workers engage in that people not involved in the sex industry may not be aware of or feel are necessary. A law that complicates condom use for many sex workers is the condom as evidence law. <sup>liv</sup> This law allows for more than three condoms on a person's body to be used as evidence that they are carrying out prostitution and grounds for an arrest. This law has led to the arrest or many sex workers in addition to people that are not sex workers but are stopped and found to be carrying condoms. As reported in a study of 25 transgender sex workers, 20% of respondents feared carrying condoms. One trans woman wrote on her survey, <sup>lv</sup>"I have been told that if I had more than three condoms that were a sign of sex work. I told the police I'd rather be safe than sorry. That really didn't mean anything to them." This policy dissuades sex workers from carrying condoms for fear of being arrested if searched and the condoms are found. This policy makes it more difficult for sex workers to engage in safe sex and avoid contracting HIV, and this policy stands in direct opposition to harm reduction practices in preventing HIV. Campaigns by

rights-based groups carrying out harm reduction work in San Francisco and New York City have been successful in overturning this law, but in practice the police continue to undermine sex workers' safety with impunity even after these intensive campaigns to end the use of condoms as evidence and to improve police/community relations. The ongoing policing of trans bodies exists independently of policy reform and the laws currently in existence and HIV prevention tools such as condoms are still being seized.<sup>Ivi</sup>

#### <u>PrEP Use Among Sex Workers</u>

Within this sample, some respondents also used PrEP as prophylaxis for HIV with 8% using PrEP and 92% not using PrEP. The percentage of the US population on PrEP is roughly .03%, making the percentage of sex workers using PrEP over 250 times greater than the general population.80 However, of all of the respondents only 59% had previous knowledge of PrEP and 41% respondents had no prior knowledge of PrEP or its ability to prevent contracting HIV. For many respondents, access to PrEP knowledge and the drug itself served as the main barriers to consistent PrEP use. In broader HIV care, PrEP has been a large focus of prevention efforts since 2015, but many sex workers feel that other areas must be addressed before PrEP will ever be used consistently. A respondent of the "Nothing About us Without Us" report released by sex workers rights organizations states:

A big struggle to access the quality, rights-based health services we need and now there is a lot of talk about PrEP and Truvada. It is a distraction from what will be effective. If you don't have the money then you cannot access these new medications. They are not solutions for us.

As reflected in this sentiment, PrEP may provide protection from HIV infection, but many sex workers are faced with more pressing issues that prevent them from prioritizing or having a desire to use PrEP. For sex workers that cannot access safe housing, food, and other basic needs, PrEP is of little importance, and until stability can be established in other areas of life. Additional concerns on the side effects of PrEP also deter PrEP use. As healthy, seronegative individuals, many sex workers do not want to introduce the risk of significant side effects when they are able to take other measures to prevent HIV infection. Outside of the United States, sex workers' right organizations have expressed concern that PrEP will become mandated for sex workers in the way the HIV screening often is, despite the preference of the sex workers themselves and the ensuing side effects. <sup>Ivii</sup> Sex worker's rights groups also fear that PrEP use could be used as evidence for sex work and grounds for an arrest in the way that condoms are. PrEP remains a fairly new technology and as a key population sex workers remain an ongoing part of discussions surrounding PrEP nationwide.

# STI Screening Among Sex Workers

In addition to condom and PrEP use, STI screening was a regular part of preventative measures for many sex workers. Respondents were actively involved in screening for HIV with 35% getting tested every 3 months or more frequently, 25% being testing every 6 months, 22% being tested once a year, 11% being testing less than once a year and 6 never been tested or having no access to testing. In comparison, the CDC reports that in the United States only 45% of the population has ever been tested for HIV.<sup>1/11</sup> HIV testing itself may not prevent HIV infection, but through testing, it is possible to identify HIV infection early, receive HIV care, and prevent the spread of the infection. The largely increased incidence of sex workers getting tested for HIV compared to the general public reflects the heightened awareness among sex workers of sexual health issues and precautions to take to protect oneself and others. Through these precautions, sex workers are actively protecting both themselves and their clients and partners in a more intensive way than the general public. These practices reflect the necessity discussed by Cyd Nova of being a "good whore" and fitting the narrative of a sex worker that takes all possible precautions to avoid STI acquisition and transmission.

These practices suggest that sex workers may have knowledge and experience practicing safe sex that could be shared with other communities and that sex workers could serve as sex educators and safe sex ambassadors, as Nova describes doing in Australia.<sup>lix</sup> However, this narrative leaves out the barriers that sex workers in the US face in accessing these HIV prevention services. As a former sex worker and current public health professional Nova writes:

This narrative requires that there is only one kind of sex worker: a person who has the opportunity to prioritize their sexual health while working, but I knew that there are many who did not. By this time, however, I had learned that public health doesn't like complications and has little room for the complexities of people's actual experiences. Public health wants to categorize people as high or low risk and decide whether or not they deserve program funding based on that categorization. It's a precarious system of social services administration that keeps people surviving just enough as to not be

accused of gross negligence.

This statement reflects many of the experiences within the HIV CoC described by respondents in this study: current interventions do not fit with the complex and varied experiences of people working in the sex industry. Respondents reported a wide range of reasons that caused them to be for or against various sexual health decisions such as testing, condom use, and PrEP use, and blanket practices policies for all sex workers did not take into account these complexities.

# Separating Risk of Labor from Risk Arising from Discrimination in Other Sectors

In describing these complex experiences within the sex industry and HIV continuum of care, many respondents wrote about their life circumstances being reduced to natural outcomes of their involvement in the sex industry alone. Respondents wrote about the struggles they face that are unrelated or occurred before they began doing sex work being attributed to sex work and stressed the importance of not making assumptions about sex work and its impact. Additionally, respondents emphasized the importance of distinguishing between the risks of sex work itself and **the risks and difficulties in many areas of life due to discrimination against sex workers.** Through understanding this distinction it is possible to obtain a better understanding of why the experiences of sex workers within the HIV continuum of care were so different from the experiences of the general public. On this subject, one respondent age 34 writes:

Just listen to what your patient has to say, try to understand/figure out what your patient is saying they need rather than assigning what you think they need to them. Sex workers are the same as other people seeking help. They will have job-related specific issues, as everyone does, but are individuals.

Other respondents echoed similar sentiments, that sex workers have health issues that may not be directly tied to escorting, stripping, camming, performing in porn, or working as a street-based worker. For many respondents, their health concerns and experiences getting care were closely tied to their status as criminalized and stigmatized due to their job but were not necessarily tied to the labor itself. The framing of sex work as a labor and not as moral degeneracy or the entirety of a sex worker's identity aides the process of separating health concerns tied to sex work from other health concerns sex workers may have.

# Pressure to Exit

Respondents also reported experiencing pressure to exit the sex industry from providers after disclosing sex worker status. Respondents discussed healthcare providers, particularly therapists or counselors, immediately blaming struggles on involvement in the sex industry and pressuring the respondent to exit the industry. As one 53-year-old respondent writes:

I wouldn't dream of telling a therapist what I do for work because I know that, despite the fact that mental illness runs in both sides of my family and I've been treated for mental illness since childhood, I'm sure I'd have to deal with some moron trying to blame my job for my mental state when in reality it's probably the only reason I haven't killed myself yet.

While many respondents had exited or had wanted to exit the sex industry at various points in their life, this pressure from healthcare providers came at times when they were not interested in exiting. As described in the introduction, consensual sex work is increasingly conflated with sex trafficking and work in the sex industry that involved force, fraud, or coercion. Respondents described experiences with providers in which providers assumed the respondent was a victim of sex trafficking. Other respondents describe scenarios in which healthcare providers understand that the respondents were not a trafficking victim, but that it was assumed that sex work was the root of health problems and that any form of healthcare would only be effective if the respondents exited the sex industry.

#### Lack of Training

A final way many respondents saw themselves treated differently within the HIV continuum of care and broader healthcare is in the lack of training providers have in caring for sex workers. Training can be defined very broadly in this sense as readiness and preparedness to care for sex workers; not necessarily a different set of practices but rather comfort in understanding the position of a patient who is a sex worker and how a provider might care for them best. Respondents reported clinicians and healthcare staff becoming flustered or unsure of how to proceed when sex work is mentioned and proceeding with medical coding or procedures that are unrelated to the respondents' initial concerns in seeking healthcare. This lack of preparation and training in treating sex workers ties into all other differences sex workers experience that have been mentioned above. Never being exposed to discussions surrounding sex work or the perspectives of sex workers allows for sex workers to be easily othered when encountered within the HIV CoC. Providers that have never engaged in conversations surrounding sex work may easily make moral judgments, assumptions, and biased decisions for their patients. The differential experiences compared to the general public that sex workers face within the HIV CoC is integrally tied to the perspectives and preparedness of healthcare providers to care for sex workers. Many of these perspectives are rooted in more general stigma and treatment of sex workers, and this discrimination that happens outside of healthcare is often what exacerbates health concerns and leads sex workers to the HIV CoC.

# Part II: Defining and Constructing Sex Worker Inclusive Care within the HIV Continuum of Care

As outlined in Part I of this chapter, there are many ways in which sex workers receive a lower quality of care within the HIV CoC than the general public. The experiences provided by respondents indicate that stigma surrounding sex work permeates through many levels of the HIV CoC, from the structure and methods of HIV care systems to interpersonal interactions with clinicians. Despite this widespread stigma, respondents were able to imagine alternatives to current healthcare and HIV care that provides more effective and compassionate care for sex workers. As sex workers that face stigma and policing in many other areas of life, respondents saw the HIV CoC as a site where tangible changes could be made within current systems to better uphold the rights of sex workers. Health is an essential human right and many of the suggestions respondents provided come from rights-based work in sectors such as education or migration. Suggestions provided in this study would reframe how the rights of sex workers could become the basis of any form of healthcare.

Sex workers' rights organizations have also conducted research and published suggestions on how sex workers could receive a higher quality of care within the HIV CoC. A key example of this is the "Nothing About Us Without Us: Sex Work, HIV Policy Organizing, and Transgender Empowerment" report conducted by the Prostitution Policy Report and the Desiree Alliance, which provides comprehensive recommendations for how to address the HIV needs of trans sex workers. These organizations look to other rights-based movements for more complete analysis and suggestions that would uphold the rights of sex workers. A policy report published by the Best Practices Policy Project and Desiree Alliance suggests that sex workers can learn from and should work in solidarity with racial justice, economic equality, and immigrant rights movements. Understanding the work of these movements not only provides tools for better upholding the health of sex workers, but also acknowledges the intersection of transphobia, whorephobia, HIV stigma, racism, and ableism and allows it to be taken into account in any future recommendations or work. Similarly, the analysis of suggestions made by sex workers in this study looks to understand the complexity of what sex workers need to maintain their human right to health within the HIV CoC.

# Isolation and Healthcare as a Site of Intense Trust/Mistrust

When discussing their experiences within the HIV continuum of care, many

respondents brought up how healthcare can be an area of intense trust and support or one of the strongest areas of mistrust and anxiety in their lives. As mentioned earlier, the majority of respondents did not feel comfortable disclosing the nature of their work with providers for fear of being discriminated against. Respondents fear being outed, in other areas of their lives and often heighten their vigilance and skepticism in healthcare settings because such personal information is often requested. However, due to the personal nature of many clinical encounters respondents also shared how that they sometimes felt able to share details of their life with their healthcare providers that they were unable to share with other people. One respondent 35, writes, "Please understand that you are probably the only person they can go to and the only person aware of these situations." Clinical encounters provide an intimate opportunity for many respondents to build trust and find support in someone they feel will care for them. Another respondent, age 36, writes, "Just being able to disclose that I was engaging in commercial sex could have been invaluable. I was completely isolated socially, and didn't believe I could trust anyone with what I was living through." The ability to place trust in healthcare providers provides social support that is often lacking in other areas of the respondents' lives in the presence of widespread stigma against sex workers and criminalization of sex work. Respondents described how healthcare can serve to alleviate social isolation if the patient feels comfortable working with their healthcare providers.

# Avoidance of Services for Fear of Being Reported or Surveilled

Through the same reasoning, many respondents described feeling further socially isolated when not able to communicate properly with their healthcare providers. Two respondents ages 34 and 21 respectively describe how this fear of being shamed prevents sex workers from seeking out healthcare:

Please keep your opinions to yourself and remember the passion for helping people that I assume is part of what drove you into the medical field... Quite a lot of us have been through so much as it is it's hard enough to find the courage to walk in your office in the first place.

Just be nice to us and understand that we deal with an unbearable amount of judgment and stigma already and cannot handle anymore side-eyeing or uncomfortable questions or unsolicited condescending advice. I don't want a lecture or your pity. I'm just here for medical care. Please don't make it any harder. Respondents describe a fear of being reported or prosecuted in the future after disclosing to their provider and choose not to for this reason. A respondent, age 22, shares:

Even if you get an understanding of medical professionals, I don't want my sexual health and history to be part of some permanent record that shows up for future professionals who might be less understanding.

Other respondents fear that their children will be taken away, they will be arrested, or they will be further stigmatized in their lives outside of a clinical encounter if they disclose. For this reason, many respondents emphasized the importance of keeping sensitive information confidential within healthcare. They additionally recommend that providers not put incriminating information about sex work on file to prevent difficulties for the patients in the future.

# Ability to Disclose Involvement in the Sex Industry

Many respondents shared the sentiment that they would like to be able to disclose their involvement in the sex industry to their healthcare provider. One respondent expressed a thought repeated by many that, "A doctor can't do their job if you don't disclose something so connected to your health." In clinical encounters, especially with clinicians that a patient sees regularly and gets to know well, it is expected that the healthcare providers know the occupation of their patient. With any other form of labor, the work a patient does is noted and used to provide a complete medical history and understanding of a patient's experiences. However, many sex workers choose not to disclose for fear of discrimination and their providers are left with a very incomplete picture of their patient's life.

Of the sample, 45% thought the ability to disclose sex worker status would improve the healthcare they received, 30% thought it depends on the situation, and 25% thought it would not improve care. As one respondent, ages 32 and 38 respectively, write:

I have disclosed my status to multiple providers. Only once did I feel it increased the quality of care I received. I disclosed to a health care provider during STI testing. She responded very positively. I was able to ask her questions regarding safer sex practices and testing that were specific to sex work and how I work. It was great and extremely useful. Other times I have disclosed, I felt it decreased the quality of care I received because the provider was whorephobic and giving care from a place of stigma. The ones

I have disclosed to I had seen regularly and knew they would be helpful. It gave me less anxiety knowing they knew and I didn't have to make up a story of why I wanted another STD test.

In this way, the respondents thought the quality of care could improve when disclosing, but only if the provider did not shame or judge them for working in the sex industry. Respondents shared that there are some healthcare scenarios in which they feel more comfortable disclosing than others. A respondent age 25 describes the only scenario in which they were disclosed, "It was one of the routine screening questions they asked me, non judgmentally (ie do you have sex with men, women or both? Have you had sex for money or other needs...). I felt comfortable disclosing \*because they asked\*. This is rare." Another respondent age 36 writes:

I think if medical professionals were educated further on the issue and industry, as well as some sensitivity training on engaging in a genuine and non-judgmental way, it [disclosure] could be invaluable. As the current stigmas and ignorance that exists among the general public, I don't know that it is generally helpful for sex workers to disclose.

The majority of respondents felt disclosing in particular situations could be very beneficial, and potentially necessary, for them to receive adequate health; however, much work needs to be done on the part of providers before sex workers will feel safe disclosing.

# Non-judgmental Care

In describing what healthcare providers can do to make their care more effective and supportive for sex workers, many respondents discussed wanting to be **listened to, treated the same as other patients, and the care they receive to be based on facts and not assumptions**. Respondents stressed the importance of healthcare providers acknowledging a sex work history if it's disclosed while also gathering a complete medical history and not using involvement in the sex industry to make assumptions about the respondents' health. In describing what more effective and sex worker-friendly care would include, respondents ages 34, 35, 29, 25, 30, and 23 respectively write:

Be patient if a sex worker tries to tell you their story because it signals that they are beginning to trust you. If you cut them off or act indifferent you will crush that trust, and you may not get another chance to regain it. Don't rush to conclusions.

Slow down. My body is very very important to me, even if you think otherwise by my

actions. I am here. I care. Treat me. Like a person.

When you reduce us to our job, then you contribute to our poor mental health.

Sex workers need to be listened to and respected, our jobs do not impair our ability to know ourselves and we are not in need of rescue, simply more options.

To help sex workers deal with the issues that come with sex work without making the actual sex work job an issue to be fixed.

Treat us like any other patient, but with unique needs (that should not be stigmatized) due to the industry we're in.

Treat us like humans. Don't make assumptions about who we fuck or how we fuck. If sexual info is necessary for care, ask using nonjudgmental, nonbiased language. A lot of us are trans, queer, survivors. Biased language hurts us.

In defining non-judgmental care, many of the respondents described care in which sex workers are not looked down upon for their choices, and assumptions are not made about their health decisions due to their involvement in the sex industry. Sex worker friendly care includes language that is respectful of sex workers and treats sex workers as patients of any other occupation would be treated. Two respondents ages 34 and 30 writes:

The exchange of money does not make our work more of a public health risk than non-sex-workers who have multiple partners. We need well-informed providers who can non-judgmentally give us the information we need to select which tests and services we need.

Don't stigmatize sex workers. Don't treat them as victims, if it's a non-victim situation. Some sex workers love what they do and not everyone is coerced. Provide services that make women feel safe to ask for them and not feel ashamed

As illustrated by these responses and many more, one of the most significant ways in which healthcare providers can be sex workers friendly is through treating sex workers the same as their other patients. This includes acknowledging the realities and experiences of sex work itself and how it may affect health while avoiding basing medical decisions off of assumptions about sex work. Sex workers want healthcare that humanizes them and is respectful of their person and their health independent of their labor.

### Sex Work-Specific Training

Respondents also highlighted the importance of healthcare providers putting in the work to understand the realities of sex work and unlearn many of their biases regarding sex work. This includes healthcare providers reading publications by sex workers, interrogating and working to break down their own stigma against sex workers, and participating in training that would allow them to discuss and understand how to provide sex workers friendly care as it has been described above. Three respondents ages 34, 42, and 31 shares:

We need our providers to do their own work, processing, and healing their own sexual wounding and stigma.

I would tell them that they need to check their assumptions, their fears, and their privilege at the door. I would advise them to read peer-reviewed research about sex work outlining clear methods of gathering data, and written by fellow sex workers. I would tell them to educate themselves on the various hierarchies within the sex industry. I would ask them to listen to sex workers and our concerns about ourselves and meet us wherever we are. View us as people. Stop stigmatizing us.

Educate yourself about specific risk patterns and awareness without stereotyping...make yourself aware of other practitioners who will provide nonjudgmental care.

Sex work-specific training would work to address many of the areas in which sex workers receive a lower quality of care through better equipping providers to work with sex workers. Trainings that allow healthcare providers to interrogate and work to break down their own biases would allow sex workers to receive care that is not rooted in assumption and feels more comfortable seeking care.

### Education for Sex Workers on Health Topics

In discussing the HIV CoC, respondents also discussed the importance of educating sex workers on sexual and general health topics. Respondents suggested that this education be focused on harm reduction through understanding the risks of particular behaviors or scenarios. It was also suggested that this information be easy to access in and out of clinical settings through clinicians, support staff in healthcare centers, and people working in other sectors. It is also important that this education emphasizes the most important areas of healthcare and how to prevent STI infections and maintain health. One respondent writes, "[Doctors] have no idea what you are doing when you say 'let's have a conversation about your behavior.' Just give me the information I need to survive." The social isolation that sex workers experience due to stigma and policing frequently cuts them off from other critical education resources. Without educational tools surrounding health sex workers are left to teach themselves about health topics or try to survive without these tools. Education on best practices in sexual health and health in general would provide sex workers with the tools to care for their health that many sex workers currently do not have access to.

# Areas of Support

Many respondents also stressed the importance of healthcare not being an isolated field but rather a support system for sex workers that is integrated into other support systems present in their life. These other support systems may be informal communities, families, groups of friends, or more official systems such as social services, educational establishments, or faith-based groups. One respondent, 54, suggests healthcare providers "offer outstanding resources if they know of any in the area and if it's needed." Additional services may be in the form of financial support, education, support with substance use, or other resources that would make maintaining health, and life in general, easier. As described earlier, the HIV continuum of care may serve as a frequent entry point for sex workers into broader healthcare, as well as helpful resources more generally. Healthcare providers that had existing knowledge of other support systems sex workers could look to outside of the HIV CoC would allow sex workers to gain the support they need but were potentially unable to previously find. These additional areas of support in turn contribute to better health, as it is easier to maintain health when other basic needs are met and social support is present. Isolating the HIV CoC from other areas of a patient's life makes it more difficult to access and working with other support systems allows for the rights of sex workers to be more comprehensively upheld.

# Part III: Conclusions and Moving Forward in Providing Healthcare for Sex Workers

Sex workers in the United States experience the HIV CoC differently than the general

public, and this project explores these differences, the context in which they take place, and how distinctive treatment within the HIV CoC impacts sex workers. In the United States, STI prevention campaigns were founded on the goal of eliminating "social evils" in order to maintain the health of the white upper and middle class. Public health institutions looked to directly target these "social evils" and designated sex workers as dangerous vectors of disease.<sup>kx</sup> In the past century new STIs, such as HIV, have emerged and STI programming has shifted to covering the entire public and not only sex workers. However, sex workers often remain exceptional within the HIV CoC, and this project explored in what ways the notion of sex workers as vectors of disease, still exists within STI care and how this impacts sex workers.

Analysis of a nationwide survey finds that the majority of sex workers do not disclose their work to their provider for fear of judgment despite thinking that it could improve their quality of care. For sex workers that do disclose, they report being judged, shamed, infantilized, and asked inappropriate questions about themselves or their work. Additionally, sex workers describe how clinicians often make false assumptions about the risks of their work and neglect to take into account other areas of sex worker's life in providing healthcare. Many sex workers face barriers in accessing healthcare outside of HIV care and find because of its focus on sex workers, the HIV CoC can serve as a way to receive other forms of healthcare.

The suggestions put forward in this research focus on treating sex workers as patients deserving of healthcare and not as hazards that need to be managed instead of cared for. This involves listening to, respecting, not judging, and communicating thoroughly with sex workers in clinical encounters. Respondents urge clinicians and policymakers to not make assumptions about sex workers' health risks and behaviors due to their work. Clinicians were also urged educate themselves on sex work and acknowledge their own stigma against sex workers; the narrative of sex workers as vectors of disease should be named and rewritten by those working with the HIV CoC. Additionally, sex workers suggest that healthcare can provide health education that allows sex workers to stay safe, especially in the face of violence and discrimination in other areas of their lives. Healthcare services that carry out these recommendations should also publicize that they are sex worker-friendly and prepared to care for sex workers to allow patients to be comfortable disclosing and building trust with their provider. Understanding the experience and suggestions of sex workers is critical in designing health interventions directed at sex workers. The experiences discussed in this study occur within structures built off of stigma against sex workers and a desire to uphold white supremacy and the history of STI care programming must be taken into account in bringing about better

health outcomes. Many sex workers are also stigmatized due to their race, gender, sexuality, class, or disability and the ways in which these stigmas function and interact with stigma against sex work must also be examined in considering health interventions. In the past few decades, many researchers and policy-makers in the field of HIV have also sought to address these critical topics in best-serving sex workers. New programming and policy have been designed, but only through hearing directly from sex workers is it possible to know how these changes appear in practice. This project looks to community-based research among sex workers to understand how the current HIV CoC regards and cares for sex workers in order to imagine alternative systems that would better uphold sex workers' right to health.

Incorporating the recommendations of sex workers into existing HIV structures involves actively breaking down the stigma within healthcare that surrounds sex work. Measures to prevent and remedy discrimination against sex workers allow sex workers to receive care that is easier to access and much higher quality care. The HIV CoC holds immense power and visibility within the United States and internal changes made within HIV programming can serve to alleviate discrimination that sex workers face in other areas of their life. Clinicians often function as gatekeepers to knowledge and resources that sex workers may only be able to access through being regarded as patients with rights that are deserving of care. The ability to receive effective and compassionate healthcare allows sex workers to be more stable and able to navigate the intricacies of being criminalized and stigmatized outside of healthcare. Additionally, changes made within healthcare may serve to reframe how other sectors consider sex workers and set an example for how to treat sex workers as laborers with rights instead of a "social evil." Healthcare may be able to serve as a site of breaking down widespread stigma against sex work through emphasizing a right-based approach to working with sex workers instead of existing approaches that frame sex workers as vectors of disease to be managed.

#### **Further Research and Conclusions**

This chapter brings up many additional questions to be examined in future projects. Many of the areas of inquiry that would build off of this project surround the plausibility and efficacy of implementing the recommendations of sex workers within the HIV CoC. This research also opens up questions surrounding the criminalization of sex work and the relationship between healthcare and criminal justice fields. Of the many questions prompted by the conclusions of this study, the primary questions are listed below:

- In what way should clinicians and healthcare policymakers be engaged with sex workers' rights? Should HIV care be the entry point to these conversations or does this further the idea of the sex workers as a vector of disease?
- 2. Are clinical settings able or willing to be trained by sex workers on how to provide sex workers friendly care and publicize that they treat sex workers? What forms of publicity would adequately inform sex workers looking for a provider while not drawing backlash or accusations of supporting a criminalized practice or supporting sex trafficking?
- 3. What are the active ways in which the HIV CoC can work to counter stigma sex workers face in other areas of their lives? Medical professionals hold significant power and influence in American society and if they support a rights-based approach, how could they work to promote sex workers rights in education, housing, migration, and other sectors?
- 4. How does the HIV CoC as it is today interact with the criminal justice system, particularly laws surrounding prostitution? Have areas of the HIV CoC ever been involved with developing or supporting legalization, Nordic model, or decriminalization proposals in the United States? What would healthcare involvement in influencing decriminalization look like? Is decriminalization even a possibility in the United States? What else would have to happen for decriminalization to be possible?

Inquiry into any of these areas would allow for a much better understanding of how the HIV CoC can provide effectively and just care for sex workers. This study concludes that interventions within the HIV CoC that look to uphold the rights of sex workers and breakdown the stigma surrounding sex work would improve not only the quality of care sex workers receive, but would also address many of the underlying assumptions made within HIV care. Within these interventions, sex workers should be treated as patients with the agency over their lives and decisions that deserve the same rights as any other patient and not as vectors of disease to be managed for the sake of the rest of the population.

As stated by Weiwei Shein in the sex workers' consensus statement before the 2014 AIDS Conference, "We don't need your pity. We need our rights." <sup>bi</sup> Health is a fundamental human right; effective and non-judgmental care within the HIV CoC can play an immense role in assuring that the rights of sex workers are upheld globally. As a sector through which sex work is frequently discussed, HIV care adopting a rights-based approach could serve to reframe the way in which sex workers are viewed in the United States, as rights-holding members of society and not disgraceful vectors of disease. Breaking down stigma and addressing criminalization of sex work are complex issues that require participation from many areas outside of healthcare but changes within the HIV CoC could immediately improve the status of sex workers and serve as an example within the United States.

Additional Tables Tables present additional data from the 2017 data set used throughout

this book [n = 711]

Table 2: Type of Healthcare Accessed

Type of Healthcare Sought	n	%
	468	65.8
Primary Care	139	29.7
Mental Healthcare	222	13.1
Emergency Room	38	8.1
STI Screening	232	49.6
Care After Assault	7	1.5
Chronic Illness	18	3.8
Accidents or Orthopedics	6	1.3
Gender Affirming Treatment or Surgery	6	1.3
Substance Abuse	2	0.5
Gynecology	24	5.1
Reproductive or Prenatal Care	9	1.9

Table 3: HIV Status and Provider

HIV Status		706	99.3
	HIV Positive	4	0.57
	HIV Negative	686	97.17
	HIV Status Unknown	16	2.27
HIV Care Provider		57	8
	Healthcare Clinic	5	8.77
	Private	23	40.53
	Other	29	50.88

Table 4: PrEP Knowledge and Use

PrEP Knowledge		469	66
	Prior Knowledge	276	58.85
	No Prior Knowledge	193	41.15
PrEP Use		414	58.2
	Uses PrEP	33	7.97
	Does Not Use PrEP	381	92.03

# Table 5: Frequency of STI Screening

Frequency of STI Screening		704	99
	Every 3 Months	246	34.94
	Every 6 Months	178	25.28
	Once a Year	155	22.02
	Less than Once a Year	79	11.22
	Never Been Tested	31	4.4
	No Access to Testing	15	2.13

Table 6: Condom Use While Working and While Not Working

Condom Use While Working		614	86.4
	Never	58	9.45
	Rarely	28	4.56
	Sometimes	50	8.14
	Most Often	119	19.38
	Always	358	58.31

	No Access to Safe-Sex Materials	1	0.16
Condom Use While Not Working		680	95.7
	Never	138	20.29
	Rarely	109	16.03
	Sometimes	145	21.31
	Most Often	159	23.38
	Always	128	18.82
	No Access to Safe-Sex Materials	1	0.15

Table 7: Disclosure of Sex Worker Status

Disclosure of Sex Worker Status		494	69.5
	Yes	206	41.7
	No	288	58.3
Does Respondent Think that Disclosing Sex Worker Status Would Improve Healthcare Received			
	Yes	199	45
	No	110	25
	Other, Depends on Situation	130	30

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