

**Challenges and Barriers Experienced by Women Sex Workers to
Accessing HIV/AIDS Services in Chandigarh: Northern India**

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Attestation of Authorship

“I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.”

Signature

Date.....

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Abstract

Despite advances in access to HIV/AIDS prevention, care and treatment services in recent years, the epidemic continues to grow. To make steady gains in achieving the Millennium Development Goals of empowering women by promoting gender-equality to combat HIV/AIDS, it is important to recognize the barriers to HIV/AIDS services which constrain women sex workers from gaining universal access to those services.

The aim of this research was to explore the barriers experienced by women sex workers to accessing HIV/AIDS services in Chandigarh, Punjab. A qualitative descriptive methodology was used to understand barriers as perceived by the women, in conjunction with the social, political and economic contexts which often contribute to women sex workers' unmet health needs. Data were collected using semi-structured in-depth interviews with seven study participants; including three non-government organisation staff members and four women sex workers. Using thematic analysis based on the data generated from the study participants, findings were organised according to the two domains of data collection: barriers to accessing HIV/AIDS services for women sex workers of Chandigarh; and socio-economic issues related to women sex workers accessing services in Chandigarh.

The key implication from this study suggested that the clandestine nature of sex work in Chandigarh and Punjab has affected the way HIV/AIDS services are delivered. The results revealed that some of the barriers to accessing HIV/AIDS services for women sex workers included the effects of clandestine behaviour resulting in stigma rooted in shame and fear; and constraints related to funding and resources resulting in provision-related disabling factors such as non-availability of trained health care personnel, and lack of medical camps and mobile testing services. Also important to consider was that no research studies were found that were published on women sex workers in relation to HIV/AIDS services in Chandigarh, Punjab.

To enhance sex workers access to HIV/AIDS services, it is important for health workers and policy makers to consider the needs of sex workers by developing local gender-specific and culturally sensitive approaches to better assure requisite behaviour change among the sex workers for HIV/AIDS prevention.

Chapter One: Introduction

1.1 Background to the Study

Worldwide, in low and middle-income countries, the Human Immunodeficiency Virus (HIV), which causes acquired immunodeficiency syndrome (AIDS), has become a major public health problem (National Institute of Health and Family Welfare [NIHFW], 2009). In 2008-09, globally it was estimated that more than 25 million people had died of HIV/AIDS; and another 34 million are currently living with HIV/AIDS to which India contributes up to three million, of which 39 per cent are women (World Health Organization [WHO], 2013; International Centre for Research on Women [ICRW], 2012). Overall, as estimated by the United Nations Programme on HIV/AIDS [UNAIDS] (2012), in India 83 per cent of people living with HIV are in the 15-49 year old age group. Unlike developed nations, India lags behind on research and medical facilities to deal with an AIDS epidemic (Sivaram et al., 2009).

India is the world's second most populous country and has the third largest number of people living with HIV/AIDS (Sarkar, Bal, Mukherjee, Niyogi, Saha, & Bhattacharya, 2005). This poses a serious public health concern in India. Heterosexual spread of HIV is the dominant mode of transmission, causing 88.2 per cent of all HIV infections (Lazarus et al., 2012), which is particularly affecting women of the sexually active and productive ages of 15-49 years (ICRW, 2012). HIV prevalence continues to spread from high-risk to low-risk populations (general population) due to the high frequency of unprotected commercial sexual practices (Claeson & Alexander, 2008). Further, the size of the Indian population will have a major impact on the spread of HIV/AIDS worldwide (Bentley et al., 2008).

The National AIDS Control Organization (NACO) of India annual report on HIV/AIDS (NACO, 2012a) noted that the HIV epidemic is concentrated in particular groups, as evidenced by the high prevalence among high risk groups, notably, injecting drug users (IDUs) (9.19%), men having sex with men (MSM) (7.3%), commercial sex workers (CSW) (4.94%) and sexually transmitted infections (STIs) clinic attendees (2.46%). Given that the heterosexual mode is the dominant mode of transmission, sex workers play a critical role in the spread of HIV which is fuelled by the sex trade (Basu et al., 2010). Indeed, HIV prevalence among women sex workers is six to eight times higher as compared to the general

population in India (WHO, 2012). The HIV/AIDS epidemic presents an intimidating challenge for Indian women sex workers who experience issues of poverty, illiteracy and gender disparities, as well as barriers to accessing HIV/AIDS services (Blanchard et al., 2003). The infection rates for women are growing due to their low social and economic status, such as gender norms which impact on behaviours and result in disparities in access to services and resources that limit the prevention of new STIs (Sarkar et al., 2005). Further, women sex workers face discrimination and stigma which prevents them from accessing HIV/AIDS prevention, treatment, and care services which heightens their vulnerability (Thomas et al., 2005).

As part of the global strategy *Universal Access for Women and Girls Now*, the Indian government has implemented a Targeted Intervention Program (TIP) to improve access to HIV/AIDS services for women (ICRW, 2012). The Indian government formulated the first National AIDS Control Programme (NACP) in 1992 which was implemented by the NACO (Nambiar, 2012). The aim was to provide universal access for HIV/AIDS prevention, care, and treatment services among high risk groups, including women sex workers (NACO, 2012a). Currently under the NACP, free antiretroviral therapy (ART) is being provided to people living with HIV; yet women sex workers continue to face challenges accessing services (ICRW, 2012). Although the government of India is making efforts to ensure universal access, research shows that there are barriers in accessing HIV/AIDS services such as lack of privacy, fear of breach in confidentiality, constraints related to resources, travel distance, and barriers to accessing integrated counseling and testing centers (Kumar & Gopal, 2012; ICRW, 2012; Lawrence & Barun, 2011). Provision-related challenges such as lack of funds and resources at the grass roots level further compound the problem.

1.2 Aim of the Research

The primary aim of the current research is to explore barriers experienced by women sex workers to accessing HIV/AIDS services in Chandigarh, Punjab state of North India. The primary question being asked in this research is: What are the challenges and barriers related to accessing HIV/AIDS services provided in Chandigarh, Punjab?

The study employed a qualitative descriptive research methodology (Neergaard, Olesen, Andersen, & Sondergaard, 2009), and used a critical policy lens to analyse the data and inform the discussion. The research was concerned with highlighting issues for women sex workers who are marginalised and discriminated in Indian society (Ramesh, Ganju,

Mahapatra, Mishra, & Saggurti, 2012), so that their experiences in relation to HIV/AIDS services within the sex industry can be better understood. A qualitative research methodology was chosen, being mindful of women sex workers' greater vulnerability to HIV/AIDS due to the disparities as a result of cultural, biological and economic factors (Pallikadavath, Garda, Apte, Freedman, & Stones, 2005).

The research design included two data collecting methods: in-depth interviews and document review. Women sex workers utilising HIV/AIDS services were the primary participants; however, key informant non-government organisation (NGO) staff members working in the field of HIV/AIDS services were also interviewed.

The study was implemented in Chandigarh, the capital city of Punjab, India, among the highly vulnerable group: women sex workers aged 20-25 years. Punjab is the north-western state in India with a population of 27.7 million (Population Census India, 2012), bordered by four states (Jammu and Kashmir, Himachal Pradesh, Rajasthan and Haryana), resulting in a high degree of mobility between states.

1.3 Context of the Study

In India, the states with the highest HIV prevalence rates (refer Figure 1, p. 4) are Manipur (1.40%), followed by Andhra Pradesh (0.90%), Mizoram (0.81%), Nagaland (0.78%), Karnataka (0.63%), and Maharashtra (0.55%) (NACO, 2012a). The estimated number of people living with HIV/AIDS in India declined from 2.73 million to 2.27 million in 2008 (UNAIDS, 2012). However, some of low HIV prevalence states, including Punjab and Chandigarh, have shown rising trends in the estimated adult HIV prevalence rates, exceeding the national prevalence by 0.31 percentage points between the years 2006-2009 (NACO, 2012b). Punjab, in spite of having a lower percentage of the population living with HIV/AIDS, is such a populous state that the total number is high, including 31, 961 HIV/AIDS cases as per estimation 2011 (NACO, 2012 b). This makes it a priority state for HIV/AIDS programmes. In high prevalence states of South India (Ramesh et al., 2012) declining figures in HIV prevalence were noticed among the youth (15-24 years of age), including young girls and women sex workers, reflecting the possible impact of HIV/AIDS interventions (NACO, 2012a). Though the focus of HIV/AIDS intervention has largely centred upon the South Indian states, the growing number of HIV/AIDS cases in Punjab should not be ignored.

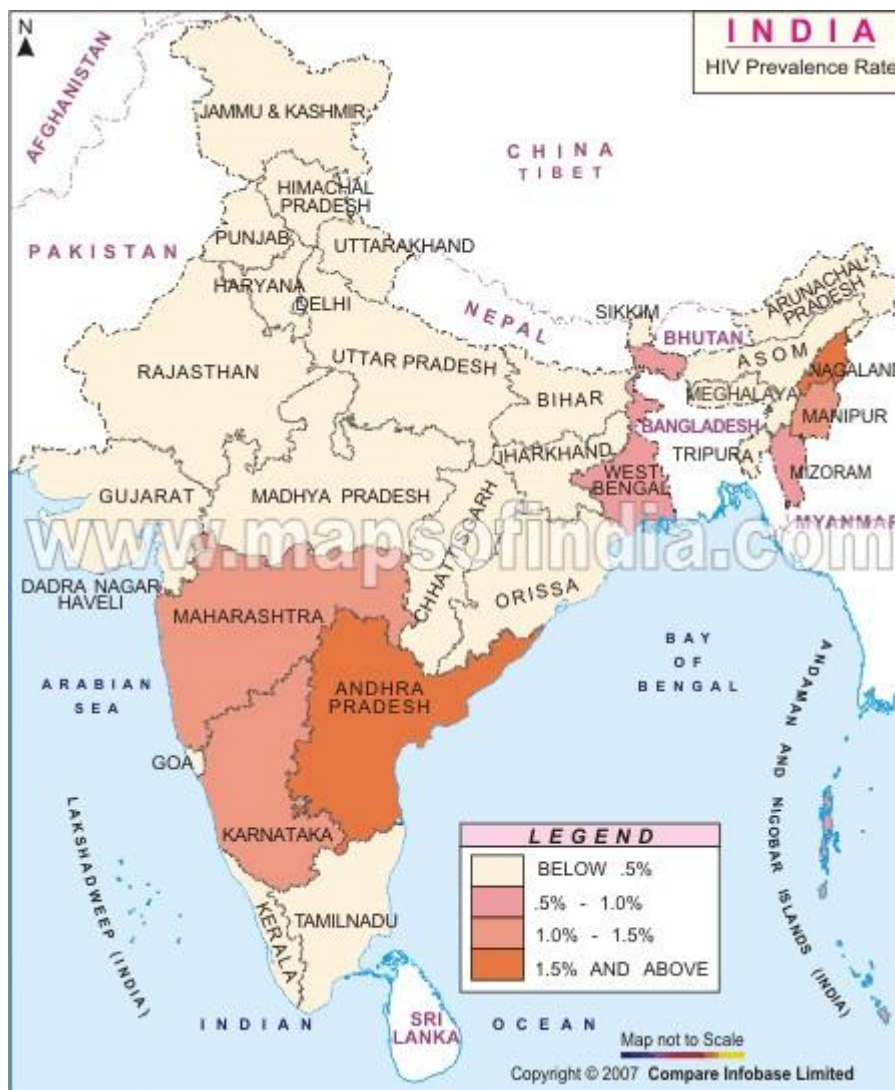


Figure 1. Map of India showing the HIV prevalence rate in each state in India.
Source: Retrieved from <http://www.mapsofindia.com/census/hiv-prevalence-rate.html>

In 2009, HIV prevalence among women sex workers in India was 4.94 per cent to which Punjab contributed up to 0.97 per cent, and the general population less than 1 per cent (NACO, 2012a). The actual figures could be much higher than those reported as this data was collected from the integrated counseling and testing centers (ICTC) (see Figure 2, p.5), while some cases might remain undiagnosed and unreported due to the hidden sex trade in Punjab. In Punjab, the estimated population of women sex workers is approximately 20,253; but there are no acknowledged ‘red light areas’ (district with many brothels) in the state (Sedhuraman,

2011). According to a recent survey conducted by the Chandigarh State AIDS Control Society (CSACS), 3,974 women sex workers (CSACS,2011) working either from the slums or proper residential areas are among the ‘high risk’ groups that have HIV prevalence rate of 0.4 per cent (NACO,2012b).



Figure 2. Map of Chandigarh showing ICTC.
Source: Retrieved from <http://chandigarhsacs.org/HIVAIDSCHD.html>

There are number of factors contributing to the spread of HIV/AIDS in Punjab such as high geographical mobility of the migrant population, the illegal drug industry, and a social environment of poverty and wider disparities in gender norms (Bhawsar,Singh, & Khanna, 2005). Geographical mobility is one of the key factors in the spread of HIV around the world (WHO, 2012). Punjab has a large population working in the transport sector such as truck drivers. A feature of the life of truck drivers is that some seek sex from paid sex workers

when they are away from home. Biradavolu, Blankenship, Devireddy, Gupta, and Reed (2011) suggested that “migration to find work causes instability related to location of work and residence may lead to the social and professional isolation that may cause concerns for increased HIV risk” (p. 711). A study by Kumar and Gupta (2000) among patients attending the sexually transmitted diseases (STDs) clinic in Chandigarh revealed high prevalence rates of HIV among the truck drivers, who often acquired infection from the sex workers of Mumbai and Chennai (South India).

In addition to geographical mobility, the HIV/AIDS epidemic in Punjab is mainly driven by IDUs. Drug abuse is a widespread issue in India with greater prevalence in Punjab and Chandigarh (NACO, 2012a). In 2009, HIV prevalence among the IDUs in India was 9.2 per cent to which Punjab contributed up to 26.1 per cent (NACO, 2012b). HIV is spread among the IDUs by sharing of contaminated needles, unsafe sex under the influence of drugs/alcohol, and sex for exchange of drugs (e.g., sex without a condom, coercive sex). In the sex trade industry, the practice of unsafe sex, under the influence of drugs, fuels the spread of the HIV epidemic from the IDU population to sex workers and to the general population (Ambekar, 2012).

1.3.1 Overview of sex work.

Globally, women sex workers are among the most stigmatised and marginalised groups and are often labelled as a high risk group in the context of HIV and AIDS (Bentley et al., 2008). In India, sex work is consensual sex between the two individuals of legal age above 18 years of age (UNAIDS, 2012), receiving money in exchange for sexual activities (Buzdugan, Halli, & Cowan, 2009). India has an equal mix of brothel- and non-brothel based sex work. Brothel-based sex workers are among the groups based in red-light areas and elsewhere, and include those who choose sex work as their profession for economic survival, as well as workers who have been sold or trafficked into prostitution (Land & Prabhugate, 2012). Non-brothel based sex workers include groups such as home-based or mobile sex workers who are hidden and more likely to contract HIV/AIDS and face sexual violence due to a lack of safe sex negotiation skills (Celentano et al., 2011). Lastly, call girls provide escort services to the wealthier clients (politicians, businessman etc.) and are among the groups with the highest socio-economic profile.

Young age is a risk factor for HIV transmission among women sex workers due to the developmental changes that take place in the period between childhood and adulthood (Santhya & Jejeebhoy, 2007). In addition to their age, the low status of women in society often places them in a subservient position which influences their vulnerability to violence and HIV infection (David et al., 2010). For biological reasons beyond social and economic dependency, young women are more vulnerable to HIV/AIDS than men (Ghosh, 2010). A cross-sectional study carried out by Bal et al. (2011) showed that young age is risk factor for HIV among women sex workers due to factors such as repeated trauma during sexual intercourse and professional immaturity which weakens their ability to negotiate safe sex and protect themselves from transmission. Primarily, harm is caused due to the women sex workers' inability to negotiate safer sex, which is fuelled by sexual violence and forced unprotected sex by the sex worker's clients who include police, passers-by, security personnel, hotel managers, gangs and pimps (Bentley et al., 2008).

In Chandigarh city, significant numbers of women sex workers are mobile and home-based (CSACS, 2011). Their sexual activities are practiced clandestinely due to society being more conservative and traditional. Clandestine sex workers are mainly housewives, single women with children, or young girls, who are not registered as sex workers but work secretly due the stigma and discrimination attached with the sex work (Tucker, 2012). They do not practice sexual activities openly and remain hidden due the fear of discovery by their family members. Hence they work occasionally when they need money (Buzdugan, 2009). Given the restrictions, sex workers are discouraged from seeking health services, and often the incidences of violence are not reported from fear of getting identified as sex workers. Another aspect of non-brothel based sex work is the multiple vulnerabilities stemming from independent solicitation of clients that places women sex workers at higher risk of sexual violence, exploitation and inability to negotiate safe sex, especially in the context of drug-use by males, which increases women sex workers' vulnerability to contract HIV/AIDS (Bentley et al., 2008).

1.4 Contribution and Value of this Research

My interest in this topic and motivation to conduct this research is due to my wish to work in women's sexual health in the future. Before conducting this research, I undertook voluntary work with the Chandigarh AIDS Society (CAS) for three weeks to familiarise myself with the working environment among the HIV/AIDS professionals (NGO staff /service providers)

who work with the women sex workers. According to the *HIV Sentinel Surveillance Report*, emerging epidemics have been observed in the low-prevalence states of North India (NACO, 2012b), which require cognisance and focused attention on HIV/AIDS in Punjab. Arguably, there remains a need to incorporate a qualitative exploratory approach to explore in depth the barriers to HIV/AIDS services experienced by women sex workers, in order to understand their unmet sexual health needs.

The research setting is of interest to me because Chandigarh is my home town. Although women sex workers of Punjab represent a small part of the Indian profile of HIV infected people, as compared to the IDUs, it is important to consider the situation of women sex workers as they are among the highly vulnerable groups in Indian society. A review of the literature showed that studies related to the topic have been undertaken in southern India. Similar studies have not been conducted among the women sex workers in Punjab. Therefore, HIV/AIDS remains an under-researched and poorly understood issue in this location.

I seek to contribute towards the improved health and wellbeing of women sex workers by advocating for their rights to good quality HIV/AIDS services. The research does this by identifying gaps in the access to HIV/AIDS services.

1.5 Organization of the Study

This thesis is composed of six chapters. Following this introduction, Chapter two reviews the existing literature regarding HIV/AIDS-related services. Chapter three describes the methodological approach, including the methods used to gather the data regarding the barriers for women sex workers accessing HIV/AIDS services. Key findings from an analysis of the research data are presented in Chapters four and five. Finally, Chapter six considers the research implications, before making recommendations for the improvement of HIV/AIDS services in Chandigarh (Punjab).

Chapter Two: Indian Women Sex Workers' Vulnerability to HIV/AIDS and HIV/AIDS Services

2.1 Introduction

This chapter reviews the literature addressing Indian women sex workers' vulnerability to HIV/AIDS and the barriers associated with accessing HIV/AIDS services. Within the Indian context of the HIV/AIDS epidemic, this review delves into identifying the barriers faced by women sex workers in relation to HIV/AIDS services. To better understand the context of the HIV/AIDS epidemic and sex work in India, this review explores the historical and contemporary situation of the women sex workers and their rights, the conservative nature of the Indian community, and the impact these factors have on available HIV/AIDS services. This chapter is a critical review of a significant global health problem in India and the implications for policy related to HIV/AIDS and sex work in India. Thus, the focus is on the factors increasing women sex workers' vulnerability to contracting HIV/AIDS. It includes an identification of the socio-economic factors that underpin the relationship between HIV and the health care needs of women sex workers in India and how the government is responding to this epidemic.

2.2 Historical Overview of Sex Work and Sexually Transmitted Infections

Venereal disease (sexually transmitted disease as it has historically been described) in India received little attention until the Contagious Disease Act (CDA) was enacted by the British colonial government in India (Pivar, 1981). The CDA was legislated in 1868 in response to the rampant growth of venereal disease among the British military (Levine, 1994). First enacted principally in 1864, almost every British colony acquired the sex trade within the military cantonments as a part of commercial sex activity within the military towns under the umbrella Cantonments Act- Act XXII of 1864 (Levine, 1994; Burton, 1992). The CDA XIV of 1868 gave power to the British colonial government to establish mandatory medical examinations under a system of a sanitary policy and restrict the mobility of sex workers. Moreover, the transmission and eradication of venereal disease was precarious throughout the nineteenth century in the colonial state due to the lack of medical knowledge and facilities available to deal with the problem. The clinical distinction between syphilis and gonorrhoea was only established in 1879; and treatment, especially of syphilis, was ineffective during the early twentieth century (Levine, 1994).

Sexually transmitted infections (STIs) have always been a problem in armies and by the middle of the nineteenth century it became evident among the British army in India, which was severely affected (Pivar, 1981). The CDA also empowered cantonment authorities to cancel the registration of sex workers if they had not undergone a mandatory medical examination (Roy, 1998). Due to the official alarm about the high prevalence of STIs in the army, the British colonial government favoured the idea of having licensed brothels under close police and medical surveillance. It required inpatient treatment through the use of 'lock' hospitals, both civil and military, attached to the cantonments for women diagnosed as suffering from venereal disease in the late eighteenth century (Levin, 1994; Peers, 1998). Police constables of military cantonments were empowered to arrest any woman on suspicion of venereal disease, and forcibly confine them for medical examination, which often violated their dignity and self-respect (Levin, 1994). If a woman, when diagnosed with venereal disease upon examination, was legally declared as a sex worker she was able to be legally restrained in a lock hospital until free of disease (Whitehead, 2007). Underscoring the mandatory examination and medical custody, these laws assumed a direct link between sex work and disease transmission, thus labelling women sex workers as vectors of disease.

Sex work in India was redefined at each stage with the enactment of major legislative interventions including the Cantonment Regulations (1864, 1880, 1889, 1893, and 1897) and the CDA (1968) (Whitehead, 2007). Revision of the containment regulations through the 1890s continued the provision of registered brothels and maintenance of lock hospitals in each military cantonment in India under the name of 'voluntary venereal hospitals' (Pivar, 1981). According to the Indian CDA, sex work in India was constituted of two classes: Class 1 consisted of those who were allowed to consort with the British soldiers only and Class 2 was kept for the local men. The annual report on the *Venereal Lock Hospitals in Punjab* for the year 1887 stated that the women of Punjab were only allowed to make sexual alliances with the British troops and not with local inhabitants (Levine, 1994; Punjab Government, 1888). In earlier efforts to control the epidemic, British colonial officials incorporated a system of classification, surveillance, testing, and confinement of women sex workers in lock hospitals (Roy, 1998). Despite efforts to prevent the disease in the Punjab, venereal disease among soldiers was contracted mostly from the unlicensed/hidden women sex workers residing around the containments (Punjab Government, 1888). This created the means of defining respectable and unrespectable behaviour within the conservative society of Punjab.

Since then, the women sex workers were symbolised as criminal, marginal and impure, who had a lower status and gradually became stigmatised in Indian society (Whitehead, 2007).

2.3 Women Sex Workers' Vulnerability to HIV/AIDS in Contemporary India

2.3.1 Vulnerability due to existing laws.

Regulated sex work appears to have been maintained in India until about 1920. After independence from colonial rule in 1956, the young Indian nation-state incorporated the Immoral Traffic (Suppression) Act, also known as the SITA in the Indian penal code (Kapur, 2005). The SITA, the primary law dealing with the status of women sex workers, allowed sex workers to practice sex work privately but not legally solicit clients publicly. With very few changes in the law in 1986, the Act was further amended resulting in the Immoral Traffic Prevention (ITPA) Act or the PITA (Gangoli & Westmarland, 2006). The amendment of legislation was intended to limit and eventually abolish sex work in India by gradually criminalising third party benefits of sex work. This included procuring women for brothels, punishments for adults over 18 from living off the earnings of a sex worker, and more importantly penalties for soliciting clients in public places. The states approach to prostitution inappropriately punished sex workers and, let off their clients, thus reflecting the face of social marginalisation where sex workers had been continually treated as unequal since Indian colonial times (Kapur, 2005). This was the legal regulation of sexuality perpetuation of a culture which continued to expose women sex workers to oppression and exclusion.

Prohibitions on living off the earnings of a women sex worker inhibited women sex workers from becoming the primary household income earners for their families. Due to the existing legal and social structures that vests more power in the hands of men than women (Ghosh, 2010), these prohibitions restricted women sex workers' ability to have control over resources. This further resulted in compromised health-seeking behaviour due to the lack of decision-making power in the hands of women in India (Pallikadavath, Garda, Apte, Freedman, & Stones, 2005). Ratifying separate laws on sex work not only has implications for women sex workers accessing HIV/AIDS services, but continues to reflect the state's approach of regulating women's sexuality. As Mary Frug (1992) articulated, "characterising certain sexual practices as illegal, these rules sexualize the female body. They invite a sexual interrogation of every female body. Is it for or against sex work?" (p. 129).

From colonial times, with minor changes, the law continued to be in practice, resulting in sex work being somewhat legal in India but the surrounding activities such as operating brothels

and pimping being illegal (Koteshwaran,2001). The rationale is that the practice of consensual sex privately should not be a matter of state intervention, but that the practice of the sex trade publicly should be regulated. As argued by McClintock (1992), the above form of state-regulation articulates sex work within a cultural domain of marginalised sexuality and separates it from the status of work. In terms of accessing HIV/AIDS services, this law has serious implications for the women who seek to practice this trade secretly. A study by Land and Prabhughat (2012) on women sex workers in Asia indicated that the hidden sex workers' are less likely to benefit from HIV/AIDS programmes due to the fact that much of their sexual activities are conducted under the guise of other activities. This would appear to mirror what is happening in India. At the state level in Chandigarh, HIV/AIDS prevalence among women sex workers has remained consistent over the years (NACO, 2012b) which may be partly a reflection of fewer women sex workers accessing ICTC services; or if accessing them, then they are identified as falling under a 'general' category, rather than as high-risk groups.

When the first HIV/AIDS case among sex workers in South India was detected in 1986, the state's response to the HIV/AIDS epidemic was denial (Bentley et al., 2008).The first AIDS Prevention Bill was passed in 1989, in which the Indian state gave the judicial power to medical authorities, and allowed authorities to forcibly test and isolate the members of high risk groups, which predominately included women sex workers (Dhanda, 1991). From a human rights perspective, this law violated women sex workers' rights by inappropriately forcing women sex workers to undergo testing, but leaving their clients alone, and also making women sex workers more vulnerable to stigma (Kapur, 2005). Later, owing to national and international pressure, there was an active debate in the country around the issue of mandatory testing of people suspected of having contracted HIV/AIDS. As argued by Dhanda (1991), the coercive piece of legislation is not only violating human rights and privacy, its high expenditure and the extra resources required make it difficult to implement effective HIV/AIDS programmes (WHO, 2011). Furthermore, the coercive and stigmatising components of the bill prevent people from coming forward to undergo HIV/AIDS testing (Biesma et al., 2009). On the other hand, as also considered by the National Advisory Council (NAC) (2003), such a strategy could be counter-productive as it may scare away a large number of suspected cases from getting diagnosed and treated. The Indian state evolved several stages of AIDS control policies and, as a result in accordance with the WHO

guidelines on HIV testing, considered voluntary HIV testing to be a better strategy to prevent and control HIV/AIDS in India (Gruskin & Trantola, 2008; WHO, 2011).

2.3.2 Vulnerability due to socio-economic context.

In the context of an expanding HIV/AIDS epidemic in India, the prevailing constructs of patriarchal gender relations and heteronormativity has posed unprecedented challenges to state and society (Ramasubban, 2008). Due to having multiple sexual partners and an unsafe working environment, women sex workers are frequently exposed to a higher risk of acquiring HIV infection (WHO, 2011). Within the context of sex work, different levels of financial security and diverse social and environmental conditions encourage risk behaviour and make sex workers vulnerable to HIV infection (Biradavolu et al., 2011). Furthermore, the low status of women in society due to the lack of education, and financial dependency on men, often puts them in a subservient position (David et al., 2010). This often contributes to women sex workers feeling powerless and voiceless to negotiate safe sex, which increases their vulnerability to HIV/AIDS infection (Ramesh et al., 2012). In a study of sex workers (Cornish, 2006), it was noted that the price a client is willing to pay normally drops when the sex worker demands a condom for safer sex. This condition is captured in several research studies, which indicate that women usually enter the sex trade as a last resort due to the economic and social conditions which force them to engage in high-risk behaviour and hence become highly-vulnerable due to having multiple sex partners (Battala, Jain, Saggurti, Sain & Verma, 2011; David et al., 2010; Panchanadeswaran et al., 2008).

Indian society is largely gender-stratified and mainly characterised by patriarchy descent. Notions of gender and power play a dominant role in shaping sexual attitudes and behaviours differently depending on the cultural and societal orientation of the people involved. In patriarchal India for instance, sexual activity is perceived to be a man's domain, where power is exercised over women's sexuality (UNESCO, 2002). Female chastity and modesty in India is further reinforced through the gendered norms linked with seclusion and segregation, whereby women are kept in the house and a close watch is kept on their movements (Chattopadhyay & Duflo, 2004). In India, women have little power in domestic decision making which often restricts their mobility in terms of accessing HIV/AIDS services. A study by Pallikadavath (2005) on patriarchal societies in India indicated that women have no power to make men use condoms which could prevent sexually transmitted disease. Furthermore,

women sex workers are marginalised and criminalised among the societies in which they live due to sex work lacking social and moral approval (Bentley et al., 2008). As a result they become more vulnerable to the HIV/AIDS epidemic due to the existing gendered and cultural norms about sex and sexuality.

Globally, sex workers remain disproportionately affected by sexual violence and the HIV epidemic (Steinbrook, 2007). Factors such as unequal power relationships resulting from gender-disparities in education and the low social and economic status of women often weaken the ability of women to negotiate safer sex and be protected from HIV transmission. The study by Biradavolu et al. (2011) investigated socio-economic factors among female sex workers in Andhra Pradesh, where HIV has largely affected sex workers. The major findings distilled from this study indicate that sex workers are among the low socio-economic groups who do not have other sources of economic support other than sex work. The research showed that sex workers were more likely to agree on unsafe sexual behaviour (sex without condom) and were often trapped in violent situations when their living circumstances were socio-economically poor. In addition, a quantitative study (Celentano et al., 2011) among 522 non-brothel based sex workers in 24 slums of Chennai elicited that gender-based violence increases the risk of contracting HIV among the sex workers. This study used survey methods to collect data, which showed that among the 522 sex workers, 28 per cent reported having forced sex with one partner and 35 per cent with two or more partners. Moreover, it concurs with the data provided by UNAIDS (2012) on the coverage of HIV/AIDS prevention services among 58 countries, including India. The data highlights that countries without comprehensive legal protections for sex workers are less likely to provide appropriate coverage of HIV/AIDS prevention services to the sex workers.

2.4 India's Policy and Programmes for HIV/AIDS Services Targeted at Women Sex Workers

2.4.1 Policies and guidelines.

Over the years, India has intensified its fight against HIV/AIDS through policies, guidelines, and programme services. NACO is the agency which formulates HIV/AIDS policies and programmes for HIV/AIDS prevention (Lawrence & Barun, 2012). In accordance with the WHO (2012) guidelines on prevention and treatment of HIV/AIDS for women sex workers, India aimed to achieve the shared global vision of zero new HIV infections, zero discrimination and zero AIDS-related deaths by 2015 (UNAIDS, 2012). Furthermore, it was

committed to achieving concrete results in the 2011 *United Nations Political Declaration on HIV/AIDS – Intensifying our efforts to eliminate HIV/AIDS* (Schwartlander et al., 2011). However, Misra, Mahal and Shah (2000) suggested that, although India is signatory to numerous obligations related to women's rights such as prohibition of discrimination and exploitation by gender, it has failed to protect the rights of women, especially those of sex workers. Reasons for this failure might be the fact that India has not fully recognised the need to adopt global guidelines and standards on prevention and treatment to improve HIV/AIDS programmes in the context of sex work (WHO, 2011). Study results drawn from clinical settings indicated health professionals' stigmatising and discriminatory attitudes towards women accessing HIV/AIDS services resulted in a lack of access to health care and a high level of HIV infection (Elamon, 2007). These findings also revealed that the discriminatory attitudes were facilitated due to the deficiencies in the legislation, coupled with the failure to provide effective enforcement of gender-equality and anti-discriminatory laws.

In addition NACO (2012a) estimated that, in 2009, 172,000 people died of AIDS-related illness without their HIV/AIDS status being diagnosed; and in many situations AIDS-related deaths go unreported due to the stigma and discrimination attached with HIV/AIDS (UNAIDS, 2012). As a result, it is anticipated that by 2015, efforts to control and prevent HIV/AIDS will be massively overwhelmed if the rights of people living with HIV/AIDS (PLHIV) are not considered resulting in the lack of proper access to health care services.

In 2005, the United Nations (UN) General Assembly adopted the declaration of commitment on HIV/AIDS (WHO, 2012). As a signatory to this declaration, India is committed to endorsing those goals by 2015. UN Millennium Development Goals include MDG6a (Halt and begin to reverse the spread of HIV/AIDS) and MDG6b (Universal access to treatment for HIV/AIDS) for all those who need it by 2015 (UN, 2013). As highlighted by Bhardwaj and Bose (2008), India is committed to the obligation that by 2015, at least 90 per cent of young women and girls aged 15 to 24 years will have universal access to information, education, and health services necessary to reduce their vulnerability to HIV/AIDS. NACP stage III, with the main focus on high risk groups including sex workers, places the highest priority on HIV/AIDS prevention services with the claim that 99 per cent of the population in the country is free from infection (NACO, 2012a). NACO data for the years 2011-2012 suggests that health seeking behaviour among HRGs has increased by 18 per cent (NACO, 2012b). However, a report by the WHO (2012) on HIV/AIDS testing and counselling services stated

that India lags behind most low and middle-income countries on the availability of HIV/AIDS services. Therefore, estimates based on surveillance data from NACO seem to give a false impression of sex workers' universal access to HIV/AIDS services and of 99 per cent of the population being free from infection.

2.4.2 HIV/AIDS intervention services.

The earlier stages, NACP I (1992-99) and NACP II (1999-2006), of the HIV/AIDS programme was aimed at creating public awareness of HIV/AIDS and keeping prevalence rates to less than three per cent in high-prevalence states and less than one per cent in the other states (Nambiar, 2011). Based on the lessons learned from the NACP stages I and II, the government implemented NACP III (2007-11). The aim is to halt and reverse the epidemic by integrating comprehensive HIV/AIDS prevention, care, and treatment strategies into the programme which is shown below in Figure 3 (p.17).

NACP-III at a glance

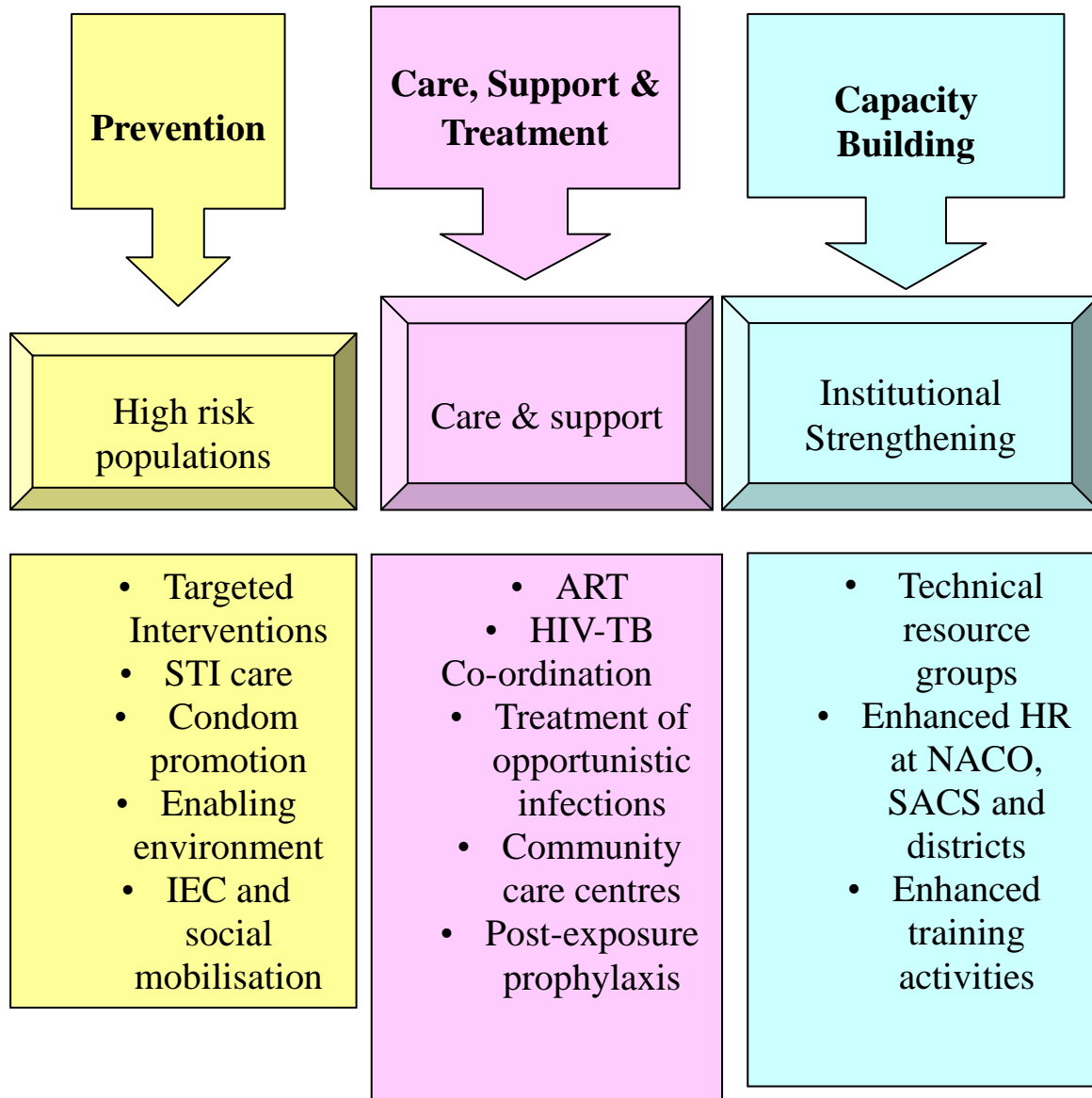


Figure 3. Services provided under NACP-III – Preventive, Care, Support and Treatment Services.

During these different stages, the focus was shifted from creating awareness to behaviour change with the increasing involvement of NGOs, community-based organisations (CBOs) and networks of people living with HIV (NACO, 2012a). To meet the prevention needs for sex workers, NACP-III has integrated peer education and community mobilisation into the Targeted Intervention Programme (TIP) with the aim of reducing high risk behaviour (Evans & Lambert, 2007). As evidenced by Lazarus et al. (2012) and Nath (2010), the CBO run by

sex workers in South India successfully increased condom use and has maintained low STI prevalence among sex workers, as compared to the sex workers of the other states. Findings in other cultural contexts of South Indian states have also demonstrated the increased effects of peer education on reducing HIV/AIDS-related risk behaviour and increased adherence to ART (Koenig, Leander, & Farmer, 2004; Nachega et al., 2006; Reza-Paul et al., 2008).

NACO implemented targeted intervention (TI) as the most important component of NACP-III. The aim is to target 100 per cent of the community and provide universal access for HIV/AIDS prevention, treatment, and care services to high risk groups, including sex workers (NACO, 2012b). As per the NACO mapping estimates of 2011, 3,974 women sex workers are covered by four TIs in Chandigarh, Punjab (CSACS, 2011). As depicted below in Figure 4, the data misleads the reader into believing that 100 per cent of the sex workers are covered by TIs. But this target achievement rate is only limited to the proportion of women sex workers receiving services from TIs. In contrast, the sex workers not receiving services from TIs are completely ignored and are not covered, which is one of the major challenges to HIV/AIDS prevention for the sex workers in Chandigarh (Ambekar, 2012). Therefore, the issue of the estimated number of sex workers in Chandigarh, Punjab, remains poorly addressed by the limited impact of HIV/AIDS intervention simply because it is implemented on such a small scale that most of the sex workers cannot be reached.

Target Intervention Projects (NGOs-TIs)						
	Total projects	Bifurcations of Core Groups				
NGO Targeted Intervention Projects	12	4 FSW Projects	2 MSM Projects	3 Migrant Projects	2 IDU Projects	1 Composite (FSW+MSM)
Percentage Population being Reached	* 100% high risk population has been saturated by all Targeted Intervention Projects					

Figure 4. Targeted Intervention coverage data.

Source: Retrieved from <http://www.chandigarhsacs.org/FFTTargetInter.html>

In India, several peer education interventions have been developed to increase the use of condoms and reduce the risk of HIV/AIDS among sex workers. But these interventions have failed to adopt and develop locally viable solutions by addressing the social, economic and cultural conditions which force sex workers to engage in high-risk behaviours influenced by their financial needs (Ghosh, 2010). A study by Singh and Narayan (1994) on condom-based prevention found that, due to the lack of education and greater needs for financial gains, nearly 41 per cent of sex workers were reported to refuse condom use after the successful implementation of education interventions. Another study by Chattopadhyay (2003) on empowering women sex workers through peer-education showed that even after the few months of education intervention, only 21 per cent of sex workers were reported to use condoms in sexual intercourse. By contrast, in Thailand, after the implementation of 100 per cent condom use programme, nearly 92 per cent women sex workers refused clients without condoms (UNAIDS, 2000). The key to success of this programme was the establishment of a commercial sex work industry which maintained proper records of registered sex workers. But this approach is not valid in India, especially in Punjab, where the brothels and sex workers do not seem to exist officially. Therefore, programme planning and implementation challenges exist where information on numbers of sex workers is inaccurate and thus they are hard to reach (Kumar & Gopal, 2012).

India receives funding for HIV/AIDS related programmes from a variety of UN partners and bilateral donors via three funding streams, including donations from national governments, multilateral funding organisations and private funding (NACO, 2012a). During the third phase of the National AIDS Programme (NACP) for the years 2006-2011, the World Bank worked closely with the Indian government and other donors to support targeted interventions and provided funding of US\$250 million (The World Bank, 2012). India has designed various HIV/AIDS prevention programmes to meet the needs of sex workers but poor regulatory systems, arising from the lack of funding and resources were considerable barriers to the programmes' implementation (Lazarus et al., 2012). In 2009, over US\$338 million of funding was disbursed to NGOs in India, with the focus on HIV/AIDS prevention services (Nambiar, 2012). But India does not compete effectively for these funds because of issues of poverty, illiteracy and gender-inequality. Therefore, India lags behind in research and medical facilities and has scarce resources to deal with an AIDS epidemic (Sivaram et al., 2009; WHO, 2012).

Given that Punjab is considered to be a low-prevalence state (NACO, 2012a), with limited attention paid to HIV/AIDS in the state, resources and funds in India have been directed exclusively to the regions with high HIV/AIDS prevalence rates (Lawrence & Brun, 2011). The *HIV Sentinel Surveillance* (HSS) report by NACO (2012b) documented rising trends in Punjab with an estimated adult HIV prevalence greater than the national prevalence (0.31%). Also, the report estimated that with 12 per cent of people living with HIV/AIDS (PLHIV) in Punjab (NACO, 2012a), the epidemic is at risk of becoming full-blown and spreading to the general population in the absence of locally appropriate and effective HIV/AIDS interventions. As a result, this report underscores the need for cognised and focused attention in Chandigarh, Punjab which has currently low HIV prevalence but high vulnerability.

2.4.3 Challenges and barriers identified in relation to sex workers accessing HIV/AIDS services.

The literature review revealed a number of barriers faced by women sex workers in accessing HIV/AIDS services.

On the basis that a targeted intervention program (TIP) can be considered to be effective and feasible in reducing HIV/STI infections (WHO,2011), various components including behaviour change communication, condom promotion, outreaching, counselling, referral and linkage services were integrated to target sex workers uniformly all through India (Nambiar, 2012). However, although TIPs are implemented so they uniformly target women sex workers, studies carried out by UNESCO (2002) indicate different patterns of STIs between North and South India. On the one hand, sex workers were reported to be the main source of infection among the men visiting STI clinics in South India; however on the other hand, relatives and acquaintances were reported as the main sources of infection in North India. A study by Basu et al. (2010) on the sex workers of South India suggested the increased utilisation of HIV/AIDS services and reduction of HIV/AIDS risk as result of establishment of clinics in women sex workers' vicinity. Whereas studies in North India have suggested that sex workers made fewer STI clinical visits as a result of cultural taboos, women's restricted mobility, non-user friendly services provision due to the lack of resources, and also due to the lack of support from family members (Pallikadavath et al., 2005; NACO, 2008). Therefore, sex workers health needs are different based on the different STI patterns and type of sex work in the area.

Although the links between gender-relations, power, sexual behaviour and HIV/AIDS infection are complex, it is becoming clearer that due to economic, social, and political inequality between men and women, the choice that sex workers have is limited (Nath, 2010). For example a report by Ghosh (2010), taking a geographical perspective on HIV/AIDS, indicated that in northern states in India, sex workers' limited awareness of HIV/AIDS and fewer visits to STD clinics were reported due to the high level of illiteracy and women's economic dependency on men. As Nyamathi et al. (2010) noted lack of knowledge and awareness about HIV/AIDS prevention stemming from low education levels and the social norms restricting women's ability often constrains women's ability to seek HIV/AIDS services. Another study by Chattopadhyay (2003) in the high prevalence states of India suggested that sex workers with fewer years of basic education and low household income were less likely to be aware of HIV/AIDS prevention and more likely to practice high-risk behaviours. The Behavioural Surveillance Survey (BSS) 2006 by NACO (2008) on health seeking behaviour reported low levels of awareness about HIV/AIDS (less than 60%) among sex workers in Punjab. Also the proportion of clients of women sex workers availing themselves of treatment from private facilities was higher (46%) than the low levels of respondents aware of ICTC services (11%) in Punjab (NACO, 2008). Thus, it may be concluded that sex workers' disproportionate vulnerability to HIV/AIDS (Rompay et al., 2008) due to poverty and gender-disparities in education poses a barrier to HIV/AIDS services.

In India's patriarchal society, there exist gender disparities in HIV/AIDS prevention and treatment services (Sivaram et al., 2009), resulting in the lower well-being of women sex workers seeking HIV/AIDS services (Chattopadhyay, 2003), despite the availability of government-sponsored resources (Nyamathi et al., 2012). Even with the growth of a large middle class in India, gender disparities in education are widest among the women (over 40%) in Punjab (Ghosh, 2010), with an unfavourable sex ratio (874 females per 1,000 males) (Bhawsar, Singh & Khanna, 2005), thus making this state more patriarchal and conservative when compared with the other states (Lawrence & Brun, 2011; Jejeebhoy & Sathar, 2001). Mapping of sex workers in North India has shown a substantial proportion of women sex workers are in traditional and homemaking roles (O'Neil et al., 2004). Given the stigma and discrimination attached with the epidemic, HIV/AIDS prevention-related information dissemination becomes very problematic. Therefore, HIV/AIDS services in Punjab are

provided under the guise of family planning activities, meaning that women sex workers are less likely to get the benefit from HIV/AIDS services (Land & Prabhugate, 2012).

A study by Bhawsar, Singh and Khanna (2005) provided evidence of compromised health seeking behaviour which has implications for women seeking HIV/AIDS services in Punjab. The study showed that autonomy and empowerment in terms of household decision-making was quite low due to wider gender disparities in the state. As supported in the study by Pallikadavath et al. (2005), the higher level of economic dependency of women on men restricts women's abilities to make decisions about obtaining health care for themselves, which influences their receptivity to communication about prevention, negotiating safe sexual practise and seeking HIV/AIDS testing.

The WHO global health sector strategy on HIV/AIDS was developed with the focus on information, access to services and creation of supportive environments (WHO, 2011), with pragmatic recognition of the violation of human rights occurring around the globe in relation to HIV/AIDS, including mandatory testing, confining vulnerable populations, and denial of access to health care facilities and education (Pallikadavath et al., 2005; Schwartlander et al., 2011). A qualitative study by Nyamathi et al. (2010) among the HIV-positive patients in India found that stigma was related to the isolation and discrimination experienced by women living with HIV/AIDS. Unfortunately, in India one of the biggest challenges for effective HIV/AIDS interventions among women sex workers is stigma (Sivaram et al., 2009), not only due to their HIV/AIDS status, but also due to them being members of socially excluded groups living at the margins of society (Chattopadhyay, 2003).

Furthermore, stigma prevents women sex workers from seeking treatment for STDs due to the fear of being accused in regards to their involvement in sex work. Studies looking at the refusal of care by physicians (Kielmann et al., 2005), and discriminatory behaviour of health care providers (Sheikh et al., 2005) have verified the low rates of access to HIV/AIDS services due to the stigma attached with the HIV/AIDS epidemic. In addition to this, qualitative studies by Thomas et al. (2005), Bharat, Aggleton and Tyrer, (2001) and Pallikadavath et al. (2005) have reported that women with HIV/AIDS were not only denied access to resources for care and treatment by health care providers, but also denied shares in, and access to, property by their families. Another study among the women by Chandra, Deepthivarma and Manjula (2010) on HIV testing-related disclosure in South India found that stigma, discrimination, and fear of getting blamed for bringing disgrace to the family

were reported as the main reasons for non-disclosure, and 73 per cent of the sample reported anticipation of negative societal reactions.

Discrimination and stigmatisation based on the grounds of HIV/AIDS is considered a major barrier for people wanting to access condoms, treatment, and information to prevent the transmission of HIV/AIDS. A study by Aggleton et al. (2007) revealed that people with HIV are often discouraged from coming forward to seek treatment, information, HIV testing, support and counselling due to the negative attitudes and reactions from people providing these services, leading to discrimination in health care. According to NACP III, where prevention services such as HIV/AIDS testing, counselling and condom distribution among women sex workers is provided for free (Lawrence & Brun, 2012), issues around confidentiality and privacy continue to occur (Chandra et al., 2010). Inadequate adherence to WHO guidelines of universal access has been further suggested by Pallikadavath et al. (2005), indicating a majority of HIV/AIDS tests were done without adequate counselling; and women sex workers reported instances where the service provider asked them embarrassing questions regarding their sexual relationships. A qualitative study in Mumbai (South Indian state) by Roth, Krishnan and Bunch (2001), based on an examination of cultural constraints to safe sexual practices, highlighted the most significant barriers in the study population as being social stigma and cultural taboos, which resulted in a lack of public discussion about sexual practices, disease awareness, and privacy in stores. That women sex workers compromise their health seeking behaviour is further evidence of the social norms of gender-discrimination (Sheikh et al., 2005) and stigma (Sivaram et al., 2009), which might explain the reason why they are afraid of accessing HIV/AIDS services and remain untreated resulting in unknown amounts of HIV/AIDS transmission (Singh & Banerjee, 2004).

Besides discrimination and stigma, a study by Nyamathi et al. (2010) has suggested poor services conditions in health care facilities and unavailability of transportation support as the major barriers discouraging people from visiting ICTC and ART centres. In addition, a study by Kumar and Gopal (2012) in a resource-limited setting highlighted that lack of medicines and unavailability of trained staff resulted in demotivating high risk groups from coming forward to seek treatments from service providers. In the study, ICTC and ART centres were situated far away and high risk groups (HRGs) reported difficulties travelling to government hospitals to access HIV/AIDS services. Beside these barriers, ICTC opening hours and desensitised staff, including health care providers, leading to stigma and discrimination, were

also reported as barriers to health seeking behaviour among high risk groups. The CAG (2006) performance review by Kumar and Gopal (2012) reported that due to the lack of trained doctors and non- installation of machines, government facilities were unable to provide a supportive environment for effective prevention; therefore HIV/AIDS services are not provided according to the needs of vulnerable groups. Given the poor health care facilities, a report by Pallikadavath et al. (2005) highlighted that issues related to transportation must be considered and measures must be taken to improve access by directing provision-related funds to HIV/AIDS intervention.

2.5 Conclusion

HIV/AIDS has reached serious proportions in India. However, dealing with this problem is a major challenge due to cultural, social and economic factors. This review has attempted to show the link between the historical and contemporary situation of women sex workers in India. Historically, policies have changed but the situation of women sex workers in Indian society has remained the same as it was in the past years. The government continues to ignore the rights-based health needs of sex workers which have further increased sex workers' vulnerability to contracting HIV/AIDS. Women sex workers continue to face challenges in terms of accessing HIV/AIDS services due to the gaps within social, economic and legal contexts. This review identified women sex workers' increased vulnerability, stemming from unequal gender norms and the low socio-economic status of women, as a significant key driver to HIV transmission in India. Given the fear attached to the HIV/AIDS epidemic, stigma is considered a major barrier experienced by women sex workers in accessing HIV/AIDS services.

There is evidence that development and implementation of HIV prevention strategies/programmes have been effective in reducing HIV prevalence among certain groups in India (Koenig, Leander, & Farmer, 2004; Lazarus et al., 2012; Nath, 2010). However despite these successes, HIV rates are still high in India (2.4 million people infected with HIV) and in some parts of India where the HIV epidemic exists, it remains unnoticed (NACO, 2012a). At the programme level, India lags behind in effective prevention of HIV/AIDS due to the issues of poverty, gender-inequality and illiteracy. Furthermore, lack of funding and resourcing are considered as the major barriers to effective prevention, which result in the poor provision of HIV/AIDS services. Efforts are being made to empower

women and girls through the process of creating awareness and providing knowledge, with the view of utilising their full potential for capacity building (Lazarus et al., 2012). However, due to the cultural and societal challenges resulting in the lack of programming and assistance to provide educational, preventive and treatment services, HIV/AIDS has the potential to develop into a serious epidemic in India.

Based on the literature review, there were no comprehensive studies focusing on the perceptions of sex workers in terms of accessing HIV/AIDS services and considering the underlying socio-economic issues which fuel the HIV/AIDS epidemic in India. Also important to consider was that there were no research studies published on women sex workers in relation to HIV/AIDS services in Chandigarh, Punjab. Therefore, this current review on HIV/AIDS has opened further opportunities where the vulnerable situation of women sex workers in relation to HIV/AIDS could be further researched.

Chapter Three: Researching the Unheard

3.1 Introduction

This chapter outlines the methodological approach and research design employed in this study, the aim of which was to give voice to the silent, providing description and explanation (Neergaard, Olesen, Andersen, & Sondergaard, 2009) of the views and experiences of women sex workers in relation to accessing HIV/AIDS services. The first half of this chapter will explore the choice of a qualitative descriptive methodology in greater detail. The second half of the chapter includes an explanation of data collection procedures, followed by the justification of methods employed; namely semi-structured individual interviews and document review. In addition, issues of ethics pertaining to the research processes are discussed.

3.2 Methodological Approach: Qualitative Research

The research was guided by the following questions: What are the barriers to accessing HIV/AIDS services provided in Chandigarh, Punjab? And, what are the views and experiences about the availability of the HIV/AIDS services provided in Chandigarh, Punjab? Given, these questions, a qualitative methodology was deemed most suited for the research.

The exploratory nature of qualitative research is best suited to elicit HIV/AIDS-related sensitive information from women sex workers. Renzetti and Lee (1993) suggested that issues involving sexual behaviors, drug use, abuse and so-called taboo topics like HIV/AIDS are sensitive areas to research. During the conduct of sensitive research, the researcher has to understand the importance of actively involving the vulnerable populations during the process of data gathering (Johnson & Clark, 2003). Furthermore, considering the sensitivity of this topic, research questions are to be raised with extreme care. Vulnerable populations generally experience diminished autonomy due to the lack of social support and this necessitates the adoption of qualitative methods especially appropriate to study vulnerable populations (Liamputtong, 2007), providing the researcher with the opportunity to voice concerns of the study population (Moore & Miller, 1999).

Qualitative research methods allow for the detailed investigation of situations and behaviour, and provide an in-depth explanation of the issue by answering *who* is affected, *what* factors are involved and *why* such phenomena occur (Marshall & Rossman, 2006). The basic aim of

qualitative research is to study human behaviour in a 'natural' setting (Taylor & Bogdan, 1998). As posited by Berger and Luckmann (1967), qualitative research attempts to document the world from other people's point of view, to know what people say and how they construct their realities (Marshall & Rossman, 2006). Qualitative research, which is primarily inductive and descriptive (Flick, 2009), provides rich contextual data that is pivotal to understanding the socio-behavioural aspects of HIV disease. The non-intrusive and subtle nature of qualitative research has been particularly appropriate in examining sensitive HIV-related issues. Further, it has contributed significantly to comprehension of, and responses to, HIV/AIDS. It also allows the researcher access to social and cultural inner circles that tend to be otherwise impenetrable to quantitative research.

Being a signatory of the Millennium Development Goals (MGDs), India is committed to combating HIV/AIDS-MDG6 and reducing gender-inequality-MDG3 by the year 2015 (UN, 2013). One way to achieve these goals is by promoting women's empowerment and equal participation across public and domestic spheres. *An Engendered Development Report of India* (2009) noted that participation of women in public dialogue and decision making has remained far less than that of men due to the cultural norms and beliefs which deny women a real voice in the governance of institutes at all levels (United Nations Development Programme [UNDP], 2011). Cultural norms and beliefs are also limiting women's influence in decisions that determine the future of their families and communities. This understanding provides the rationale for adopting qualitative research methods to look for alternative ways of encouraging women to explore their perspectives on accessing HIV/AIDS services. Furthermore, it could also bring the unheard dark experiences of women sex workers to 'light' in ways which quantitative research is unable to match.

The TIP approach for HIV/AIDS prevention, care, and treatment in Chandigarh, India, has relied on providing information, education and communication (IEC) to influence individual behaviour (NACO, 2012a). Further, it creates awareness among the general health care facilities to ensure that high risk groups can access HIV/AIDS services without facing stigma and discrimination (CSACS, 2011). Although TIPs tend to provide HIV/AIDS services to the women sex workers in Chandigarh, none of those interventions comprehensively focus on the women sex workers' different needs and constraints when accessing those services. Furthermore, these approaches are lacking components which address such elements as power differentials (unequal power relationships), cultural and social structures (gender

disparities) and local forms of knowledge which support the development of effective interventions to enhance women sex workers' access to HIV/AIDS services. Being familiar with the cultural and social context was intended to provide the researcher with the opportunity to establish trust and rapport among the potential participants and enable the gathering of more culturally/socially appropriate data. In particular, Reinharz (1992) argued the importance of qualitative research in offering challenges to existing ideologies and practices that oppress women. This ability is enhanced through employing an in-depth interview method that documents women's hidden voices; illuminating gender-based stereotypes and unearthing women's subjective knowledge and their experiences (Marshall & Rossman, 2006).

3.3 Recruitment/Sampling

3.3.1 Participants: Purposive sampling.

This research focused on a multi-faceted vulnerable population (Radley, Hodgetts, & Cullen, 2005); namely women sex workers who face stigma and discrimination in their everyday lives. The women present a doubly vulnerable group of society due to the fact that they are firstly, often young; and secondly, are involved in high-risk behaviour (Moore & Miller, 1999). In Punjab, women sex workers are characterised as a hidden or difficult to access population (Sedhuraman, 2011). Given the difficulty in accessing women sex workers due to the illegal and clandestine sex trade in Punjab, purposive sampling was employed. For this research, the purposive sampling supported by CSACS, was considered as the most suitable recruitment method to gain access to the vulnerable group because it normally targets a specified group of people (Liamputtong, 2007). CSACS was identified to assist with recruitment as they currently have four HIV/AIDS targeted interventions for prevention, care, and treatment running successfully among the women sex workers in Chandigarh, Punjab.

The purpose of this research was fully explained to the women sex workers and NGO staff working within the organisation. A pool of participants was created by the organisation and once the interest to participate was received via a form left in a drop-box, the researcher then contacted the participants to ensure their willingness to participate in the research and collect information for inclusion criteria. After gathering the information over the phone, the researcher invited the potential participants to attend the individual interviews. In this way,

the organisation involved in the recruiting process did not know who was participating in the research; thus keeping participants' information confidential.

The participants were comprised of two groups (see Table 1, p. 30). Group A included TI staff and group B was comprised of women sex workers. In qualitative research, the logic of targeted sampling involves recruiting small samples (study participants) with the aim of gaining an in-depth understating of individuals' social situations (Hesse-Biber & Leavy, 2007). To maximise the understanding of challenges and barriers, participants (four women sex workers, three key informants) from different colonies under the TIP were recruited for this research.

Women sex workers, working either from the cities or slums/rural areas, with working experience within the sex trade and attending or have attended any HIV/AIDS services in Chandigarh, Punjab, were invited to participate in this research. CSACS generated a pool of potential participants who were sent information about the study (see Appendix A). Potential women interested in the study put their contact details in a drop-box to which only the researcher had access. The researcher then contacted the participants to ascertain their willingness to participate in the research and collected information from participants to ensure they met the inclusion criteria. Legal age of consent for sex work in India is 18 years (UNAIDS, 2012) and to meet the consent criteria, the researcher recruited participants aged 20 years and above. This age-based criterion for recruitment was in order to interview those who have spent some time within this trade and who had good understanding about the provided HIV/AIDS services. Eligible key informants to participate in this research needed to have been working among the women sex workers and have understanding about provision of HIV/AIDS services for a minimum of three years.

Once potential participants indicated their willingness to participate in the study, they were asked to sign a consent form (see Appendix B) at the time of interview. Three of the participants were illiterate; therefore the researcher provided an oral explanation (word-for-word information was read in front of participants individually) about the study before conducting the interview session. To maintain confidentiality, participants were interviewed individually in an assigned room at the drop in centre of CSACS which was publicly safe for both researcher and participants. Furthermore, participants were asked to choose a pseudonym to protect their identities from the organisation involved in this research and other parties who may be able to identify them.

Table 1

Participants' Background Information

Name	Gender	Age	Participant group	Time spent in the organisation
Danny	Male	34	NGO worker	12 years
Karam	Female	30	NGO worker	3 years
Gagan	Female	32	NGO worker	2-3 years
Reema	Female	25	Sex worker	4 years
Lata	Female	27	Sex worker	5 years
Sharmila	Female	21	Sex worker	3 years
Param	Female	22	Sex worker	2- 3 years

3.4 Data Collection Procedure

Based on the methodology discussed above (section 3.2), this study used two different types of qualitative methods to generate information about women sex workers and challenges they face in accessing HIV/AIDS services. In-depth interviews and document analysis were considered appropriate when the focus was on description and explanation; the researcher was encouraged to portray the reality of women sex workers by employing particular methods justified by critical theory (Snelling, 2006).

A questionnaire to guide the semi-structured interviews was designed (see Appendix C). Semi-structured interviews were conducted to uncover different perceptions of HIV/AIDS service provision and allow the participants to express views in their own terms. To get more reliable and comparable data, questions were formatted differently for the sex workers and the staff. For example, TIP staff was asked about their understanding of the barriers and challenges faced by women sex workers in accessing HIV/AIDS services, and experiences in relation to challenges faced by TIP staff during the provision of HIV/AIDS services in Chandigarh, Punjab. Women sex workers were interviewed about their understanding regarding the availability of HIV services and their experiences in relation to the barriers and challenges faced during accessing HIV services in Chandigarh, Punjab.

On average, interviews lasted for approximately 90 minutes. All the interviews were conducted and transcribed verbatim into Hindi and then translated the transcription into English for data analysis. To ensure the accuracy of collected data, each interview was audio-taped after getting the permission from the study participants. The use of a tape recorder further encouraged the researcher to be more attentive to gather reliable information from the pool of collected data (Patton, 1999). For example, when I undertook the process of translation and transcription, the audio device was used to write word-word information provided by the study participants to ensure accuracy during data analysis.

3.4.1 Primary data collection (Stage 1: Individual interviews).

The primary aim of undertaking individual interviews was to obtain data in the field setting. Conducting day time interviews in a closed assigned room situated within the TIP centre provided a safe and secure environment for participants and minimised noises and other distractions while conducting the interviews (Brown, 2001). To maximise the depth of data gathered, the researcher was involved as a volunteer at the NGO service for two weeks prior to the data collection. This helped the researcher become familiar with the working environment and build rapport among the study participants (Flick, 2009). Warm up questions were asked prior to the individual interviews to ensure the active and direct involvement of the research participants where they could comfortably share their views and experiences without any hesitation; for example, “how are you feeling today?” “How was your day up till now?”

Given the historically oppressive nature of the sex trade in India, the researcher had to ensure that this research did not further stigmatise a highly vulnerable population. An individual interview was considered the most appropriate data collection method for this study as it provided complete privacy and maintained the confidentiality of the research participants, thus ensuring participants could acceptably communicate and describe their experiences of barriers and challenges in their own terms (Gubrium & Lolstein, 2001). The concept of the individual interview was used so that participants could voice their concerns and represent the situation as experienced (Hesse-Biber & Leavy, 2007). The researcher attempted to empower participants by involving them actively and directly through individual interviews where they could maintain their own point of view without any fear (Ritchie & Lewis, 2005). Qualitative methods such as semi-structured interviews can ultimately help to prolong the

conversation and gather a richer form of data as compared to telephone interviews and focus group discussions (Flick, Kardorff, & Steinke, 2004).

Initially, sex workers were reluctant to open up, but slowly they started to share their perceptions and lived experiences of accessing HIV/AIDS services. The interview method in this study helped the researcher to achieve the same deep level of information and knowledge as the participants of this research. For example, in-depth interviewing was used to explore the situation of women sex workers in relation to HIV/AIDS services and seek a deeper understanding of the challenges they faced during accessing HIV/AIDS services. This helped the researcher penetrate to a deeper, more reflective understanding of the participants and uncover the issues that are usually kept hidden due to the fear of getting exposed in front of others.

3.4.2 Secondary data collection (Stage 2: Document analysis).

The secondary method was to gather data from documents including research reports, service reports, government policies and programmes focusing on the needs of women sex workers in Chandigarh, Punjab. The substantive information was culled from the internal documents and annual reports provided by an NGO, the Family Planning Association of India (FPAI). In order to bring out the useful information, the researcher focused on highlighting the information which fell under the themes used for data analysis. Document analysis was carried out to review current knowledge about the availability of HIV/AIDS services for sex workers and experiences of the barriers to accessing HIV/AIDS services in Chandigarh, Punjab. Later the collected documents were supplemented by literature from around India in order to analyse the broad economic and social foundations of sex work in relation to HIV/AIDS services.

In undertaking the document analysis, the researcher was encouraged to reveal the deeper meanings of those documented sources which were not possible to be investigated by direct observation (Ritchie & Lewis, 2005). For example, submitted procedural documents including meeting minutes, and personal documents including personal notes, were useful for this research because the aim was to consider participants' experiences where the written organizational notes were central to the enquiry.

3.5 Data Analysis

Following data collection, the audio recordings of the interviews were transcribed from the Hindi recorded version to an English translation. To ensure the accuracy of the information provided, participants were revisited and transcribed scripts were read out to them. The advantage of being well versed in the local language gave the researcher the chance to clarify and modify interpretations as pointed out by some participants (Corcoran & Stewart, 1998). Qualitative thematic analysis was then used to analyse the main issues emerging from the interviews and written documents, which Anderson (2007) defined as synthesising, summarising and analysing of key themes emerging from the collected data. The initial step was to review the text several times in order to understand the contents of the document. The researcher looked for the saturation of ideas and moreover, what was mentioned during the interview sessions and what could be extracted from the text to create themes focusing on women sex workers and barriers to HIV/AIDS services. Themes were identified by hand using cut-and-paste/highlighter method. Data relevant to the analysis was highlighted, selected and grouped together to form themes. Next, the similar concepts and quotes which seemed to connect to sex workers' experiences of barriers to HIV/AIDS services were labelled to develop themes from the collected data.

This research started with a broad focus on the challenges and barriers faced by the women sex workers in accessing HIV/AIDS services in Punjab, Chandigarh. Based on the aim of this study, the coded texts emerging from the analysis were further interpreted with reference to the literature on HIV/AIDS services in India. For example, texts were coded in terms of the quotes that seemed to connect participant's experiences of HIV/AIDS services and women sex workers' social, cultural and economic context. Next, the coded texts were reduced to smaller groupings in order to develop themes which are discussed in Chapters four and five. In this study, interview and document review data were coded for the identification of any thematic trends and variations in participants' knowledge and experiences of the barriers in relation to women sex workers' health needs and HIV/AIDS services.

Responses regarding challenges and barriers in relation to HIV/AIDS services were segregated and constantly compared to identify any emerging relationships between the themes. Selected transcript quotations were highlighted to illustrate dominant themes which were further clustered to structure the text into a coherent whole. Finally, the findings were presented in the form of discrete but interrelated prominent themes, which constitute barriers

to HIV/AIDS services in Chandigarh, Punjab. Findings were organised according to the two domains of data collection: barriers to accessing HIV/AIDS services for women sex workers of Chandigarh; and socio-economic issues related to women sex workers accessing services in Chandigarh.

3.6 Rigour

As it applies to research, triangulation involves the careful reviewing of data collected through multiple methods in the investigation of a single construct in order to achieve accuracy of the qualitative results (Oliver-Hoyo & Dee, 2006). To enhance credibility and research utility, Denzin & Lincoln (2011) suggested four basic types of triangulation:

1. Triangulation of source and time involving data gathering at different times and locations from a variety of sources; for example people in different roles (such as health professionals, social workers, women sex workers) or documents of different types (research reports, services reports, government policies);
2. Investigator triangulation, involving multiple interpreters or researchers;
3. Methodological triangulation, employing multiple data collection procedures;
4. Triangulation of theories, using multiple perspectives to interpret and analyse data.

For qualitative research, triangulation can occur at three layers: data sources; data collection; and data analysis (Freeman, 1998). This research utilised three forms of triangulation; namely, methodological, time and data source triangulation.

3.6.1 Methodological triangulation.

The use of a multiple method approach, including in-depth interviews as the primary data collection method and document review as the secondary data collection method, should generate multifaceted information by drawing on multiple perspectives of the same phenomenon (Berg, 2009). Given the importance of design and validity in the choice of research instruments in understanding the multifaceted realities of women's lives, the process of combining different methods increases the likelihood of researchers understanding what they are studying, and convincing others of the rigor of their results (Reinharz, 1992). Qualitative, descriptive research using different methods articulates the commitment to conscientiousness, and willingness to be open-ended and change oriented due to risk taking nature (Reinharz, 1992). Due to the limitations associated with the sample size, time, and the

study context, a multiple method research approach to data collection was adopted to collect sufficient data to promote rigour in this research and strengthen the study design.

3.6.2 Triangulation in time and data source.

Freeman (1998) posited time and source triangulation as time and /or in location, involving same type of data collection and/or using similar method(s) in multiple data gathering sites over multiple time periods (e.g., individual interviews in the first four weeks and document review from weeks three to six. As shown below in Table 2, the two basic data collection methods of in-depth interviews and document review were adopted consecutively on a weekly basis. Different sources targeted for data collection were women sex workers connected to the CSACS and community AIDS professionals/key informants (social workers, NGO heads, and NGO advisors) working among the women sex workers in CSACS. The ‘data triangulation and time triangulation’ combines data drawn from different sources at different times and from different people in order to investigate and minimise any biases the participants might have due to their different roles (Flick, Kardorff, & Steinke, 2004).

In summary, the multiple method strategy was identified as the most appropriate for the present research as it:

- allowed for a thorough examination of phenomena by combining different methods to enhance understanding both by adding layers of information and by using document review data to validate or refine the interview data;
- enhanced reliability of the research data through methodological and time triangulation;
- enhanced validity and reliability of the research data through source triangulation.

Table 2

Matrix of Methodological, Time and Source Triangulation

Week	Document review	Interviews (sex workers)	Interviews (key informants)
1		X	X
2		X	X
3	X	X	X
4	X	X	X
5	X		
6	X		

3.7 Ethics

Ethical approval for this study was obtained from the Auckland University of Technology Ethics Committee (see Appendix D). Permission to carry out this study was also obtained from the CSACS (see Appendix E). Verbal consent was sought from each participant along with the written consent. Although the proposed research did not directly involve Māori participants or particular Māori issues, the study was conducted following the *Health Research Council's Guidelines for Researchers on Health Research* (Health Research Council of New Zealand [HRC], 2010), and acknowledges the three Treaty principles: partnership, participation, and protection.

3.7.1 Partnership.

The research was focused on the behavior of a high-risk group (sex workers) and the views of health workers about the availability of HIV prevention services and unmet health care needs of women sex workers. This research was carried out in partnership with the relevant local authority officials (organisations working with the sex workers). Thus, the relationship with CSACS and the TIP outreach service provider at the grass roots level was vital. The TIP staff members had a thorough knowledge of the area and were known to the target population in a context of service provision for three or more years. Therefore, the research was able to work closely alongside them to access the women sex workers whose voices were pivotal for this study.

3.7.2 Participation.

Participants were informed about the purpose of the research, the expected duration, and procedures through a Participant Information Sheet (see Appendix A). Research participants were also given the complete right to decline to participate and to withdraw from the research at any point. Participants played a crucial role in this research because their principle involvement provided the researcher with the useful information/data which was used further as research findings. Participants were offered counseling sessions if they were upset at any time during the interviews; however this did not transpire.

3.7.3 Protection.

The researcher was responsible for protecting identities and maintaining confidentiality of all potential and enrolled participants of this research. Participants' responses were audio taped

and both audio recordings and written data were stored in a safe and secure place to which only the researcher and supervisors had access. The target population of this research was women sex workers, a group that is highly marginalised and stigmatised in Indian society. In order to carry out research in a culturally and socially appropriate way, relevant local authority key informants, the CSACS and NGO Family Planning Association of India staff, were involved to minimise the potential risk by identifying any sensitive cultural and social issues. For example, the researcher is from Punjab and therefore is aware of the conservative culture. Study participants were interviewed in their local language, which made participants feel comfortable and secure during the interview session. The researcher was also aware of using socially acceptable language during the interview. Such as, instead of using term sex work, household work was used, which was socially acceptable for them.

3.8 Conclusion

This chapter has explained the rationale behind adopting a qualitative methodology as best suited to this research study. Although the TIP is implemented uniformly throughout India to influence behavior and create awareness, they have failed to provide a comprehensive understanding of barriers for sex workers that impinge on their ability to access HIV/AIDS services. In Chandigarh, no such research has targeted women sex workers' needs in terms of HIV/AIDS services.

The chapter has described how, given the cultural context, qualitative methodologies were best for getting the in-depth sensitive information and important for giving the women, who are vulnerable and marginalised, a voice. This chapter has also detailed the actual methods, such as who the participants were, and how the data was collected and then analysed. Furthermore, it has explained how the multiple methods promoted rigor by adopting different research instruments which explored the previously unheard realities of sex workers and strengthened the study design. Finally, an overview of ethical issues was discussed. Study findings will be discussed in the following Chapters four and five.

Chapter Four: Women Sex Workers of Chandigarh and Socio-Cultural Barriers to Accessing HIV/AIDS Services

4.1 Introduction

This chapter explains the study findings related to socio-cultural issues and barriers to accessing HIV/AIDS services for sex workers in Chandigarh. The data shows how the socio-economic conditions have limited sex workers' ability to access available HIV/AIDS services and practice protective measures. Moreover, the data uncovers the issue of dominant patriarchal power structures in Punjab and the effects on women sex workers. Further themes are made visible including the stigma and discrimination that contribute to making women sex workers more vulnerable, while diminishing their rights; and the resultant compromise in health seeking behaviour.

4.2 Socio Cultural Barriers to Accessing HIV/AIDS Services

Interviews with NGO staff and women sex workers pointed to a number of barriers relating to socio-cultural issues and sex work. The data showed that the patriarchal nature of the society acts as a hurdle for HIV/AIDS advocacy in Punjab, with male domination in the areas of sexuality, and the exploitation of women both within the household and outside at work. During the interview with the Family Planning Association India staff, one such theme emerged relating to the low socio-economic status of women and women's constraints as a result of domestic work and lack of control over resources. As mentioned by Danny:

“Without family consent, sex workers exposure to the outside world is curtailed. From morning till night she is involved in household chores such as cooking; cleaning compromising her need of accessing HIV/AIDS services.”

The other staff members explained how the low status of women in society does not easily allow them to demand and access condoms, thus resulting in unsafe sexual activity:

“Women in India are considered as second class citizens, who play a submissive role in the society. A home-based sex worker often accepts unprotected sex due to the pressure from her client and need of money to support her family.” (Gagan)

This sentiment was also echoed by Karam:

“She cannot ask for condoms openly, what she will say that I need condom, the biggest challenge for young girl is the fear raised from society which will never let

her ask for condoms openly, hundreds of heads will turn around for that girl when asking for condom, and society is not that open in India.”

Lack of independence to make decisions for themselves and the household due to wider gender-disparities in the state were the main determinants of the choices the women sex workers made, including determining their access to HIV/AIDS services. From the interviews, the data revealed that women sex workers compromise their needs in terms of access to health care, due to heavy workloads and various cultural taboos and restrictions. As mentioned by Reema:

“I am illiterate. To fulfil my family needs I have to work in this trade. Upon earning some money my husband gets suspicions and asks me that from where I got this money. I cannot tell him about this trade and when I do not answer him, he beats me.”

This is a good illustration of how control over resources and authority is entirely in the hands of men. Lata spoke of how she had to lie about her extra earnings:

“My husband does not allow me to go anywhere without his permission, he gets suspicious when I come here, even today if he will come to know that I visited this office he will start beating me and take me from here. So I had to lie that I am going outside to do maid work.”

Sharmila shared a similar story:

“I always have to inform my family about my whereabouts when I go outside during the day time. I am not allowed to go anywhere after sunset. I have to lie when I go for outside for this work; I tell them that I am going for the work in beauty parlour.”

These statements illustrate the issue of being pressured to stay at home, and the limited opportunities and freedom to get employment and thus have some resources for themselves. Despite the availability of government funded resources, sex workers are burdened with the opportunity and transportation costs (discussed further in Chapter Five).

The practice of clandestine sexual activities was also a feature of the discussions with the NGO staff and sex workers. The broad themes were those of stigma and gender - inequality leading to the hidden sex trade in Chandigarh, which resulted in stigmatising attitudes by the community and health providers. During the researcher’s initial visits to the TI centre, the sex

workers were at first reluctant to open up and share their stories, almost in denial of their activities due to the fear of getting exposed in the media for their involvement in this trade. As mentioned by Param:

“Madam, I just do cooking and cleaning in the homes of neighbouring colonies, and whatever you are asking me is not getting into my mind.”

Initially, the sex workers were reluctant to talk because in front of the general public or in their neighbourhood they are homemakers. The research data revealed an important aspect of the NGO services, which was to deliver appropriate HIV/AIDS services under the guise of family planning activities to the home-based sex workers in Chandigarh. Furthermore, FPAI staff found it challenging to address HIV/AIDS directly due to the cultural restrictions and stigma attached to HIV/AIDS. As evidenced by Buzdugan, Halli and Cowan (2009), home-based sex workers are often hard to target because they are not legally registered as sex workers. Due to the unstable nature of sex work, it is a challenge to access this population in Chandigarh. To overcome such problems, FPAI try to reach sex workers through outreach initiative such as TIP group meetings and medical camps. Within these camps, general health- related information is provided with the focus on information related to HIV/AIDS awareness and prevention. As mentioned by Karam:

“The NGO is providing HIV/AIDS-related services to the target population by creating awareness about STIs, HIV/AIDS prevention and testing services during TI meetings. FPAI joins with the other organizations to sponsor general health camps. Due to the HIV/AIDS-related stigma, programme focus on general health issue with the main focus on information related to HIV/AIDS prevention and testing services. This approach encourages general public to come and get HIV/AIDS related information. This way the sex workers are able to receive services and we are able to deliver services.”

Another issue raised was around accessing services in the vicinity of sex workers. Participants noted that when sex workers visit TIP meetings, it is difficult to keep them attached with such programmes due to the fear in the sex worker’s mind of their attendance getting known about by their families and other members of the society. Moreover, the sex workers were reluctant to receive services due to the location of TIP being in their houses’ vicinity. They feared breaches in their confidentiality and avoid visiting TIPs.

As mentioned by Lata:

“Place where service is provided is just next to my house, everyone in this area knows that TIP meeting are only held for the women sex workers, how can I attend those meetings, my family will get to know about my profession, they will not accept me.”

Another participant said something similar:

“We attend TI meetings with fear, hide faces and come. Sometimes, surrounding people complains the police about the gathering of sex workers at TI due to which we have to run from that place.”(Sharmila)

However, the above mentioned findings contradicted the document review findings provided by the NGO which related to the NGOs meeting targets. According to the documents,

“74% of women sex workers are visiting at TI centre to receive HIV/AIDS services”
(*Impact Union Territory Female Sex Workers*, p. 1).

Another NGO document reported that:

“696 out of 800 sex workers are referred to the ICTC Chandigarh. FSWs visited for regular medical checkups and got checked herself for STIs with help of project services” (*Impact Union Territory Female Sex Workers*, p. 1).

Since colonial times (see Chapter Two), sex workers in Punjab continue to not get legally registered due to the lack of social approval. As evidenced by O’Neil (2004), women sex workers in North India are home-makers who hide their sexual activities due to the stigma attached with the sex work. Peer educators networking via medicals camps help NGO service providers to access sex workers and deliver HIV/AIDS outreach services. Implications in terms of accessing HIV/AIDS services in the vicinity was the fear of discovery by family members which resulted in compromised health behaviours such as visiting customers without condoms, and inability to consistently attend meetings or trainings and access testing services.

One side effect of the clandestine trade, and fear of the family and community finding out, was that condoms were not kept by sex workers in the home. Again these findings contradict

the above mentioned documents which discuss sex workers' usage of condoms due to appropriate counselling.

As mentioned by Sharmila:

"I fear to keep condoms at home and often see clients without condom. And if I go to the local shop near my colony it is the other problem because people will come to know about my activity. So instead of getting known by others it is better to see client without condom."

Another participant also noted:

"I am scared of using public transport specially buses because I might get someone known on the bus who will ask me questions about my visit to the hospital." (Reema)

Thus the effects of clandestine behaviour can lead to women not using protective measures and available HIV/AIDS services. Women sex workers shared their experiences of stigma and discrimination by health care providers during their visit to the hospital on accessing HIV/AIDS services. As mentioned by Param:

"I took testing card from my pocket and kept it on the table for the testing staff to sign off and write down my next visit. He rummaged in his pocket for a pen but couldn't find one. I took out my pen and offered him to use. With the weird emotion on this face, he asked me to keep the pen inside and preferred borrowing it from his colleague sitting far."

The above statement indicates the strong physical reaction and negativity from HIV/AIDS service providers. It possibly indicates lack of knowledge of the transmission of HIV/AIDS, but also social attitudes. Given the barriers, the additional likelihood of poor communication between sex workers and service providers due to the stigma attached with HIV/AIDS has resulted in sex workers feeling insulted and disrespected. Instead of being treated with respect and care, women sex workers are blamed for their lifestyle choices. Furthermore, the health professionals' discriminatory attitudes towards women sex workers discouraged women sex workers from coming forward and receiving HIV/AIDS services. According to Danny:

"Sex workers are uncomfortable to get open with the staff due to the personal attacks experienced during the access of HIV/AIDS services in the hospitals. Many times sex workers report the instances of ill-treatment and rejection at the hospital. They often

complained for queuing for long hours due to the number of patients and inadequate staff, but also reported favouritism in seeing people from the general population earlier.”

Sex workers shared a similar experience:

“I was next in the queue and when I told him that I am HRG (high-risk group) and wants to have HIV tests done then I was asked to stay behind and wait until all the patients from general category gets seen. This attitude was just because I wanted to have HIV test done. It will be more likely see here that people with multiple partners are asked for HIV/AIDS and hardly people from general category get tested due to having one sexual partner. This is the reason why we are tagged with the name of target groups. By giving this name we already get excluded from the society and discriminatory behaviours are obvious because we are the targets according to the NGOs.” (Sharmila)

Another participant added:

“I took few girls for blood testing at PGI hospital. One of the staff member said, why are you coming forward, just stay back in the line, I am going for tea, so wait for me to come back. I stood waiting with the girls but didn’t get chance to have blood tests. No one listen us whether its doctor or other hospital staff.” (Param)

FPAI staff have witnessed that even though the police and other government officials are aware of clandestine sexual activities, they avoid becoming part of HIV/AIDS prevention programs due to the fear of going against cultural and religious norms and beliefs resulting in a violation of rights of women sex workers. As mentioned by Sharmila:

“Several times I have experienced violence from my clients. I cannot seek help from police because then people will get to know that I do such activities.”

According to Danny:

“HIV/AIDS programmes are running under government sector but due to the stigma attached with the HIV/AIDS, this programme (HIV/AIDS) is pushed aside and just considered as the part of one organization-State AIDS Control Society, this programme is not considered as a shared responsibility of other government organisations. Problem arises as soon as HIV/AIDS is discussed, government and

medical officers recommends contacting AIDS Control Society, it is not considered as part of their duty and from there we start getting gaps in service delivery.”

Something similar was added by Param:

“Hidden sexual activity is almost practised in every house, in DMC (Daddu Maajra) colony everyone knows that liquor is sold and such activities are practiced but police does not take any action. Police knows everything but stays quiet from bringing this issue in public openly due to the involvement of home-based women in this trade. Issue is that we cannot report any case. In case, under the pressure of media police raids but dissolve the case internally after getting their share of money.”

According to TIP staff, the majority of women who visit the NGO belong to the lower socio-economic group. Furthermore, as reported by David et al. (2010) women sex workers are among the lower socio-economic groups of society due to a lack of education, and financial dependency on men which often results in lack of control over resources and family decision making. However, a study by Biradavolu et al. (2011) has suggested that women sex workers rely on sex work for economic support. Yet the women are often hard to target because they practice this trade secretly because of the wider conservative society in Punjab. Sex workers often fear getting exposed in regards to their involvement in the sex trade. As described by Danny:

“We try to approach her (sex worker), educate her about the importance of using condoms but she is not ready to accept her work and refuse to listen about anything. I know so many girls in this trade, initially who did not open up but as soon as they started getting problems such as vaginal fluid or vaginal itching they approached us. Due to her fear of getting blamed by society for doing this work, she is unable to receive HIV/AIDS services properly.”

A sentiment supported by Gagan:

“Most of the family members of sex workers are unaware of their involvement in sex trade due to the conservative nature of the society resulting from wider gender-disparities. They question her visit to the clinic periodically as we have TI meetings every month. The girl usually replies saying, ‘I am having stomach pain’. For the family she looks fine and they doubt on her frequent visit to the clinic. Due to this fear of self-disclosure women avoid coming here. When I ask them the reason for not

providing their contact details and for not attending the meeting they give me these reasons. Few of them have revealed the instances of family violence at many times.”

Karam further added:

“Sometimes they also provide us with fake names and addresses from the fear of getting disclosed in front of their family members. The other reason for misleading with wrong names is due to their fear of getting diagnosed with HIV/AIDS upon testing can affect their daily earning.”

From the examples, it can be seen that socially and economically disadvantaged women sex workers have less control over their ability to access health care, leading to many of the STIs remaining untreated. They fear isolation and discrimination based on the grounds of their HIV/AIDS status. This might explain why they fear accessing services and remain untreated.

4.3 Conclusion

The broad theme explored here was that of the prevailing culture which provided the opportunity to explain the women sex workers' situation in Chandigarh, Punjab, in terms of accessing HIV/AIDS services. Culture plays a prevailing role in parts of Punjab (Jejeebhoy & Sathar, 2001), which makes it difficult to address the issues of sexuality and sexual health in open public discourse (Land & Prabhugate, 2012). Additionally, stigma related to HIV/AIDS along with the social biases against women in sex work has worsened the situation. Furthermore, the practice of the hidden sex trade has limited their ability to access services, thus making women sex workers vulnerable to contracting HIV/AIDS.

In Punjab, where sex workers are not registered, it is hard to reach them and provide services. The prevailing culture seems to be the biggest hurdle for HIV/AIDS programmes and services in Punjab. Tacit acceptance of cultural and gender norms restrict women sex workers from accessing HIV/AIDS services and increases their vulnerability to contracting HIV/AIDS. Additionally, lack of access to services was reported due to the service providers' discriminatory attitudes which discouraged women sex workers from receiving health services.

Chapter Five: Barriers to Accessing HIV/AIDS Services for Women Sex Workers of Chandigarh

5.1 Introduction

This chapter explores the challenges and barriers related to accessing HIV/AIDS services through the perspective of sex workers and NGOs, the latter whose work has become critical in providing HIV/AIDS programme services to the female sex workers in Chandigarh. In this chapter, the provision of HIV/AIDS services, including the perceptions of NGO staff and women sex workers about the available services, is discussed and concluding themes and subthemes addressed.

5.2 Barriers to Accessing HIV/AIDS Services

The data collected from both NGO staff and women sex workers contextualises their experiences and explores the barriers faced by sex workers in accessing HIV/AIDS services. During the interviews, the primary research question being addressed was”

What are the challenges and barriers related to HIV/AIDS services provided in Chandigarh, Punjab?

5.2.1 Service availability.

Sex workers had knowledge and understanding about the HIV/AIDS services provided but their main concern was related to how they are treated by the service providers, who obstruct them from receiving those services. The main concern among TIP staff was in regards to inadequate funding and lack of resources for service delivery at the grass roots level. Both the groups raised the issue of shortfalls in the service delivery environment and the resources for HIV/AIDS related services relative to the needs of the target community of women sex workers.

FPAI played a key role in making HIV/AIDS testing and STI management services available for the sex workers in Chandigarh. Mainly, the testing services are provided at government integrated counselling and testing centres (ICTC), along with the testing van provided by the NGO.

All the sex workers interviewed agreed they knew about the available testing services, except one who mentioned:

“What should I say, I don’t know anything about it, whenever madam (peer educator) tells me to come along with her for the tests, I just go with her. I do not know where to go for testing myself because I have never been to the school and I cannot read and write, so it is quite difficult for me to go alone.”(Reema)

NGO documentation was studied alongside the interview transcripts. According to the document data provided by FAPI, considerable improvements have been seen in the delivery of services of targeted interventions in the years 2009-2010 based on different service delivery parameters laid down by NACO- ICTC/STI in terms of referral and testing, increased condom distribution (as shown below in Figures 5 and 6) and providing trained staff for capacity building.

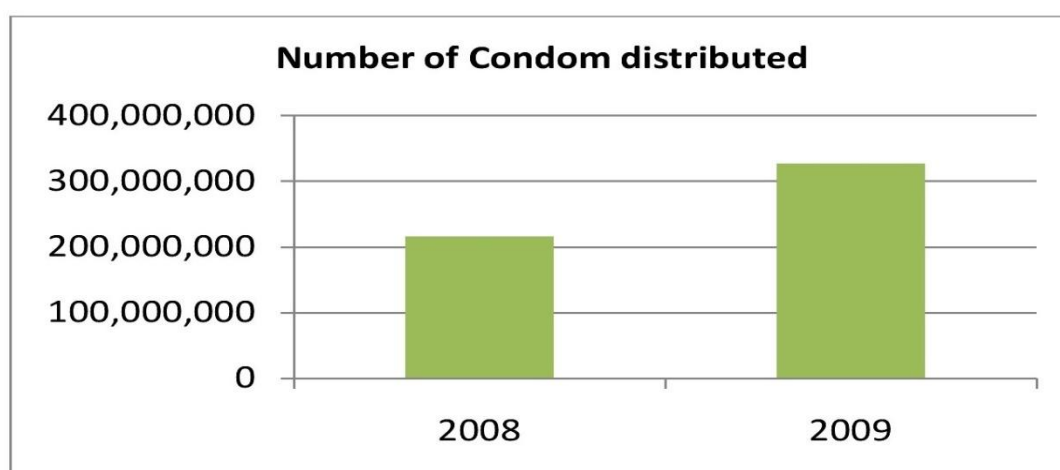


Figure 5 .Increase in the distribution of condoms in the years 2008-2009.

Source: Notable Achievements in Targeted Interventions, 2009-2010

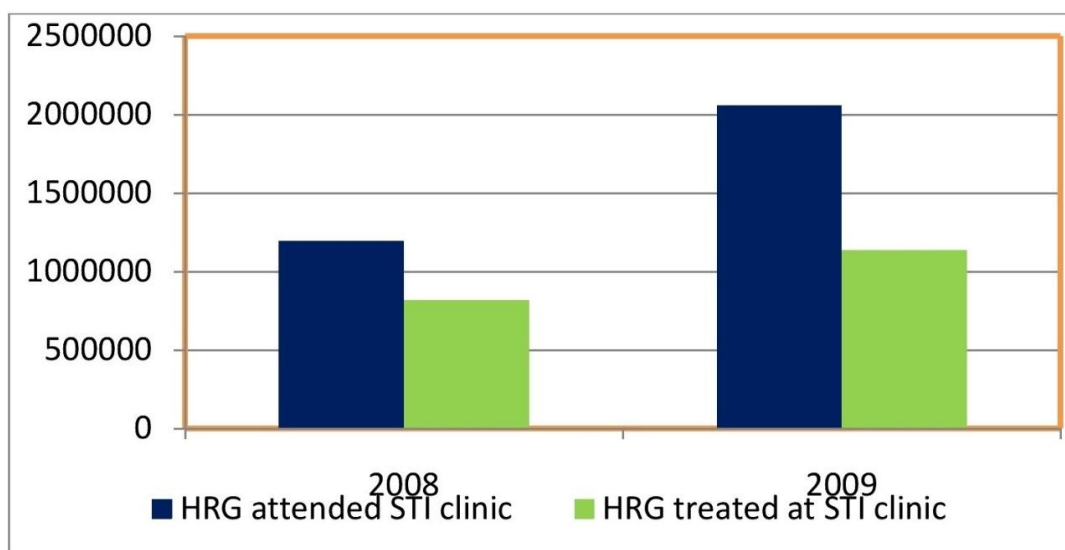


Figure 6. Numbers of the high risk group (HRG) attending, and being treated, at STI services in the years 2008-2009.

Source: *Notable Achievements in Targeted Interventions, 2009-2010*

According to the NGO staff, HIV/AIDS services in the area are provided according to the health needs of sex workers. As verbalized by Karam:

“Our NGO provides full services and sex workers use this service as well, there is no gap at NGO level. HIV/AIDS related services such as condom distribution; ART treatments at ICTs along with the routine medical checkups are provided for free.”

Gagan commented regarding testing van services:

“NGO has provided mobile ICTC vans which runs once a month. TI staff will tell if they need van in their area after one month or not.”

Yet another document provided by NGO states:

“The maximum targets are achieved due to the services being provided according to the needs of target group” (Impact Union Territory Female Sex Workers).

However, sex workers shared a different scenario. According to the sex workers, HIV/AIDS services are not provided according to their needs. Sex workers in particular shared their concerns around the availability of service.

As mentioned by Lata:

“Vans provided by the NGO are target-based. Sometimes we are refused and ignored for the tests because the field workers blood sampling targets have completed.”

Another one added something similar:

“More vans should be provided. It should come more frequently so that all of us can get those services comfortably and there is no need for us to go to the hospital. Government ICTCs are just open till 3pm which is an issue for us because we get more clients during that time.” (Param)

In addition, shortage of camps arose as an issue according to the sex workers, around the availability of services which was not according to their needs. As mentioned by Sharmila:

“Government camps should be arranged from colony to colony. The camps are not sufficient and sometimes we miss the advantage of going due to the client, so it should be arranged more frequently.”

Another participant added:

“We do not get noticed and receive services being part of general public. More of such camps should be arranged, information should be given on HIV/AIDS to those who are uneducated, such camps will create awareness among the general public who is uneducated.” (Param)

This perspective was reinforced by Lata, who commented:

“Camps are arranged no doubt but they are not enough, we are more comfortable in attending medical camps then going for TI meetings.”

The NGO involved in this research cited the case of one government hospital and various other government dispensaries responsible for providing HIV/AIDS services in Chandigarh, Punjab. According to the data provided by the FPAI, appropriate services do not get delivered to the sex workers because supplies cannot meet the demand. As a result, the government hospitals/dispensaries and targeted intervention centres supplied by the NGO are often understaffed and untrained. FPAI personnel mentioned that the ICTC centres at government hospitals for HIV/AIDS testing and treatment lack the provision of appropriate services due to the shortage of trained staff. During the researcher's visit there was no doctor available in the clinic and the dispensary was closed for the afternoon.

This observation was reinforced by Danny:

“Doctors available for limited period like 2-3 hours per day, pharmacist is giving injections and medicines on behalf of doctors, fruit man delivering condoms on social cause and mostly government dispensaries remain closed for 1-2 months.”

From the above examples, it was of no surprise to know that service providers face economic gaps at the grass roots level which affects the delivery of services. According to the clients of FPAI, time given during counselling sessions was not sufficient. As mentioned by Lata:

“We are not getting complete information about HIV/AIDS from the hospital staff. If we consult doctors regard sexual health problems then he will just give us medicine rather than giving proper time to explain why we are having this problem and how can we avoid it from having it in future.”

Something similar was mentioned by Sharmila:

“Sometimes counselling is not given properly because they are in the hurry to leave for the day and sometimes, they are not happy to give up proper time because they have other patients to do, so they finish session in 10 minutes.”

According to the NGO document, the

“Majority of sex workers are receiving proper counselling on HIV & STI management and they are able to make own decisions” (Impact Union Territory Female Sex Workers, p.2).

However, the findings of this study presented a different view that was shared by the sex workers. Along with the issue of insufficient information and time provided during counselling, one sex worker also reported an instance where she was taunted for her involvement in the sex work. As mentioned by Param:

“Counselling room has other staff sitting along with the counsellors; cabin being tightly close breaches our confidentiality. Rather than giving proper counselling session, we are asked private questions which have nothing to do with our visit. Questions like –How many clients did you satisfy today, How much you earned today?”

The above quotations indicate the need to provide appropriate training to the staff at government hospitals regarding treating patients seeking HIV/AIDS-related care and treatment. A cross-sectional survey was conducted among patients with HIV/AIDS receiving care and treatment at public and private clinics in India (Ramchandani et al., 2007). The survey results indicated low levels of knowledge and access to HIV/AIDS related services among the patients attending public clinics as compared to the patients attending private clinics. The major barrier to HIV/AIDS knowledge when seeking care at public clinics was the provision of poor quality services.

5.2.2 Accessibility/convenience.

Volunteers recruited by the organisation, including peer outreach workers and the man delivering fruit, were the main sources of condoms for home-based sex workers. The condoms were made available at the fruit shop outside the dispensary for easy access by the sex workers during the closed dispensary hours. Although the condoms were made available at the depot holders, dispensaries, fruit shops or TIPs centres, major barriers to accessing condoms existed due to the fear of being identified as a sex worker. All four women sex workers interviewed had appropriate knowledge about the use of condoms for safer sexual activity. The main concerns raised were around service access difficulties and poor quality services. As one participant mentioned:

“We have fear in our mind to ask for condom openly because it is attached with sex. We do not want to get identified by others because our work is hidden from our families and neighbours. Instead, names are given such as toffee, chocolate; umbrella when we ask for them at the shops.” (Param)

According to the NGO document,

“Sex workers are using Condoms after proper counselling services by FPAI counsellor and staff” (Impact Union Territory Female Sex Workers, p. 1).

However, the study findings contradict the NGO document. According to the participants in this study, alongside issues of condom accessibility were also concerns surrounding the deficit in quality condom services:

“It has happened with me for three times that the condom got burst while having the activity. Free condoms provided are not of good quality. I pay myself to buy the condoms, why to take risk when I know this condom will burst for sure.” (Sharmila)

Reema made the same comment:

“Sometimes the condoms are too short that it automatically comes off and I think there is no use of providing free condoms when it is not giving us any protection.”

Among the sex workers, awareness about condom use was high due to the various HIV/AIDS prevention programmes; however the internalisation of this knowledge was not seen as a behaviour change. As a result, they avoided seeing the doctor due to the lack of awareness about their sexual health. As narrated by Reema:

“I use it (a condom) every time. Recently, my partner and I used the condom which got picked from TI centre. After finishing off with the activity, I felt something inside the vagina. I touched and felt the condom which got stuck inside my vagina. I thought it will come off automatically but nothing happened for 2 days. I rushed to see didi (peer leader) on third day because I was shy to see doctor myself. Didi accompanied me to the doctor where she removed the condom with some instrument and gave me antibiotic.”

According to the annual report by the National AIDS Control Society (2012a), the fourth phase of the Condom Social Marketing Programme was launched in July 2011 with the aim of optimising the provision of free condoms and ensuring availability by setting up condom vending machines for easy access by targeted groups. During the interview sessions not one participant from both groups mentioned knowing about this service. Furthermore, the above concerns shared by the participants indicate the need to pay more attention to the monitoring of quality services.

5.2.3 Targeting.

FPAI staff in particular shared their concerns about resourcing, availability, accessibility, and the issue of the government only targeting sex workers as target groups and not other members of society. As a result, it divides the community into target and non-target groups.

Data provided by the TIP staff suggests that the donor agencies prefer to fund the programmes focusing on high-risk groups, such as sex workers and IDUs. This approach divides the population into groups of targeted and non-targeted, ignoring other members of the community with the need to access HIV/AIDS related services. Based on the notion of the

HIV/AIDS epidemic being driven by the high-risk groups, targeted interventions are designed to control the HIV epidemic by targeting the groups of sex workers. This raises the question: why target only sex workers and not their clients who are among the non-targeted groups of society including shopkeepers, rickshaw drivers, and police constables? This fundamental issue seems to be ignored by many NGOs and donor agencies; thus leaving the partner to spread the disease within the community.

As verbalized by Param:

“Organization is covering female sex workers but leaving our clients. We are blamed for HIV/AIDS and responsible for getting tested but what about our clients. We are not fully protected because our partners do not get tested. There should definitely be a program which focuses on sex workers and clients together.”

Using a targeted approach is potentially more stigmatising as it focuses solely on the women rather than clients and the wider patriarchal society. This is likely to make women sex workers feel even more ashamed and reluctant to come forward and receive services because the services are just provided for the target groups. As mentioned by Danny:

“We try our level best to provide them with the appropriate services. Monthly review meetings and weekly TI meetings are arranged in which we educate them for behaviour change by creating awareness to adopt healthy lifestyles and relationships. Police station visit are arranged among the sex workers to advocate them about their rights by voicing their needs and concerns and bringing them to the attention of government and public.”

During the interviews, TIP staff explained the importance of creating an enabling environment. FPAI has identified the need to create an environment where the women sex workers would work and receive services without the constant threat of violence and discrimination. They network with the different NGOs and other government agencies to advocate and promote sexual and reproductive health rights. This activity includes relationship building with the larger community such as the police, health care professionals, and business owners. Despite the efforts made by the NGOs, discrimination and gender-inequality continues to place women at higher risk due to the targeting system.

According to Karam:

“Local and central governments are still not sensitised about this topic (HIV/AIDS); they lack genuine commitment and responsibility towards the effective implementation of HIV/AIDS programmes. They (government) remain stuck in the own moral framework of blaming sex workers for this situation.”

A similar concern was shared by Lata:

“Nothing happens with these police station visits. These police man are corrupt. They know everything about us, they know we are sex workers and from where we work. They arrest us when they need money from us. Once they take us to the police station, no one gives us respect. They treat us like animals and use abusive language with us. But if we pay them money, they release us immediately.”

5.2.4 Affordability.

Limited opening hours of ICTC centres, transportation, opportunity costs and insensitive staff were additional reasons why sex workers were reluctant to receive HIV/AIDS services from the government based health facilities. The FPAI’s targeted intervention centre does not offer HIV/AIDS testing services, except for a mobile blood testing van which is available once a month. Mostly, the clients have to travel to the government hospital PGI, Chandigarh. Additional opportunity costs include poor transport options and long queuing resulting in the loss of their business. As Sharmila mentioned:

“The problem is that lot of time and money is wasted. I can’t travel on a bus from the fear of getting seen either by my family or neighbours due to which I have to take the auto rickshaw (tuk tuk). That cost me almost Rs.190 for return. As soon as I reach, I queue there for long hours which mean my half of the day is gone and have missed at least 5 clients for the day. Then after all this if I will be blamed for my lifestyle choice which supposedly led me visit hospital for HIV/AIDS testing, do you think I will be encouraged to back again. Instead I will focus on clients and take money home”.

Another participant added:

“For us problems starts from our families. What excuse we will make to our family members for our visit to the hospital. Then we will go to the hospital, get ticket and queue in the line for at least 2-3 hours, then after spending half of the day in hospital

we will get blood tests done. It is very time consuming process and we prefer not to have it done.” (Param)

As reported by Gagan:

“Services are not provided according to their needs, when we ask them the reason for not going to the ICTC centres then the answer we get is that madam, our client will be missed, if the test would have been in the evening then I would have definitely gone. I had to go with the client in the afternoon and testing centre opens between 9am-3pm”.

Notably, the above mentioned quote by the NGO staff member contradicted with the NGO document which mentioned that services are provided according to the needs of the target population.

5.2.5 Funding.

According to the NGO staff, funding for NGOs comes with conditions and guidelines, typically with parameters of interest to the funder, with the aim of lifting results for them. Therefore, questions must be asked whether the services provided by NGOs reflect the needs defined by the target population, or the donor agencies that are providing funding for the programme. Funds provided by the donor agencies are more popularly used for prevention-related activities such as free HIV/AIDS testing services, free condom distribution and medical camps for other HIV/AIDS related health services. Whereas the importance of provision-related funds is largely ignored, this causes the target population to suffer, despite the services being provided for free. Provision-related funds include those allocated for the training of staff, developing the capacity of TIP centres, covering transportation costs, and arranging frequent camps and mobile vans for appropriate service delivery.

With the primary focus of NACP-III, NACO has given significant thrust to the prevention-related activities rather than the provision of HIV/AIDS services. In the race for funds, provision-related issues such as proper training of staff, sufficient camps to provide outreach services for the target population and helping patients get to the hospital and receive services according to their needs are grossly under looked. As mentioned by Lata:

“Economic gaps are felt on receiving services. Half of our day is wasted when we go and receive services. The better option for us is to pay and receive treatment

privately. It saves our time and privacy is also maintained. We are also able to see our clients and practically it will save our money as well.”

Another participant added:

“It is not like we are receiving ICTC services for free. Getting services for free is of no use when we have to queue up in the line for whole day. Then in return we are ill-treated and our confidentiality is also breached.” (Param)

According to the participants from both the groups, limited funding and resources at the grass roots level was the biggest challenge in reaching the target population, which means quality services do not get delivered. As Danny put it:

“The funds provided for a month gets finished in 1 week and staff working at grass root level face problems in outreaching the target population as a results after 1 week the volunteers lacks in proper facilitation and services gets suffered due to the limited approach.”

Something similar was mentioned by Sharmila, also a peer educator:

“Services are not provided properly due to the limited resources at grass root level which makes it difficult for us to work and provide proper services within those funds. “I get paid 1700, so basically I am working on social cause, whether I have to take women sex workers for blood sample tests for 3 times or 4 times , all the expenses are paid from my pocket and I pick them by my car. If woman sex workers wants go by themselves then the transport cost goes from their pocket as the NGO does not pay for their travelling allowances.”

Another issue raised concerned the extra funds and resources used on outreaching sex workers such as arranging medical camps, TIP meetings etc. As Karam mentioned:

“The biggest challenge in outreaching sex workers in Punjab is because this population is home-based and the reason we need adequate funds and resources is because this population is scattered. Extra energy and resources are used to visit them. We have to visit 3-4 times in order to convince them for testing and receive other HIV/AIDS related services. With limited resources-time, funds, and manpower it becomes really hard to make timely approaches.”

Another participant added:

“We face consistent challenges to fundraise our initiatives. So many times we experience problems for raising money for medical camps. Even though we are successful in arranging camps, we still get short of medicines, medical staff and our expenditures increases. We stay in debt and end up fighting long-term war for home-based population.”(Gagan)

During the interview with the NGO staff another issue raised was of the emerging problem of accountability. Funding and advocacy is entirely directed towards certain regions (high-prevalence states) and groups which are identified as high-risk groups on the basis of epidemic trends. Such a narrow identification of the epidemic patterns has resulted in a loss of funding from donor agencies and has affected the work of several NGOs in the Northern states including Punjab and Chandigarh. As mentioned by Danny:

“Huge donor agencies won’t fund HIV/AIDS programmes in the regions of North India including Chandigarh and Punjab because they are among the low-prevalence states.”

From an economic point of view, the above mentioned classification may be more efficient for the funding agencies because it gives a false impression that the other states of the country are immune to the epidemic. In some respects, NGOs seem to be less accountable to the people they serve. Donors tend to look for higher returns for their investment due to which the NGOs focus shifts away from meeting the needs of target group. As Karam mentioned:

“NGOs get’s funding with conditions and guidelines. To continue getting funds we have to shift our focus from providing services according to the needs of target population to the needs and demands of donor organisations.”

Because of the above mentioned anomaly, lack of financial support is the main concern for service providers because they are dependent on donor agencies to finance their initiatives. As mentioned by the staff members of FPAI, the aim is to meet the demands of the target population by responding to their issues; so far inadequately addressed by the government and other non-governmental and social welfare agencies. According to the above concerns shared by the FAPI staff members, finance-related dependency on donor agencies has lead them to concentrate more on fulfilling the demands of the donor agencies. The following is the experience shared by a sex worker which clearly shows how the work of NGOs has

become extremely target-orientated due to the donors preference for providing funding for initiatives aimed at the target groups in a bid to earn profit from overly quantitative results. Thus, repeating the tests on the same patients and misusing the funds and resources.

As mentioned by Lata:

“I have the target of taking 60 ladies for blood test and this test is repeated every 6 months. In a month I take 10 ladies for blood test, next month I will take 10 more, when I do not get more ladies then those tests get repeated on the same ladies. This is also the case that sometimes I have more ladies, I have to stick to my target and take only 10.”

Given the multilevel intermediaries involved at NGO level, several hurdles and regulations restrict the flow of resources from the original source of funds to the actual beneficiaries (target group). As mentioned by the NGO staff, community centres allocated to provide social services remain empty and social structures such as temples, open parks and empty houses are utilised to provide HIV/AIDS related services:

“Community centres remain closed, it becomes jungle, but it is not used to provide services.”(Gagan)

Accountability to the funder agencies of the HIV/AIDS programmes has raised the concerns around conflicting objectives stemming from the shift of NGO decision-making to the donor agencies. This is the additional indicator of NGOs’ shift from focusing on the needs and demands of the target population towards the donor agencies’ expectations. As mentioned by the FPAI, for NGOs’ survival and existence, NGOs’ working guidelines are set up in response to the funding opportunities rather than in response to the needs of the target population. As mentioned by Danny:

“There are always conflicts between NGO staff and grass root level staff, NGO thoughts/ ideas dominates and programme runs according to their understanding. They do not work according to the needs of community members because they never worked at grass root levels and we also get helpless to work according to the needs of targeted community, if we will conflict the decision made by NGO staff then the next day we will be sacked.”

5.2.6 Lack of resourcing / misuse of resources.

Donor agencies hold the power over which programmes get priority. Furthermore, the donor agencies have higher return expectations of their investment which influences the TIPs performance at the grass roots level. At a field level, TIP staff members' growing division of roles and increased activities due the donor expectations has led to staff exploitation. As verbalized by Danny:

“Our system works in wrong direction we have those people recruited for higher level posts who has never worked at grass root levels, sitting in closed AC rooms how do we expect them to understand the situation and needs of those working at grass root levels.”

TI staff also incisively commented on the high level of corruption involved in the NGO due to political connections. Monitoring is actively discouraged due to the political and government connections enjoyed by many of the NGOs and their higher level staff, some of whom are retired political and religious leaders. As mentioned by Karam:

“Organisation is getting huge amount of money, they have no tension but those funds get limited when it comes to the grass root level, we feel lack of funds, funds decrease by the time it gets up to those people for whom these services are being provided.”

Whereas, another participant explained corruption based on the example of tap water,

“I would like to say only one thing here funding is like tap water, when initially tap is opened it has sufficient funds at the top, by the time it reaches to the grass roots level only few drops remain which is not sufficient to deliver quality services to the target population.” (Danny)

Staff at the grass roots level is more actively involved in delivering HIV/AIDS related services to the target population but they seem to have no right to have a say on how those funds should get utilised.

According to the NACO (2012a) report, active management of resource mobilisation and fund utilisation has been done to strengthen the enabling environment for TIPs to deliver quality services. But during the interview session, TIP staff talked about limited funding and resourcing due to which staff are unable to stay attached to the programmes for long. With

the limited resources, staff members were unable to deliver appropriate HIV/AIDS programmes in response to the needs of women sex workers at the grass roots level. As mentioned by Karam,

“With limited manpower and time, TI staff member’s burn out to supply according to the demand and quality services get suffered.”

NGO staff also mentioned how the ground level staff members enter a burnt out situation due to the limited resources which affects the quality services in various ways:

“TI staff is involved in into the other NGO programmes that are not relevant to our programme, we also have to consider NGO vision and mission, and we also get involved in so many activities due to which in our own TI program the delivery services get suffered. Like already due to limited resources we are achieving the target up to 50%, and then imagine if we get involved into the other activities it will then drop the figures down and then instead of achieving 50%, we just achieve 25%.”(Danny)

Another participant added:

“We have to visit NGO head office for weekly meetings and the distance of NGO head office from our TI office is 8-10 Km which is very far. Only 1 meeting/per is relevant to HIV programme and the rest 2 are irrelevant but we have to attend. Now in the remaining 3 days we have to finish the paper work of 6 days. Firstly, we travel long distance for 3 days then by the time we get back to TI office we already get so tired that we are unable to focus on delivering services because then our concentration is just to focus on completing our targets and submit. So we have the burden of finishing paper work of 6 days in 3 days due to which we are unable to deliver quality services to the sex workers.” (Gagan)

The increased decision-making in the hands of more senior level NGO staff has led to what FAPI staff members consider staff exploitation. According to the FPAI, multinationals tend to offer better salary options and hire trained and experienced staff, taking them away from the local NGOs. This creates numerous problems for the grass roots level NGOs like FPAI, thus making it hard for them to retain experienced staff. Additionally, this increases the overhead costs for recruiting new staff and training them in the field of expertise which continues to happen over and over. Furthermore, this results in the distorted allocation of

funds and resources due to which the appropriate HIV/AIDS services do not get delivered to the target population. The other aspect of staff exploitation identified was the unnecessary recruitment costs associated with large amount of expenses which are indirectly passed to the TIPs, resulting in scarcity of resources at the grass roots level.

5.3 Conclusion

This chapter has explored the involvement of FPAI in the provision of HIV/AIDS programmes and services to the women sex workers in Chandigarh. The broad theme explored was the barriers in HIV/AIDS service delivery which impede women sex workers from accessing HIV/AIDS services.

The qualitative nature of the research was effective in exploring the experiences of barriers faced in relation to HIV/AIDS services. Whereas the NGOs seem to have a growing role in providing programmes and services in India, government service providers appear to ignore the needs of the communities they seek to serve. Emerging problems of accountability and lack of funding, resourcing and monitoring within the NGO sector have resulted in compromising the needs of the target population.

Chapter Six: Implications of the Study Findings for HIV/AIDS Services

6.1 Introduction

This study set out to explore the barriers experienced by women sex workers to accessing HIV/AIDS services provided in Chandigarh. The previous chapter discussed the findings of the study in relation to the barriers experienced by women sex workers. This chapter will consider those barriers and present the implications of the findings of this study for HIV/AIDS services in Chandigarh. The research findings provided insights into the reality of women sex workers lives; their sexual behaviours, experiences and the ways in which socio-political and economic factors impact their needs in terms of accessing HIV/AIDS services.

6.2 Implications for Policy and Services on HIV/AIDS and Sex Workers in India

HIV/AIDS have become a growing public health problem in India, requiring various strategies to be put in place. A major shortcoming of the current approaches noted by this study is that services implemented uniformly all over India have failed to consider the subject of the clandestine sex trade as a fundamental barrier to women sex workers accessing HIV/AIDS services in Chandigarh, Punjab. The clandestine sex trade issue explored in this study has not been addressed anywhere in the programmes targeting women sex workers in relation to HIV/AIDS services. Therefore, there is a need to consider the concealing socio-cultural issues which affect women sex workers' health needs and also have serious implications for the spread of HIV/AIDS in India. There is a need for a policy change in the light of knowing about the clandestine trade which might lead to improvements in the provision of HIV/AIDS services in Chandigarh, Punjab. Such changes might include offering ways of accessing services with greater emphasis on maintaining privacy and confidentiality during service delivery.

In addition, the development of HIV/AIDS-related strategies needs to be informed by the following issues discussed under each of the subheadings.

6.2.1 Clandestine sex trade and policy.

The issue of clandestine sex trade reflects the characteristics of Punjab, but circumstances may vary by state across India. Therefore, it would seem appropriate to have state level HIV/AIDS policies which could be designed in a way that reflects the local circumstances. The literature review revealed that despite colonial efforts to prevent disease in Punjab,

soldiers continued to contract venereal disease from the hidden sex workers (Punjab Government, 1888). This created the means of defining respectable and unrespectable within the conservative society of Punjab. Between then and now in Punjab, sex workers continue to be inscribed as criminals who hide their sexual activities due to the stigma attached with the sex work. In South India, several peer education interventions among the brothel-based sex workers have increased the condom use and maintained low HIV/AIDS prevalence. But this approach does not seem to be valid in Punjab because neither brothels nor sex workers exists officially. Therefore, the issue of the estimated number of sex workers in Chandigarh, Punjab, remains poorly addressed by the limited impact of HIV/AIDS intervention simply because it is implemented on such a small scale that most of the sex workers cannot be reached.

Furthermore, the findings concur with the study by Land and Prabhughat (2012) which indicates that the hidden sex workers are less likely to benefit from HIV/AIDS programmes due to the fact that much of their sexual activities are conducted under the guise of other activities and they remain anonymous to others. Although the HIV/AIDS control programme is essentially well planned and designed, the impact will remain ineffective unless the services are provided according to the local needs of the target population.

6.2.2 Targeting of high risk groups.

The literature review, supported by the findings, shows that HIV/AIDS policy has been specifically targeted towards high-risk groups (Lazarus et al., 2012). However, there is a danger that the general population do not see it as a problem for them. Therefore policy needs to ensure that the general population also take precautions to prevent HIV and are able and willing to use HIV/AIDS services. The literature review reveals that inappropriately asking women sex workers to undergo testing, but leaving their clients alone, results in violating the rights of sex workers (Kapur, 2005). By targeting women sex workers and leaving their clients, the wider patriarchal society is potentially more stigmatising as it gives the false impression of sex workers as being the only vectors of disease. This is manifested in the legal regulation of sexuality and culture which continues to expose women sex workers to oppression and exclusion.

For instance, sex workers in this study consistently mentioned their concerns about HIV/AIDS service provision under the targeted intervention programme, which prevented them from coming forward to undergo HIV/AIDS testing. Due to the fear of self-disclosure,

sex workers avoided accessing testing services provided at government hospitals. According to them, this fear was genuine because the testing services provided at hospitals were only targeted at them as a high-risk group. This was seen to have impacted on the sex workers' accessing needs due the fact of services being only available for the target groups and not for the general population. This fundamental issue seems to be ignored by NACO and thus leaves the sex workers' clients to spread disease within the community. Therefore there is a need to develop the new strategies which should provide anonymous and appropriate services for sex workers, but also similarly provide services for their clients and the wider community for the prevention of HIV/AIDS.

6.2.3 Gender inequality and policy.

The problems of sex workers are related closely to the patriarchal and socio-cultural context and therefore there is a need to address issues of gender inequality. Therefore, not only is health policy important, but so also is gender equality-related policies which are likely to be cross-sectoral and require high level political and social consensus. The study identified that the male-dominated and conservative culture of Punjab has a profound effect on HIV/AIDS service provision and utilisation. The qualitative research provided an opportunity to create safe spaces for dialogue with women sex workers (O'Neil, 2007) and explore the challenges they face in accessing services due to the existing cultural and social context of the state. There were instances where sex workers were forced to engage in high risk behaviours influenced by their financial needs. Furthermore, it concurs with the study by (Chattopadhyay, 2003), suggesting that women sex workers with low educational levels and low household incomes are more likely to practice unsafe sexual behaviour. Women sex workers portrayed their understanding of the dangers associated with accessing HIV/AIDS services based on the social norms that exist in the society. For instance, stigma and discrimination based on the grounds of HIV/AIDS status was considered an immediate barrier for sex workers wanting access to condoms, treatment and information to prevent the transmission of HIV/AIDS.

Despite the efforts made by NGOs, discrimination and gender inequality continues to place women at higher risk due to the targeting system (Sivaram et al., 2009). The findings showed that there is stigma associated with HIV/AIDS services and policy needs to address this by finding ways of reducing stigma. One possible way of doing this could be through the training of health professionals to deliver HIV/AIDS services to sex workers without

discrimination. Further, programmes may consider greater involvement of sex workers initially in the development of HIV/AIDS interventions. This study also showed the importance of in-depth interviews which encouraged marginalised groups to raise their voices and share the HIV/AIDS service challenges that they had experienced (Snelling, 2006). The findings of the current study also revealed that the participation of sex workers in programme advocacy will serve as a catalyst to help disseminate and communicate messages to reduce HIV/AIDS stigma. Even though the provided services are largely government funded, the government HIV/AIDS testing and treatment centres seem not to provide services according to the sex workers needs due to the stigma attached with HIV/AIDS infection. For instance, participants reported instances where they were humiliated and blamed for their lifestyle choices, which resulted in discouraging sex workers in seeking and receiving HIV/AIDS services.

6.2.4 Lack of knowledge in the society.

Lack of knowledge about HIV/AIDS transmission and social attitudes towards sex work were other reasons for stigma among the sex workers upon accessing HIV/AIDS services. This finding corresponds with a study that suggests that more than 40 per cent of Indians avoid going to the doctors who are treating patients with HIV/AIDS (Lawrence & Brun, 2011). The lack of privacy in stores where condoms are bought and cultural beliefs about using condoms discouraged sex workers from taking protective measures. Also pointed to in the literature review was health professionals' stigmatising attitude towards women accessing HIV/AIDS services which resulted in a lack of access to health care and a high level of HIV infection (Elamon, 2007). These findings also revealed that the discriminatory attitudes were facilitated due to deficiencies in the legislation, coupled with the failure to provide effective enforcement of gender equality and anti-discriminatory laws.

6.2.5 Role of government in HIV/AIDS control.

The role of government in HIV/AIDS control seems limited. Within the political context of the epidemic, several social and government departments are under-involved due to the stigma attached with this disease. Instead of working in collaboration with the other government departments, NACO works on its own due to the local and state government's lack of commitment towards the HIV/AIDS issue. The study findings revealed the NGOs' growing role in HIV/AIDS prevention, together with the government shunning responsibility, has weakened the response to the epidemic in Chandigarh. This situation is also compounded

by the understanding that NGOs are getting more dependent on donors for funding HIV/AIDS interventions. The political sector, including police and government officials, avoid being part of HIV/AIDS programmes given the social taboos and stigmatisation surrounding the disease. Due to inadequacies in the laws to provide effective enforcement of gender equality and protection against sexual harassment, sex workers are considered as the victims of violence and sexual harassment who are unable to defend themselves. Police and various government officials, although aware of violence involved in sex trade, avoid becoming part of HIV/AIDS programmes due to the fear of going against cultural norms, resulting in blaming the victims for their situation. Furthermore, the situation criminalises sex workers who lack social and moral approval for being involved in the sex trade (Battala et al., 2011). Therefore there is a need for the government to play a bigger role and for that to be reflected in policy; that is, greater emphasis on HIV/AIDS in health policy, more funding and either increasing government services or greater support for the NGOs.

6.2.6 Multi sectoral environment and HIV/AIDS control.

A UNAIDS (2012) report on the coverage of HIV/AIDS prevention services found that countries without comprehensive legal protection for sex workers are less likely to provide appropriate coverage of HIV/AIDS prevention services to women sex workers. In addition, Misra, Mahal and Shah (2000) suggested that although India is signatory to numerous obligations related to women's rights such as the prohibition of discrimination and exploitation by gender, it has failed to protect the rights of women, especially those of sex workers. Therefore, keeping in mind that HIV/AIDS is a public health concern, the government of India needs to adopt rights-based policies which could comprehensively provide legal protection to sex workers.

As well as the socio-cultural barriers and issues found in the study, a shortage of resources was identified as a significant problem which needs to be addressed. For example, there is a shortage of staff to provide appropriate services, including being trained in issues such as privacy. Although staff members were trained under the programme, they were less involved in the NGO activities requiring their skills and knowledge, which seemed to affect programme delivery and quality. The counselling was done without much privacy, with shared space between the waiting room and counselling room. Besides that, the unavailability of doctors resulted in sex workers' health need being compromised. Unfortunately, the study also verified the situation where pharmacists provided injections and medicines in the

absence of doctors. Therefore, proper attention is needed towards the improvement of quality service delivery by looking at the reality issues at the ground floor for the development of mechanisms to strengthen, empower and capacitate government staff and social groups.

NGOs were shown to play a bigger role in services, but need more support from the government. The pressing issue that was raised by the TI staff was about the inadequate funding and resourcing which was a barrier to quality service delivery. Lack of financial support at the grass roots level is a considerable issue which is so far inadequately addressed by the government, non-government and social welfare agencies. At the grass root level, extra funding and resourcing is required in the delivery of HIV/AIDS outreach services because the sex workers' population in the study area is unorganised and difficult to reach. Service provider participants shared their long-term continued battle for health services for the home-based population due to the challenges they face to gain funds. Shortage of medical staff and medicines due to the limited resources and funds was the main reason behind the shortage of medical camps.

In particular, the medical camps were of benefit for the study population to receive HIV/AIDS services because these services were provided under the guise of family planning activities. Therefore, providing such outreach services needs immediate attention because HIV/AIDS service delivery challenges in Chandigarh and Punjab cannot be met without additional and sustained resources. In contrast, the literature review revealed that funds and resources are disbursed to the NGOs with the focus on prevention-related services (Nambiar, 2011) exclusively to the regions with high prevalence rates based on HIV/AIDS epidemic trends (Lawrence & Brun, 2011). Considering Chandigarh and Punjab as a low prevalence state (NACO, 2012a), with the narrow criterion of the epidemic pattern, has resulted in the loss of funding from donor agencies which has affected the work of several NGOs in Chandigarh and Punjab. Therefore, it gives the false impression that Punjab, as compared to the South Indian states, is immune to the HIV/AIDS epidemic. As a result, it underscores the need for cognisance of, and focused attention (WHO, 2012) on the state which has low HIV prevalence but high vulnerability, with 12 per cent of people living with HIV/AIDS in Punjab (NACO, 2012a).

Given the important role played by donors there would appear to be a need for more coordination by government of NGOs, donors and other key stakeholders. Furthermore, the increased accountability of NGOs to the funders of HIV/AIDS programmes has resulted in

conflicting objectives of donors and senior NGO staff which are entirely disconnected from the grass roots-level reality. Outreach initiatives are competing with all the HIV/AIDS programmes, and limited resources lead to the recruitment of low salaried, inexperienced staff and overwork, which in turn leads to staff exploitation and tends to demotivate the outreach workers resulting in poor quality intervention. Also mentioned by NGO service providers were the undue pressures from donors, with the emphasis on achieving targets just on paper, which has added additional pressure on the staff. Donor expectations to look for higher returns for their investment have led NGOs to respond to the funding opportunities rather than addressing the health care needs of the target population. Therefore, there is a need to redefine the working relationships and consider the staff needs if programmes are to be sustainable.

India is a growing economy more than capable of funding a comprehensive health system. However, it needs to find a better mechanism than it currently has. As a result of current operations, HIV/AIDS services suffer, as do other health services that are reliant on the public sector. Despite the government funded HIV/AIDS services, the study population continued to be burdened with additional costs due to the lack of assistance in accessing services. In many instances, the study participants were discouraged in visiting ICTCs due to the transportation costs and unavailability of free medicines and other services such as quality condoms, which burdened them to pay for their services. The study findings revealed that the funds provided by the donor agencies are more popularly used for prevention-related activities such as free HIV/AIDS testing services, free condom distribution and medical camps for other HIV/AIDS-related health services. Accordingly, the importance of provision-related funds is hugely ignored, resulting in sex workers' compromising their health needs even although the services are provided for free. There are no such programmes designed which could provide assistance to the patients for accessing HIV/AIDS services according to their health needs. Immediate attention is needed on the provision-related assistance services including training staff, developing the capacity of the TIP centres, covering transportation costs, and arranging frequent camps and mobile testing vans in order to create an enabling environment for the sex workers.

6.2.7 Programmes sensitive to women sex workers.

In addition to the macro policy and services suggestions mentioned above, there needs to be attention to services and programmes for sex workers in the community. The current TI

approach appreciates the integration of peer education and community mobilisation to increase condom use and reduce the risk of HIV/AIDS. Studies by Koenig, Leander and Framer (2004), Nachega et al. (2006) and Reza-Paul et al. (2008) among sex workers in South India have shown increased condom use and low STI prevalence as compared to North India. The study by Basu (2010) among the sex workers of South India showed that the clinics set up within the vicinity of sex workers' area of work resulted in the increased outreach of prevention and clinical services for the sex workers. In comparison, according to the findings of the study presented here, HIV/AIDS service provision did not sufficiently address women sex workers' health needs; rather these services were deemed to be more appropriate if clients were assured privacy and safety. For instance, TIP and public spaces in the women sex workers' vicinity were used to deliver services, instead of community centres that the workers considered safer to receive HIV/AIDS services. In this study, women sex workers were less likely to use HIV/AIDS services provided at TIs in their vicinity due to the TIs close proximity to the sex workers' homes. Therefore, sex workers in this study feared breaches in confidentiality upon accessing HIV/AIDS services from TIs based in their neighbourhood. As a result, efforts to control and prevent HIV/AIDS among the high-risk group remain inadequate due to the lack of proper access to health services without considering sex workers' health needs.

There is a need for strong linkages between counselling / testing and other health services. In order to meet the prevention needs of target population, TIs ensure sex workers access to the services without stigma or discrimination by networking with the community care centres, counselling and testing centres and the ART centres (Evas & Lambart, 2007). But according to the study findings, there are still gaps in the provision of services which needs immediate attention.

The qualitative component of this study revealed the insights into the service delivery, with the help of observational techniques, which might have been hard for the project staff to articulate. For example, during the researcher's visit she did not see any doctor available in the clinic and the dispensary was closed for the afternoon. Some of the participants reported their concern over improper counselling sessions resulting in the provision of poor quality services. Also, as mentioned by the participants, community centres are the safest places for them to access HIV/AIDS-related services. But the community centres allocated to provide social services seemed to remain closed and social structures such as temples, empty houses,

and parks were utilised to deliver HIV/AIDS services. This resulted in situations where sex workers feared breaches in confidentiality due to factors such as using public places which might expose their hidden identity which discouraged them to use HIV/AIDS services. Further, it supports the fact that India has not fully recognised the need to adopt global guidelines and standards on prevention and treatment to develop HIV/AIDS programmes within the context of sex work (WHO, 2012).

Some improvements indicated by the findings include making services close to communities such as by utilising community centres to provide HIV/AIDS services, which would also ensure the privacy and confidentiality of the target population. Furthermore, to ensure the availability of free condoms, vending machines should be situated for easy access by sex workers. Providing more convenient ICTC timings, frequent medical camps and mobile testing vans would not cut into the business timings of sex workers and would also encourage them to use services according to their needs. Lastly, providing safe and secure transport-related assistance would help sex workers use services without burden and fear.

In addition, some of the participants mentioned about the burden of additional costs due to the poor transportation, long queuing and limited ICTC opening hours cutting into their time for business resulted in compromising their ability to access HIV/AIDS services. These findings concur with the literature review findings which suggested sex workers' disproportionate vulnerability to HIV/AIDS due to limited awareness about HIV/AIDS prevention; and fewer visits to STD clinics by the sex workers of Punjab, with low levels of respondents being aware of ICTC services (11%) (NACO, 2008; Ghosh, 2010). So the programme strategies appropriate for the brothel and non-brothel based sex workers of South India may not be appropriate for the home-based sex workers of Chandigarh and Punjab. The literature indicated women sex workers had diverse health needs based on the nature of sex work and STI patterns. A study by UNESCO (2002) on different patterns of disease indicated sex workers were the main sources of infection in South India, whereas relatives and acquaintances were the main sources of infection in North India. This notion is further supported by Tucker (2012), who characterises clandestine sex workers mainly as a housewives, single women or young girls who do not consider themselves as a sex worker and work only when money is needed. Therefore, the current study identifies the need to develop locally accessible and appropriate intervention services according to the needs of marginalised populations who are vulnerable to HIV/AIDS.

The presence of a scattered sex worker population in Chandigarh and Punjab is an additional matter of concern for providing outreach and delivering HIV/AIDS services. Apparently, NACO surveillance data for the years 2011-2012 indicates that 99 per cent of the population is free from infection (NACO, 2012b). Furthermore, the mapping exercise by CSACS (2011) on the sex workers' population has provided more critical insights into the operational aspects of the sex trade in Chandigarh. It also provides the misleading figure of 100 per cent of women sex workers being covered by TIs (refer Figure 4), because this target achievement is only limited to the proportion of sex workers receiving services from TIs. HIV/AIDS prevalence rates in Chandigarh have remained consistent over the years (CSACS, 2011), which may be partly a reflection of sex workers being less likely to access ICTC service, or if accessing them, then being categorised under the 'general' category not as high-risk. Thus these statistics may be regarded as being highly suspect. Given the nature of STI patterns and the sex trade, the current study findings indicate that sex workers have unmet health needs which adds complexity to the epidemic in Chandigarh due to the probabilities of infection remaining constant and unnoticed. Therefore, intervention challenges exist where estimates of the numbers of sex workers are inaccurate and they are hard to reach (Kumar & Gopal, 2012). Furthermore, it means that outreach ability of TIs in Chandigarh remains poor due to the sex workers' hidden population, which means the epidemic is at risk of becoming full-blown and will spread to the general population.

6.3 Limitations and Further Research

Firstly, the study utilised a small sample size, so the barriers to accessing HIV/AIDS services were only relevant to the context of Punjab. The study sought the participation of the home-based sex workers of Chandigarh through purposive sampling. So the knowledge and experiences shared by the home-based sex workers may not apply to other groups of sex workers in India. As such, except for home-based sex workers, the findings of this study may therefore not be generalisable to other sex worker groups and the wider community in India.

Secondly, the study findings only describe sex workers' and NGO staff's perspectives on HIV/AIDS services. The study could have been strengthened by incorporating the views of other key stakeholders such as health care professionals and clients. As a result, the study findings might not present an accurate portrayal of HIV/AIDS services in Chandigarh.

Thirdly, lack of state-specific HIV/AIDS-related epidemiological data posed a further challenge to data collection. Even if available, it was in scattered form and publicly unavailable. In that situation it was really difficult to understand the current situation of the HIV/AIDS epidemic in Chandigarh. The main reason behind this could be the redundancy of data, as the home-based sex workers do not register themselves, which means the accuracy of the statistics is suspect.

A more rigorous approach has to be adopted with a larger study sample to understand the situation in a better way. In the past 10 years, the state has not been able to commission a single research study except for a behavioural survey which was conducted in the year 2006 (NACO, 2008). The state may, and should, consider the commission of research studies to generate useful evidence-based data which could be further used in planning and action to prevent and control HIV/AIDS locally. Furthermore, to strengthen the research studies on HIV/AIDS, qualitative research methods should be employed using a feminist lens, which has the ability to create open spaces where women's social roles, experiences, and perceptions in terms of health needs could be analysed. As argued by Snelling (2006), the feminist perspective recognises the political, social and economic context which contributes to women sex workers' unmet health needs. Therefore, it would help to promote the development of more culturally sensitive strategies customised locally according to the patterns of vulnerability and needs of women sex workers.

6.4 Concluding Statement

This current study, from the women sex workers' perspective, emphasised the need to consider sex workers' equal participation across public and domestic spheres for HIV/AIDS programme development. This qualitative study encouraged sex workers to explore their unheard dark experiences which have, to date, largely been ignored in previous studies. This study also noted that sex workers' autonomy and empowerment, in terms of decision making, was low due to wider gender-based disparities in the state. Also, unequal gender relations restricted sex workers' abilities in making decisions about obtaining health care which further influenced their access to communication about prevention, ability to negotiate safer sex and access to HIV/AIDS services. Thus, the effects of clandestine behaviour led women sex workers to not using protective measures; practicing risky behaviours such as visiting

customers without condoms, and being unable to consistently attend meetings, trainings and access testing services.

This study has contributed to the development of an understanding of this issue from a woman's perspective which is helpful in exploring the dynamics of power, culture and social structures. This perspective might support the development of effective HIV/AIDS interventions to enhance access to HIV/AIDS services in Chandigarh and all over India. Furthermore, it might also be considered important as a contributing in exploring the various entry points for HIV/AIDS services for other populations and the creation of social spaces in order to consider the unmet needs of women sex workers. Social norms and clandestine behaviour retarded the ability of sex workers to have control over resources which resulted in compromising their health needs. Given that prevailing culture of Punjab discourages addressing the issues of sexuality and sexual health publicly, there is need for further research to explore how these cultural and societal dynamics influence HIV/AIDS prevention. HIV/AIDS programme approaches should therefore work to address the social determinants of health if sustainable and effective efforts are to be made towards social inequality. This reorientation of view also suggests the importance of an epidemiological approach along with a cultural approach, mainly to reach every corner of society, which will make HIV/AIDS intervention services effective and accessible for the marginalised populations. Furthermore, to enhance sex workers' access to HIV/AIDS services, the study emphasises the necessity of considering the needs of sex workers by locally developing gender-specific and culturally sensitive approaches to better assure requisite behaviour change.

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Appendix A: Participant Information Sheet



Languages: Copies of this information sheet are available in Hindi, Punjabi and English

Date Information Sheet Produced: 25th August 2012

Project Title
Challenges and Barriers Experienced by Women Sex Workers to Accessing HIV/AIDS Services in Chandigarh: Northern India.

An Invitation

My name is Supreet Sodhi and I am currently enrolled in the Masters of Public Health degree at AUT University in New Zealand. As part of my studies I would like to invite you to participate in this research project that study the barriers and challenges to the access of HIV/AIDS services provided among the women sex workers in Chandigarh, Punjab. Your participation in this research is completely voluntary and you may withdraw at any time.

What is the purpose of this research?

The purpose of this research is to study the challenges and barriers faced by women sex workers in relation to HIV/AIDS services in Chandigarh. The research is therefore aimed to raise the issues for women sex workers who are discriminated in Indian society so that their experiences in relation to HIV/AIDS services can be better understood. The researcher hopes to contribute towards the improved health of women sex workers by making them aware of their rights and available HIV services.

How was I identified and why am I being invited to participate in this research?

You have been identified to be invited to participate in this research as it focuses on women sex workers 20 years and over and are attending or have attended any HIV/AIDS services. You have received this information about the study because Chandigarh State AIDS Control Society (CSACS) has expressed an interest to assist me with recruiting participants and has identified you as meeting the above criteria. CSACS will be provided with copies of the participant

information sheet and consent forms in English and the relevant native languages. Once potential participants have indicated their willingness to participate in the study, they will be asked to pass the information to me via drop box placed at CSACS.

What will happen in this research?

If you choose to participate, you will need to express your interest via drop- box placed at Chandigarh State AIDS Control Society community care centre.

When I receive your expression of interest, you will then be contacted by me to gather information such as occupation, your current age, and languages you can converse in. Based on the gathered information, you will then be invited to participate for an individual interview session of approximately 1.5 hour at Chandigarh State AIDS Control Society drop in centre. Researcher will also provide an oral explanation about the research before conducting individual interview session if you need help with reading the written information to clarify before you agree to participate.

Consent will be obtained at the time of the interview and if consent is given, the interviews will be recorded and typed up after the interview. I would like to ask you some questions around the challenges and barriers faced in relation to HIV/AIDS services, understanding and experiences about the availability of HIV/AIDS services in Chandigarh, and the barriers to access HIV/AIDS services. Interviews will be conducted in English or in your native tongue. Information collected from these interviews will only be used for this study and any type of personal information collected will be kept private and confidential. However the findings may be used publish research reports and articles in relevant journals.

What are the discomforts and risks?

I will aim to ensure that you do not experience any kind of trouble and it is not my intention to ask questions that may cause you any uneasiness. It is possible, however, that you may experience minor emotional distress when discussing about your understanding and experiences in relation to HIV/AIDS services.

How will these discomforts and risks be alleviated?

You may choose at any time to not answer a question, or if you become uncomfortable at any point you can choose to ask for the audio-tape to be turned off or to finish the interview. Should this occur immediate consultation with the Chandigarh State AIDS Control Society advisor regarding best course of action will be sought.

If required, a free counselling session will be arranged through the Chandigarh State AIDS Control Society counselling service. If you wish to arrange a counselling session please contact on the following address to book an appointment:

Sandeep Mittal
Deputy Director (TI)
Chandigarh State AIDS Control Society
International Hostel, Madhya Marg,
Sector 15-A, Chandigarh - 160015
Phone: 0172 - 2544563, 2783300
Mobile: 094175-79664
Fax: 0172 - 2700171
www.chandigarhsacs.org

Mail any query on HIV/AIDS at
aidshelpline@gmail.com

Chandigarh AIDS Helplines
1097(TOLL FREE)
91-172-2542365
91-172-2542367

What are the benefits?

It is hoped that this research will contribute towards the improved health and wellbeing of women sex workers by making them aware of their rights and available HIV/AIDS services. Thus, more suitable, programs and policies can be developed and put into action for effective HIV prevention among the women sex workers focusing on their rights, protection and participation in program/policy decision making processes.

How will my privacy be protected?

You will be invited to choose a pseudonym (fictitious name) for use in the interview transcripts and when quoting any information from the interview in research reports or articles. No material which could personally identify you will be used in any reports on this study. If necessary, confidentiality will be maintained by changing any identifying details in the transcripts and in any reports, presentations, or publications arising from the research.

All material belonging to the study, including transcripts of interviews will be stored in a locked filing cabinet. During the study, only the researcher and supervisors will have access to the information. The original audio-tapes and interview transcripts will be stored for 6 years in

a locked cabinet at AUT University, School of Public Health and Psychosocial Studies. At the end of this time, the audio-tapes will be destroyed and the transcripts shredded.

What are the costs of participating in this research?

There will be no cost to you for participating in this study. Any cost of travel for interviews will be paid for by the study. I will provide refreshments at each interview in recognition of your time given for the study. You will need to contribute some time to the study. Initially you will participate in up to 1.5 hours of interview. After this you may choose to spend up to 1 hour reading the final research report and/or attending a community forum. In total, you may give up to 2.5 hours for the project. There is no financial costs to you.

What opportunity do I have to consider this invitation?

You have up to 2 week to consider your participation in the study. You may contact me to clarify any information or to ask any questions. If I have not heard from you within this time, I will phone you to ask if you would like to proceed

How do I agree to participate in this research?

If you choose to participate in this research, you just need provide me with the expression of interest via drop- box placed at CSACS. After that, I will contact you to inform with the place and time for interview. Consent will be obtained at the time of the interview.

Will I receive feedback on the results of this research?

Yes, you will get information about the results of this research. You will be offered the opportunity to receive a written summary of the research findings and/or to attend a community meeting in which the results will be presented.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Dr. Cath Conn, cath.conn@aut.ac.nz, 0064 9 921 9999 ext 7407.

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTEK, Dr Rosemary Godbold, rosemary.godbold@aut.ac.nz , 0064 9 921 9999 ext 6902.

Whom do I contact for further information about this research?

Researcher Contact Details:

Supreet Sodhi- supsodhi@yahoo.co.nz

Project Supervisor Contact Details:

Dr. Cath Conn, cath.conn@aut.ac.nz, +64 9 921 9999 ext 7407.

Dr. Shoba Nayar, shoba.nayar@aut.ac.nz, +64 9 921 9999 ext 7304.

Appendix B: Consent for individual interview



Project title: Challenges and barriers Experienced by Women Sex Workers of Accessing HIV/AIDS services in Chandigarh: Northern India.

Project Supervisor: Cath Conn

Researcher: Supreet Sodhi

- ☐ I have read and understood the information provided about this research project in the Information Sheet dated dd mmmm 2012.
- ☐ I have had an opportunity to ask questions and to have them answered.
- ☐ I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
- ☐ I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.
- ☐ If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.
- ☐ I agree to take part in this research.
- ☐ I wish to receive a copy of the report from the research (please tick one): Yes ☐ No ☐

Participant's signature :

.....

Participant's name :

.....

Participant's Contact Details (if appropriate):

.....

.....

.....

Date:

Appendix C: Semi-Structured Interviews

For the Women Sex Workers

- What is your understanding about the provision of HIV/AIDS services in Chandigarh, Punjab?
- Would you like to share your experiences about the availability of HIV/AIDS services provided in Chandigarh, Punjab?
- What are the challenges and facilitators to the access of HIV/AIDS services provided in Chandigarh, Punjab?
- What would you like from HIV/AIDS services in future?
- Any changes you would like to see in HIV/AIDS services?

For the Key Informants

- What is your understanding about provision and access to HIV/AIDS services provided to young women sex workers?
- Would you like to share your experiences and understanding about the availability of appropriate HIV/AIDS services for the young women sex workers in Chandigarh, Punjab?
- What is your understanding of the challenges and barriers faced by the young women sex workers in terms of the accessing HIV/AIDS services provided in Chandigarh, Punjab?
- What would you like from HIV/AIDS services in future?
- Any changes you would like to see in HIV/AIDS services?

Appendix D: Ethical Approval from the AUT

MEMORANDUM

Auckland University of Technology Ethics Committee (AUTEC)

To: Cath Conn
From: Rosemary Godbold, Executive Secretary, AUTEC
Date: 26 October 2012
Subject: Ethics Application Number **12/256 Challenges and Barriers Experienced by Women Sex Workers of Accessing HIV/AIDS services in Chandigarh: Northern India.**

Dear Cath

Thank you for providing written evidence as requested. I am pleased to advise that it satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC) at their meeting on 24 September 2012 and I have approved your ethics application. This delegated approval is made in accordance with section 5.3.2.3 of AUTEC's *Applying for Ethics Approval: Guidelines and Procedures* and is subject to endorsement by AUTEC at its meeting on 12 November 2012.

Your ethics application is approved for a period of three years until 25 October 2015.

I advise that as part of the ethics approval process, you are required to submit the following to AUTEC:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/research/research-ethics/ethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 25 October 2015;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/research/research-ethics/ethics>. This report is to be submitted either when the approval expires on 25 October 2015 or on completion of the project, whichever comes sooner;

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research,

including any alteration of or addition to any documents that are provided to participants. You are reminded that, as applicant, you are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

Please note that AUTECH grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to make the arrangements necessary to obtain this. Also, if your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply within that jurisdiction.

To enable us to provide you with efficient service, we ask that you use the application number and study title in all written and verbal correspondence with us. Should you have any further enquiries regarding this matter, you are welcome to contact me by email at ethics@aut.ac.nz or by telephone on 921 9999 at extension 6902. Alternatively you may contact your AUTECH Faculty Representative (a list with contact details may be found in the Ethics Knowledge Base at <http://www.aut.ac.nz/research/research-ethics/ethics>).

On behalf of AUTECH and myself, I wish you success with your research and look forward to reading about it in your reports.

Yours sincerely

Dr Rosemary Godbold
Executive Secretary
Auckland University of Technology Ethics Committee

Cc:Supreetinder Kaur Sodhi supsodhi@yahoo.co.nz

Appendix E: Ethical approval from the CSACS



CHANDIGARH STATE AIDS CONTROL SOCIETY, UT, CHANDIGARH
INTERNATIONAL HOSTEL, MADHYA MARG
SECTOR 15-A, CHANDIGARH - 160015
PHONE: (0172) 2544563, 2783300 FAX: 2700171
E-mail: chandigarhsacs@gmail.com Website: www.chandigarhsacs.org

To

Ms. Supreetinder Sodhi
Student, Masters in Public Health
Auckland University of Technology
New Zealand

Memo Number CSACS/DD (TI)/2012/ 5037.

Dated, Chandigarh the 31/08/2012.

Subject: Approval for postgraduate research proposal: HIV/AIDS among young women sex workers in Chandigarh, Punjab (India)

Dear Ms. Sodhi,

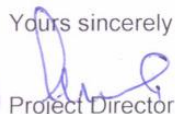
This is in reference to your postgraduate research proposal - **HIV/AIDS among young women sex workers in Chandigarh, Punjab (India)** received through e-mail. This is to inform you that the approval is accorded to carry the postgraduate research cited above subject to following terms and conditions.


- i) The proposal must be recommended and forwarded by the head of the department under which the study is proposed to be conducted. A hard signed copy needs to be submitted to the office of Chandigarh SACS
- ii) Clearance from ethical committee must be obtained and a copy to be submitted to Chandigarh SACS
- iii) Written informed consent from all subjects included in the study will be taken in the language understood by the respondents
- iv) Confidentiality of all the clients must be maintained
- v) Partner NGOs and Chandigarh SACS must be acknowledged adequately in the study
- vi) Chandigarh SACS can only facilitate the process of research and cannot have bearing on the respondents proposed to be included in the study.
- vii) The reports of the study will have to be vetted by Chandigarh SACS before submission to any agency/university/department
- viii) A copy of the study must be shared with Chandigarh SACS
- ix) There will be no financial burden on Chandigarh SACS in carrying the proposed study

Kindly submit the photocopy (duly signed) of this letter to the office of Chandigarh SACS as token of acceptance of above terms and conditions.

Thanks and sincere regards

Yours sincerely


Project Director,
State AIDS Control Society,
Union Territory, Chandigarh

 31/08/12

