

**Assessing the HIV Prevention Needs of
Diverse Communities of Women**

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Assessing the HIV Prevention Needs of Diverse Communities of Women

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Introduction

The issue of increasing HIV infection rates among women in Canada is cause for concern. More specifically, the causes of HIV infection among women are not only a public health concern, but also highlight the need to better explicate the connection between women's risk for HIV infection and social, political, and economic factors. Issues such as age, social class, race or ethnicity, and gender at both the individual and societal levels all influence women's vulnerability to HIV infection. Without careful consideration of these issues, many HIV prevention programs will continue to overlook the complex factors that contribute to HIV infection among women in Canada. As UNAIDS (2000a) points out, without an examination of the relevance of the HIV prevention program for the target group, including cultural and contextual factors, the prevention program is likely to fail. In addition, UNAIDS also argues that the efficiency, impact, sustainability, and ethical soundness of HIV prevention programming must be taken into account when attempting to determine the HIV prevention needs of diverse populations of women.

The purpose of this project is to examine HIV prevention within the experience of women who have been socially excluded due to racism, socio-economic prejudice and bias against the sex trade profession. In particular, this project examines the HIV prevention needs of several key groups of women, including African Nova Scotian women, lower income single mothers, and women in the sex trade. The information gathered from this project will be used to help shape the development of Planned Parenthood Metro Clinic's (PPMC) HIV prevention services.

Objectives

As a health service provider in Halifax, Planned Parenthood Metro Clinic is interested in learning more about the HIV prevention education and service needs of women. However, we are also interested in exploring how the social determinants of health impact these women's experiences of HIV and HIV prevention. The population health framework illustrates the importance of the social determinants upon people's health status. Yet, there is little evidence available that documents women's voices describing the impact of these social determinants upon their experience of HIV. This project will document these voices.

The objectives of this project are fourfold. With the previously described purpose of the project in mind, the objectives are as follows:

Objective 1: To identify the priority HIV prevention education needs of African Nova Scotian women, female sex trade workers, and lower income single mothers in the Halifax region.

Objective 2: To identify the HIV prevention services needed by African Nova Scotian women, female sex trade workers, and lower income single mothers in the Halifax region.

Objective 3: To examine the impact of social determinants of health (such as gender, ethnoculture, and socio-economic status) on women's experience of HIV and HIV prevention.

Objective 4: To communicate the results of this research with key stakeholders and share the results of this research with the communities involved.

Program Description

Planned Parenthood Metro Clinic has been promoting sexual and reproductive health in the Halifax Regional Municipality for more than thirty years. Specifically, we have always been at the forefront of the effort to provide comprehensive sexual and reproductive health care to women who may have nowhere else to turn for these services.

Since 1994, we have also provided anonymous HIV testing to residents of Halifax Regional Municipality and the rest of Nova Scotia as needed. There is currently no other organization that provides this service within the province of Nova Scotia. Planned Parenthood Metro Clinic was the chosen site due to, among other things, its long history of providing quality reproductive and sexual health information to the community as well as its ability to provide many sexual and reproductive health-related clinical services under one roof.

Recognizing that some individuals at risk for HIV may not feel comfortable coming to the clinic for HIV testing, the clinic has always provided outreach testing services at various community agencies. These organizations have varied, depending on the perceived need, following dialogue between the coordinator of the HIV testing program and members of the interested agencies. Some current and past organizations have included a community-based AIDS organization, a needle exchange, a methadone clinic, a First Nations AIDS organization, a teen centre, a centre for homeless and at-risk youth, and a support centre for gay, lesbian and bisexual youth.

Planned Parenthood Metro Clinic's anonymous HIV testing program has also had a history of adapting its services to meet the needs of the community. In 1998, after repeated requests for hepatitis and syphilis testing, these services were added. Since 2003, free hepatitis A and B vaccinations have been provided to individuals deemed by Public Health to be at high risk (including men who have sex with men, injection drug users, and individuals who have multiple sex partners). Our clinic has proven to be very flexible and accommodating when it comes to meeting the needs of our clients.

Planned Parenthood Metro Clinic has a long and well-respected history of providing quality sexual and reproductive health services to women of all backgrounds. We are known for our ability to work in partnership with a variety of community groups and agencies. Having operated the anonymous HIV program for many years, we are uniquely positioned to understand HIV prevention education and services. This experience, knowledge, and skill set makes us well suited to working with women who may be marginalized by society and the community groups who work with these populations.

Literature Review

Women are affected and infected by HIV/AIDS in many unique and complex ways. Women who are socially excluded due to structural inequalities based on racism, for example, may experience HIV very differently from other groups of women. Women working in the sex trade may face HIV vulnerability in ways that women who are not involved in the sex trade do not face. The question remains: how do we develop HIV prevention programs for diverse populations of women that are both meaningful and respectful of the complex ways in which women negotiate and experience their own sexual lives? This is particularly problematic when HIV prevention needs assessment data may not currently exist for more diverse communities of women in Nova Scotia.

The review of the literature is organized into the following sections:

- 1) A brief overview of women and HIV/AIDS;
- 2) An examination of current paradigms in women and HIV/AIDS prevention programming;
- 3) The social determinants of health as a conceptual framework; and
- 4) Intersecting dimensions of women's HIV prevention programs.

It is important to note that the following review of the literature provides an overview of the findings and is not meant as an exhaustive review. It is equally important to acknowledge that much of the literature cited in this paper is drawn from non-Canadian sources and should not be generalized to the Canadian context. What follows is an aggregate of the findings from various literatures and therefore it is important not to stereotype from these findings to the categories of diverse communities of women explored in this paper.

Overview of women and HIV/AIDS

Despite the fact that HIV prevention strategies, such as condom use, have been used for over 20 years, infection rates continue to increase among women in Canada. According to recent Health Canada (2002b) statistics, there are an estimated 6,777 positive HIV test reports among Canadian women aged 15 years and older. The majority of these infections occurred as a result of two main routes of HIV transmission: injection drug use (40%) and heterosexual contact with an HIV infected male sexual partner (49%). It is important to stress that these statistics do not include individuals living with HIV infection who have not been tested and are therefore unaware of their HIV status.

In addition to those with a known HIV positive diagnosis, there are approximately 1,534 women living with AIDS in Canada (Health Canada, 2002b). Issues of age, geographic location, socioeconomic status, language, race and ethnicity further complicate the factors that lead to the initial HIV infection and to a subsequent AIDS diagnosis. Despite the recognition of the centrality of issues such as race

or ethnicity in relation to HIV vulnerabilities, very limited information about this connection has been incorporated into the federal HIV/AIDS surveillance databases. In fact, Health Canada only provides data on numbers of AIDS cases by year of diagnosis and ethnic status where the physician has collected ethnicity information. While it is noted that information on ethnicity can be used to help prevent new HIV infections and assist in the development of appropriate care and treatment programs, Health Canada notes that “approximately 15% of reported AIDS cases and over 90% of positive HIV reports did not contain information on ethnicity” (Health Canada, 2002b, p.57).

Current Paradigms in Women's HIV Prevention Programs

A significant amount of literature reviewed for this project suggests two key paradigms for understanding women’s HIV prevention needs. The first is grounded in the individual, micro-level, cognitive processes of HIV risk behaviour change and focuses on concepts such as individual compliance, empowerment, self-efficacy and self-esteem. The other is founded upon the assumption that structural or societal influences transcend the individual level of behavior change and suggests that a variety of external factors such as access to affordable, gender-appropriate health care resources, racism, poverty, gender stereotyping and sexual norms, and other societal constraints serve to prevent meaningful HIV prevention at the individual level. Despite individual desire for sustained behaviour change, women will continue to be at risk for HIV infection until the systemic inequalities in the health care system and in society more generally are eliminated.

Much of the literature on HIV prevention for women emphasizes the need for women to empower themselves to negotiate safer sex, primarily through the use of male or female condoms with their male sexual partners. How empowerment successfully occurs, within which contexts, and to what extent is less well described. Limited discussion exists on issues of structural or contextual factors that can contribute to women’s inability to adhere to safer sex and condom use. Very little of the literature argues for the inclusion of male sexual partners in the development of HIV prevention programming aimed at the prevention of HIV infection through heterosexual sex with a male partner.

Determinants of Health as a Conceptual Framework

When looking at the health of populations and factors that influence outcomes of their health, it is important to acknowledge the determinants of health. The determinants of health framework has been adopted by Health Canada to recognize the key factors contributing to the complex interaction of social, environmental, political, and biological aspects of health. Growing evidence has shifted health paradigms to focus on the “complex interactions between social and economic factors, the physical environment and individual behaviour” (Health Canada, 2002a, p.1). This shift has significant consequences for the way

in which health programming and research should be conducted and changes the focus of health promotion and disease prevention to include the wider range of intersecting determinants of health beyond the individual level.

The inclusion of such factors as income and social status, social support networks, education, employment/working conditions, social environments, physical environments, personal health practices and coping skills, healthy child development, biology and genetic endowment, health services, gender, and culture is of significant importance to the analysis and subsequent creation of health programs. This framework recognizes that health is affected by considerably more than individual behavioural choices and factors and that these factors do not exist in isolation from one another. In addition, the determinants of health approach looks at the combined influence of these factors on overall health status. As such, these considerations are critical when assessing the health needs and experiences of diverse populations (Health Canada, 2002a).

Utilizing a determinants of health framework when evaluating the HIV prevention education needs of women in Nova Scotia is imperative in terms of understanding the diversity of women's experiences and vulnerability to HIV, the priorities and foci of HIV prevention, as well as the perceived needs and gaps in current HIV prevention services. The complexity of women's lives demonstrates the need for an understanding of the interplay between the various determinants of health and the context of women's perceptions, attitudes, beliefs, experiences and realities in relation to HIV prevention.

Intersecting Dimensions of Women's HIV Prevention Needs

HIV Prevention Considerations for Ethnically and Culturally Diverse Women

As HIV/AIDS infection rates have continued to increase among North American women over the past two decades, we see disproportionate numbers of HIV and AIDS cases among ethnic minorities that “underscores the importance of implementing and sustaining effective culturally sensitive and ethnic specific interventions” (Bassey, 2002, p. 8). A literature review was conducted to explore the specific concerns and experiences of ethnically and culturally diverse women and their HIV vulnerability and prevention needs. As there was insufficient specificity in the literature to provide an analysis of the needs and experiences of specific ethnic and cultural groups in a Canadian and Nova Scotian context, a presentation of general findings on experiences of culturally and ethnically diverse populations in North America will be provided in the following section.

The exploration of cultural and ethnic diversity is relevant to HIV experience and prevention efforts as it is recognized that “some persons or groups may face additional health risk due to socioeconomic environments, largely determined by dominant cultural values that contribute to the perpetuation of conditions such as

marginalization, stigmatization, loss or devaluation of language and culture and lack of access to culturally appropriate health care and services” (Health Canada, 2002a, p.8).

Experiences of systemic discrimination and racism throughout the lives of women of ethnic diversity impact significantly on their health status by “restricting economic opportunity” (Williams, D.R., 2002, p. 594) thus creating an environment where poverty and financial struggles may dictate living conditions and health care opportunities. The diversity of women, in terms of their cultural belief systems and the systemic/institutional marginalization, has contributed significantly to their vulnerability to HIV and requires unique and specified prevention efforts (Health Canada, 2002b). A study conducted by Okwumabua et al (2001) revealed the following negative experiences of African American women within an HIV testing service: “Remarks by female participants underscored the negative attitudes of health workers who conducted these (HIV) tests. One stated, ‘Health workers’ attitude is so bad it turns people off from getting tested.’ Another remarked, ‘They assume that those who come forward for testing are poor, promiscuous, on welfare, and have many babies.’ If a client tests negative for HIV, they say, ‘You are lucky this time.’ The general opinion among participants is that public health workers who conduct HIV tests are not ‘customer friendly’” (Okwumabua et al, 2001, p. 483). This is an example of the institutional discrimination experienced by ethnically diverse women and the negative effect of culturally inappropriate HIV services and service providers.

Studies have shown that the main method of HIV infection for ethnically/culturally diverse women is through heterosexual transmission, the majority becoming infected by lovers/spouses (Health Canada, 2002b). Discussions around safe sex and HIV prevention must be relevant to women’s experiences and must not assume stereotypes about their relationships. Prevention programs that have traditionally focused on partner reduction, condom use and abstaining from sex do not confront the realities that may place women at the greatest risk of HIV (AIDS Action Council, 2002). Prevention services must also utilize culturally appropriate materials that address HIV vulnerability and prevention through a health model that is compatible with the target population's health belief systems (Oxmam-Martinez, Abdool, & Leonard, 2000).

It has been discovered that some HIV prevention materials including brochures, pamphlets, posters, and pictures are offensive and may in fact cause resistance among ethnically/culturally diverse populations, especially where sensitivities and sexual taboos are common in culture beliefs surrounding sexuality (Lechky, 1997). It is important to utilize culturally appropriate and relevant communication methods and styles when addressing HIV prevention in diverse communities. Realizing that different segments of the population are familiar with and respond to different communication methods, it is important to consider these factors in creating appropriate prevention efforts (Cunningham, Davidson, Nakazono & Anderson, 1999) Another important consideration is the ability of diverse

populations of women to identify with facilitators and investigators in the HIV prevention programs. While presenting information to a group of African American women, Jackson discovered that “identity and status as an African American woman investigator were significant” (Jackson, F.M., 2002, p. 563). It is imperative to consider all of these factors in the creation of a culturally appropriate and ethnic-specific HIV prevention program. It is equally important to note the need for culturally relevant and appropriate means of gathering information from diverse communities of women on their perceived HIV prevention needs.

Socio-economic Status and Women's HIV Prevention Needs

A literature review was conducted to explore women's HIV perceptions and HIV prevention experiences in situations of low income and social status. It has been widely accepted and realized that poverty and low socioeconomic status significantly impact health outcomes (Health Canada, 2002a). Health Canada states that “considerable research indicates that the degree of control people have over life circumstances, especially stressful situations, and their discretion to act are the key influences. Higher income and status generally results in more control and discretion” (Health Canada, 2002a, p.1). By understanding the unique interconnectedness of socio-economic status on health outcomes, the particular HIV vulnerabilities and prevention needs of low-income women can be better explicated and adequately addressed.

As the incidence of HIV cases associated with heterosexual contact with an infected male partner continues to increase, with “women accounting for two-thirds of persons contracting AIDS through heterosexual contact” (Morrison-Beedy, Carey, & Lewis, 2002, p. 122), it is necessary to analyze the specific HIV vulnerabilities experienced by low income women to better understand the situations where they may be most vulnerable. It has been found that “impoverished women are reportedly at increased risk for HIV infection as a result of heterosexual exposure to multiple sexual partners at risk, specifically with men who have been in jail or prison, bisexual men, and injection drug users” (Nyamathu, Bennett, & Leake, 1995, p.600). Condom use and compliance has been found to be a significant factor contributing to HIV risk for these women. “Condom use is relatively low among male partners of women at risk for HIV infection and is partner specific: rates of use are lower with main or steady partners than with other partners, even when the main partner uses drugs or has other HIV risk characteristics” (Lauby, Smith, Stark, Person, & Adams, 2000, p. 216).

It has also been found that populations of low-income women are more likely to use other forms of HIV prevention than condoms. In their study 'Prevention Strategies Other Than Male Condoms Employed by Low-Income Women to Prevent HIV Infection' Crosby et al found that “low-income women in predominately steady heterosexual relationships with male partners indicated

that multiple strategies other than male condoms or female condoms were employed to prevent HIV. Being tested for HIV as an HIV prevention strategy was reported by more than two-thirds of the women ... more than two-thirds reported using HIV testing as a prevention method” (Crosby, Yarber, & Meyerson, 2000, p. 57). This indicates the potential for serious misconceptions about HIV risk and prevention practices.

The issues related to barriers to condom use must be considered when creating effective prevention strategies focusing on the needs and realities of impoverished women. The perceptions of these women relating to intimacy, emotional commitment, and male partner resistance are important factors that influence adoption of condom use. Persuasive debates have arisen as to the impact of male-partner resistance on the likelihood of these women to negotiate condom use; considering the impact of the economic/emotional relationships with their partners, this may have significant consequences for prevention practices (Crosby et al, 2000). Whether or not women are ready to use condoms has also been cited as a barrier to HIV prevention messages. “Tailoring prevention interventions to those women ready to use condoms (those in preparation or action) would limit such programs to a small number of women...many of them may need to be moved from precontemplation to contemplation before they will be ready to respond to HIV prevention messages and interventions about condom use” (Morrison-Beedy & Lewis, 2001, p. 155).

The development of prevention efforts directed at tackling the barriers to condom use, correcting misconceptions surrounding HIV risks and protection, and addressing women's readiness to use condoms will create prevention efforts that are relevant to the needs of low-income women and their experiences. “Researchers have also realized that if programs are to succeed at educating impoverished women at risk for HIV infection, attention must be directed toward meeting their survival needs before providing informational and skill building strategies” (Nyamathu, Bennett, Leake, Lewis & Flaskerud, 1993, p. 65). It has also been suggested that strategies such as couple-focused interventions (Nyamathu et al, 1995) and the education of public health nurses in clinical settings to understand women's particular barriers to condom use and negotiation, may be effective HIV prevention efforts for low-income women (Morrison-Beedy et al, 2002).

The literature also suggests that single mothers are a particular population of women with heightened vulnerability to HIV infection. These women have been found to “engage in behaviours that place them at high risk for HIV acquisition. Some studies have found, for example, that 40% of young adolescent mothers will become pregnant again in the next two years” (Brown, Lourie, Flanagan & High, 1998, p. 565). Brown et al, in their evaluation of the HIV-related attitudes and risk behaviour of young adolescent mothers, revealed significant implications for heightened HIV vulnerability due to risk behaviours. These HIV risk behaviours were found to relate to the interaction between the women's concern

for HIV and their subsequent condom use (Brown et al, 1998). It was also found that “they sometimes engage in sexual behaviour to continue dependency on unstable relationships, to fulfill perceived expectations for womanhood within the family and culture and to act out feelings from other relationships... and even when they recognize the risk of unprotected sex, they often feel incapable and powerless to discuss safe sex or request that their partners, often older, use a condom” (Brown et al, p. 565). Addressing the needs and realities of single mothers and their particular vulnerabilities to HIV is critical in lowering the potential for HIV infection. By focusing on factors that lead to risky behaviour, misconceptions about HIV susceptibility and relevant issues experienced by these women can be adequately targeted in prevention efforts.

Experiences of Sex Trade Workers and HIV Vulnerabilities

An investigation of the literature that focused on the experiences of women working in the sex trade, their particular vulnerabilities to HIV, their prevention needs and realities, as well as barriers to these services will be examined in this section. The realization that there are many different contexts, conditions, and venues for sex trade work is imperative in understanding the complexity of the workers’ HIV prevention needs and the existing gaps. In the early years of the HIV/AIDS epidemic, female trade sex workers became perceived as “vectors of transmission” or a high risk group, responsible for the spread HIV to the general public (Meaghan, 2001). More recent data has shown that these early assumptions and evidence were misleading for a variety of reasons.

Seroprevalence rates for HIV infection among non-drug-using sex workers has been found to be significantly lower than initially perceived. It has also been realized that narrowly focused data on sex workers, due to inaccessibility and methodological issues, has left out experiences of differing groups of sex workers (Jackson, Highcrest, & Coates, 1992). Numerous studies have also found that within the sex trade profession, the majority of the workers are very aware of HIV/AIDS and use condoms with their clients as a protective measure. Condoms have become symbols “associated with commercial sex, they come to demarcate private from commercial experiences” (Cusick, 1998, p. 134). The majority of HIV prevention programs in North America have focused on the message of 'safer sex' within commercial exchanges between client and sex worker. These programs have overlooked the actual situations in which sex workers are not using prophylactic measures and are risking HIV infection (Jackson & Hood, 2001).

These situations have been referred to as 'exceptions' to the normal commercial exchange between client and sex worker. Cusick refers to 'exceptions to condom use in the commercial encounter' as having five possible scenarios:

- i. the 'special' regular,
- ii. the romantic leap,

- iii. urgency to earn,
- iv. powerlessness, and
- v. condom failure.

As condoms often signify a psychological/physical barrier between the sex worker and client, the first two 'exceptions' to condom use represent familiarity and the impact of social relationships on prevention efforts. Condoms have become the symbol signifying daily commercial exchanges, and when these interactions evolve and change, condom use becomes less desirable. In the case of the 'special' regular, the condom is used as “a signifier and hence as a tool to manage these business relationships for their longer term commercial advantage” (Cusick, 1998, p. 139). Cusick goes on to suggest that in the case of the 'romantic leap', “the use the condom is put to is when its application is discontinued to mark the development of the relationship as non-commercial” (Cusick, 1998, p. 139). Urgency to earn and economic incentives from clients can lead to condom non-compliance as well. As sex trade work is task-oriented and the number of clients is directly related to profit earned in most cases, a slow night or certain undesirable conditions such as poor weather or violence can lead to significant pressure to finish work quickly and/or without a condom. (Jackson, Highcrest & Coates, 1992).

As a large number of women working in the sex trade are economically disadvantaged, these scenarios can leave women in desperate situations where “attention to the more immediate concerns of food, housing and addiction often takes priority over future concerns of HIV infection” (What Are Sex Workers' HIV Prevention Needs, 1996, p.1). Powerlessness and unsafe working conditions, where sex workers often experience violence, including rape, contribute significantly to condom negotiation and use. “For a female prostitute, insisting upon condom use can actually exacerbate the dangers that are a part of this work insofar as a male client whose demands for unsafe sex are not heeded may become violent” (Jackson & Hood, 2001, p. 31).

The illegality of sex trade work has significant consequences for HIV prevention efforts as well. “For prostitutes, political and legal issues related to prostitution may be especially important in influencing risk practices while working. The enforcement of laws concerning solicitation may influence a prostitute's economic well-being, and in turn, the decision to defer to a client's economic incentive for the non-use of a condom” (Jackson, Highcrest & Coates, 1992, p. 285). The illegality also forces the sex trade 'underground' and consequentially results in unsafe working conditions such as poor lighting or a strangers' vehicle, and nowhere or no one to turn to when violent episodes occur. Distrust of police and the confiscation of condoms, which are used “as evidence of prostitution and therefore can be grounds for arrest for street-based and off-street sex workers” (What Are Sex Workers' HIV Prevention Needs, 1996, p.1), can be significant barriers for HIV prevention efforts. Reluctance to participate in prevention programs due to fears of confidentiality, legal repercussions and general distrust

of public health officials are all factors to consider in the creation of effective HIV prevention programs.

The private lives and relationships of sex workers are critically important aspects when considering HIV prevention efforts. Studies have revealed that although sex workers' frequency of condom use with clients is quite high, condom-use within private relationships is shockingly low. "Research has consistently shown that when having sexual relations with a husband or lover, use of condoms is low even when a private partner is potentially at high risk of HIV because of injection drug use. As prostitutes have noted, their private partners often insist on the non use of condoms because they do not want to be just another 'John'" (Jackson & Hood, 2001, p. 36) As condoms have previously been described as symbols of commercial exchange, the intimate relationships where emotional closeness is desired are characterized by non-use of condoms (Jackson, Bennett, Ryan, & Sowinski, 2001). Other reasons for non-use of condoms within these relationships are dependency issues such as economic/emotional support, as well as fear of violence from their partners.

Significant gaps in HIV prevention efforts exist in terms of sex workers' barriers to both prevention and services. The needs and realities of these diverse groups of women have been neglected in many mainstream prevention services and programs. Programs focusing on condom use and HIV education have been the norm, ignoring the existing reality of high condom use in commercial exchanges. The focus of HIV prevention should address the situations in which these women are at significant risk of HIV infection: 'exceptions' to client condom use, economic desperation and incentives, unsafe working conditions, powerlessness, violent episodes and private relationships are all realities where condom use is compromised for varying reasons. These are only some of the gaps in current HIV prevention efforts. These gaps may suggest where the HIV needs and vulnerabilities are located for women involved in sex work.

Methodology

According to UNAIDS (2000a), there are a variety of key issues to keep in mind when developing HIV prevention programming for women, including the determinants of health framework. These include:

The use of a multifaceted approach that addresses economic and other needs which may take priority over HIV/AIDS in the daily lives of women living in poverty; focus on improving communication between sexual partners which acknowledges the difficulties women encounter in talking and negotiating with men about sex; increase awareness of the importance of including men in work for the prevention of HIV among men, women and children; acknowledge the importance of a gendered approach to HIV prevention work, which includes discussions of power relations between men and women; provide access to voluntary counseling and testing services, along with appropriate referrals; and acknowledge the support that women can provide each other through open discussion and the development of networks (p. 8).

Given the need to look at a complex variety of factors that can contribute to HIV vulnerability among women, there is a growing interest in the combining or triangulating of methods related to women's HIV prevention research. A variety of approaches are found in the literature and include participant observation, the collection of information from service users through focus groups, surveys, needs assessments, community asset mapping, and objectives or outcome based program evaluations. Tools and methods used by community-based organizations are often informed by available resources and capacity of staff to collect, analyze and use the findings for program development or improvement. The tools and methods used differ widely and can each contribute to a more comprehensive understanding of the successes and shortcomings of particular approaches to HIV prevention programming for women.

Following a thorough examination of the risks and benefits of each method, focus groups were chosen as the methodology for this study. Focus groups or group interviews can be useful in collecting information on issues such as perceived program needs, barriers to accessing services or programs, experiences with particular types of services or service providers and attitudes regarding "best case" or "best practice" scenarios. Often, focus groups are used to collect broad, rich, contextual information from those within the target population of interest to help inform more structured, broader data collection methods such as a mail questionnaire or survey. Focus groups can be used to provide an overall sense of the most salient issues faced by a particular group of individuals on particular issues. However, there can be difficulties in ensuring that all participants have an opportunity to express their opinions or experiences. The need for a skilled focus group facilitator, preferably someone with the ability to develop rapport with the

participants and someone to whom the participants can relate, is crucial in achieving the goal of the focus group. Potential disadvantages of focus groups include intimidation of certain participants, conformity in types of answers and information given, and also group pressure may bias the types of information shared with the group. Despite these potential disadvantages, focus groups remain one of the most efficient means of gathering in-depth, contextual information on perceptions, experiences, and attitudes of those from particular target groups.

Ideally, the development of tools such as a focus group guide, interview guide, or in-depth interview guide should involve direct community input from the target group or community. In addition, ethical considerations should be discussed and consensus reached on how to ensure that the data collected remain confidential, that personal identifying information is removed, that any potential legal ramifications that could arise if a breach in confidentiality occurs have been considered. It may be advisable to seek out the assistance of a university- or hospital-based ethics committee to determine that none of the ethical principles of conducting research with human subjects has been jeopardized in the needs assessment design, including the questionnaire or focus group instruments, data collection, analysis and data storage, etc. For this reason, an advisory committee was struck to ensure the input from both academics with experience in ethical principles of research as well as members from the communities involved.

The collection of information from the target communities that allows for open-ended response categories, such as focus groups, is an ideal place to begin when determining the needs of particularly underserved populations of women. A clearly delineated program plan requires contextual information that can often be gleaned from focus group data. These data can in turn be utilized to help develop additional closed-ended tools such as an in-take survey for new, incoming clients to help identify immediate needs and to provide valuable baseline data on why there are using the services of a particular agency or organization and not others.

With the input from the members of the advisory committee, we chose to conduct two focus groups with women from each of the three communities. Acknowledging the advice of the committee members who suggested that women from the African Nova Scotian communities would be more comfortable speaking with a focus group facilitator from their own community, we hired a separate facilitator for those two focus groups. This individual was highly skilled in the facilitation of focus groups and also had extensive experience working in the field of HIV. She is a highly respected member of the local African Nova Scotian community.

Promotional flyers were developed and posted in areas that were frequently accessed by the women we wished to target. In the African Nova Scotian communities, knowledge of this project was spread largely through word of

mouth as opposed to by individuals noticing the flyers. We quickly received many telephone calls from several sex trade workers, and the African Nova Scotian facilitator received many responses from women from the Preston communities and the Hammonds Plains area. Our initial intent was to target lower income single mothers from the Spryfield area; unfortunately, despite heavy distribution of the flyers by the staff of the area's single parent centre, we received only two telephone calls and one agreement to participate from that entire region. We then broadened our catchment area to include a single parent centre from the North End of the city. With this approach, we were able to attract many willing participants.

Each woman was given a description of the study upon first telephone contact. The confidentiality of the study was explained. It was explained that each focus group might last as long as two hours. The women were also informed of the provision of both a light lunch as well as an honorarium to help offset the costs they may incur from their participation in this project. This telephone contact was important not only to provide information but also to begin establishing a rapport with the women, as this is an important aspect of exploratory interviews (Reinharz, 1992).

It was important to conduct the focus groups in an area in which the women felt comfortable. The sex trade workers were offered the option of having the focus groups conducted at Stepping Stone, an organization that offers supportive services to sex trade workers, but, for reasons of confidentiality, some of the women expressed a preference to come to Planned Parenthood Metro Clinic for the focus group, while the rest had no preference between the two locations. Both those focus groups were therefore conducted at the clinic. The single mothers made it clear that due to financial and child care reasons it would be a hardship to have to leave their community. For that reason, I traveled to their family resource centre to conduct the focus groups. One focus group with the African Nova Scotian women was conducted in a community centre in the Preston area, and the other was conducted in a library in central Halifax near where many women had connections.

Each focus group had between six and twelve participants. From information gathered informally, the women ranged in age from early 20s to late 50s. While the women were not required to reveal their age, some volunteered this information during the focus groups. The single mothers and the sex trade workers were also not required to reveal any ethnocultural information, but one third of both the sex trade workers and the single mothers at some point in the focus group self-identified as being African Nova Scotian. One sex trade worker also identified as being of both African Nova Scotian and Aboriginal descent. One sex trade worker voluntarily self-identified as being HIV positive.

Each focus group was audiotaped with two separate tape recorders. All women were informed of this and also of their right to refuse to answer any question with

which they were not comfortable. They were also informed that they could leave the focus group at any point. Following the focus group, they were also given the opportunity to ask any questions they liked. They were all informed of the services offered at Planned Parenthood Metro Clinic; the sex trade workers had an added advantage as they were sometimes able to access Planned Parenthood Metro Clinic's services that very day due to having their focus groups conducted at the clinic. Many sex trade workers left the clinic with free condoms, and two more received the first in a series of vaccinations for Hepatitis A and B.

Following the focus groups, all the audiotapes were transcribed by an outside source with an outstanding reputation for confidentiality and accuracy. Each participant was provided with a copy of her group's transcript and asked to verify that their words were accurately captured. To ensure confidentiality, any names of participants or outside parties which appeared on the audiotapes were disguised in the transcripts (except for names of community people who were recognized for their expertise). Once the report is complete, the audiotapes will be destroyed.

A phenomenological approach was taken to describe the experience from the participants' point of view and analyze the meanings underlying these experiences through the eyes of the interviewees (Leedy, 1997). By using a phenomenological approach, it is possible to examine the meaning of an experience from the point of view of the individual who has had that experience (Moustakas, 1994).

In the next section, the results of this applied methodology are presented in the descriptive manner with which the participants in this project tell their stories.

In The Words of Women

In this section, a description of the experiences of the participants in relation to HIV prevention is presented. Dorothy Smith (1987) explained how, because typical research designs do not account for the lived experiences of women or other oppressed groups, the voices of women are frequently silenced. For this reason, the words of the women are used to emphasize these experiences whenever possible to convey the power of these thoughts. When multiple individuals are speaking, the letter "P" will indicate that these are the words of a participant, and the letter "F" will indicate that the facilitator is speaking.

The Buzz About HIV

The women who participated in the focus groups generally stated that HIV was not talked about in their communities anymore. One stated theory amongst the group of sex trade workers was that many people are in a state of denial when it comes to their risk for acquiring HIV.

I find that you know, it's almost getting back to the ostrich syndrome where you know I stick my head in the sand. If I don't hear it, it ain't around. It ain't happening. It seems to be going back to that more.

I find you don't hear as much about it as you used to, do you know what I mean? Like, and I find there's a tendency to not talk about it.

You would think in this day and age though after so many years of it being out there that it wouldn't be like that though. You know, you would think that it would be like okay, well, so many people have it now, but a lot of people still don't. You're scared and you know it's there but still you're following the same pattern as you were before but... it's kind of like denial, like you know...

Other women in the same focus group related their opinion that as the novelty of HIV as a new disease wore off, so has the sharing of information about it in the community. While HIV was talked about extensively in the 1980s and 1990s, this communication has since diminished.

I don't even hear about it no more. It was like when it first, you know, HIV first started, it was like... everybody was talk, talk, talk about it right, new disease. But it seems like it's something like... like when the Herpes came out, you know what I mean. It was talked about for a while and then it just kind of mellowed out and went under. And I find the same thing with HIV. It's like people nowadays... not that they're not worrying about it but just that it's not talked about because you're not hearing about it so much as when it first... when the virus first came out right, so...

P: I think they would talk about it (in the early 90s) because it was on the rise and people were scared, you know, of catching AIDS and I think at that time.... I don't know if that was back in the time when Magic Johnson also had...

P: Yeah, I think it was.

P: So it was so common then and people would... you know, anybody could catch it you know, that's what they were thinking at that time, you know, and the fears of catching it and people didn't know that much about how you caught it and that, you know.

The women in the African Nova Scotian focus groups repeatedly stated that HIV was often not seen as being relevant in their community, nor to themselves as Black women.

I never hear talk about directly as it relates to the community but as it relates to other parts of the world whether it's through the media or through the papers if there's incidences or outbreaks. Never directly related the community itself.

And I think for the lack of information and lack of discussion, I don't think people around here really realize that there are even cases of HIV here in the Black community...

And you know what, it's really strange that I know guys that have AIDS but I don't know any women. I don't know any women.

The single mothers observed that when women in their community talk about HIV, it is not in the context of how they may be at risk themselves. It is usually only discussed in relation to its effect on the gay community.

P: I think sometimes women feel too that it's more... it doesn't affect heterosexuals or...

P: Yeah, they still have this...

P: They just sort of... the message is still sort of, young gay men or something, there's still that kind of idea or...older, gay men that generation the younger... because none of the younger men don't think they'll get it so... there's a range now.

Recognizing that HIV is largely not being discussed within these communities, it was important to discover what specific messages these women thought would be important to disseminate in their communities.

Messages

The women who participated in the focus groups had very concrete and introspective ideas into what messages their communities needed to hear to understand the threat of HIV. Many of the sex trade workers felt that women needed to be reminded that HIV is still a real risk.

Oh, yeah, it could happen to you. It could happen to you, anybody.

AIDS doesn't have... AIDS is not prejudiced. AIDS is not prejudiced which means age, and colour and culture, it doesn't care.

AIDS is out there, think with your head, you know. Wake up.

There's no good AIDS or bad AIDS, you're going to die, you know, if you're not properly taken care of and all those issues are there regardless of how you contract the disease okay.

These same women also offered practical ideas on how to present these messages. One woman stated that hearing from someone with HIV would be particularly powerful.

I would say by bringing people who are willing to speak that are HIV, that would really help a lot of people. Yeah, because I remember one time when I was in jail, there's this woman and she didn't get it by having sex with her, she got it from her husband with trans... what is it, needles, what's her name Janet Connors, her, yeah she got it from that, and that was good too, she came to jail and she talked to all of us. It could hit the jails too. You know, it could go to the jails too.

Many women also believed that posters and pamphlets would be useful, particularly if they were placed in areas where sex trade workers frequented.

If people do take time and go out and pass things (pamphlets) around. And some people just yeah, they're going to take it and biff it, they're not going to pay any attention, but maybe you can catch them at a low moment and, you know, and they'll say oh, man, you know what, I've got to really start studying this shit, you know, it might be... they might be down and they'll say yeah, and you know, and something might just click in.

We were saying that it's not talked about a lot because the only place where you really see like posters and things like now is in like Stepping Stone or clinics, things like that. Like it's not out there on the street no more so people really... you know what I mean...

Like it was before, but now it's not. Like you could go, walk down the street, and on a lamp pole you could read like this big sign, like HIV testing, anonymous, free. You know what I mean? You don't see that no more, at all. I don't never see it.

With respect to information being disseminated through publicly displayed posters and pamphlets, some of the sex trade workers indicated that even though much of this material seems to be directed more at the "johns" than at them, they still were able to benefit from this information.

P: And that's the attitude, you know, so they don't do little things that they would do downtown. Because downtown we had the posters... they would have had the posters, not for our benefit it was actually to try to prevent the dates from not going out most of the time. You know what I mean? It was actually to do that, like maybe if they see this line, they'll think twice before they take one of them out. You know, now maybe it worked that way but then also the women got the information.

P: That's what I was going to say because it made us aware of what was going on.

Some women even thought of relevant and meaningful mottos that could be used when trying to reach sex trade workers with HIV prevention education.

...but something like, you know, or even like out on the street tonight, you know, a doctor takes his bag and he goes to work. The lawyer takes her briefcase and she goes to work. Take your condoms and go to work.

You know, we've got that much knowledge of that and I mean within the sex trade workers, the bottom line to me is, if you drive a cab, you take care of your car, you know.

The women from African Nova Scotian communities also believed that personal testimonies would bring some relevance to the issue of HIV for women in their communities.

I think one of the things that L. talked about before and it's a difficult thing especially with the Black communities, if you could get someone that is so strong in their belief that has had that problem, are personal testimonies.

A unique issue, which resonated throughout the focus groups with the African Nova Scotian women, was the importance of the church. These women believed it was imperative to involve the church in spreading the message about the significance of HIV. However, they also recognized that encouraging the church to talk about HIV could present a challenge.

P: Well, I think that that takes onto the... this is where we come back in, I'm sure there would be other communities have this type of problem too, but me talking... being Black, and living in the Black community, I think the best way... my mind's eye to reach out to people is the most powerful place in the community and that would be the church.

P: Okay, but first you have to unblock the church.

Right, and do it through the church because I'm telling you one thing about the church, now we all know that once the church is on your side, then you got the people... the community on your side.

The minister may not even be prepared to even talk about it over the pulpit because of many reasons. A) He may not find that he's informed enough, you know, to speak on the issue. But I can see them interjecting someone into the program for the day, unbeknownst to the congregation okay, and all of a sudden that individual will maybe take ten minutes and speak about what is the facts.

Another key issue with the African Nova Scotian women was the lack of information directed specifically at their community. These women felt that HIV prevention messages directed at the Black community were very specific to the United States and that this made Canadian women feel as though HIV was not as much of an issue for them.

P: But I don't think the young people take it that seriously because they don't think that it's here because those shows are coming from the States.

F: So where we failed is there's not enough research itself within the Black community to put the information... the statistical data out there to bring the people in to make them realize there is an influx of this disease in our community and we have to stop it.

P: But you got to see... you got to realize this is about... see a lot of stuff we don't see at local. When we... when we see it from abroad, we think abroad. We have to see it local in order to think local. Even if it's a local broadcast on our local TV station. We have to see it locally.

P: Sisters. For those of you who think this cannot affect you, I want to introduce you to my friend. That would be good.

P: You know, remember the... Like remember the commercials we used to see? We should have local ones. Remember the commercials we used to see, this is your brain. This is your brain on drugs and they crack the egg. That's what you need. Dartmouth Cable or whatever, you need some local stuff to be going on that.

P: This is the beginning of AIDS, and this is full blown. Do you see what I'm saying? You need that shock. You need that shock to say, oh this shit's for real. It's scary but I mean when you look at... when you look at Africa and you see in Ethiopia and you see all these children and you see, you know, they're amputees and you see the diseases and you see... like doesn't your heart go out there?

These women also stated that while the message may be getting across to younger members of their community, older individuals were often not targeted. This was an issue that was seen as being quite significant.

And the message is getting to younger people, not the older people because not a lot of old people watch that (BET, or Black Entertainment Television) but the message is getting to younger people.

...just a plain message that it's out there in our community because I really think it's like what we were saying before, we like to block things out. And there's so many... especially I think the older people don't believe that it's out there. So just... I mean, just... you know, some kind of blurb saying, Hello, it's here.

The focus groups conducted with the single mothers repeated the message of the importance of personal testimonies when talking about HIV prevention in their community.

P: And they should like show like... it's a horrible thing to show but like people with AIDS, what actually happens when it hits the last stage...

P: What the body goes through and the mental and the physical.

The issue of race arose during these focus groups as well, but interestingly these women felt that while there was a significant amount of information directed at the Black community, there was less directed at other races.

F: So do you think that society is kind of looking at HIV as being a problem of the poor?

P: Poor people yeah.

P: Poor people, minorities...

P: Look at the BET. When they talk about HIV on BET they only talk about Black people, they're not talking about white people

P: That's right.

P: They should just say you know, wrap it up, no matter what colour you are, it don't matter.

P: It's the same here as the BET having, you know, education to Blacks, why aren't they... the other station educating the white...

Several women expressed the importance of having well educated teachers in the schools. They also felt that more emphasis should be placed on well-rounded sex education.

I think teachers should be educated more about it. I think teachers should have to... are required to take more education on STDs and AIDS and everything so when they're in a health class, they're not saying, you know... the same things they've been saying for years and years and years. I think it should be... they should have textbooks on it. They should have everything, like these kids should be so knowledgeable on this that in a split second if a question was asked, they could pick it right out.

The single mothers also acknowledged that there needed to be more publicity surrounding HIV prevention. They offered some ideas as to where these messages could be promoted.

So what about... I think that a woman's washroom. Why not? I mean you know the washroom is a secret place and it's only us women in there and if you want to... you know, if you're thinking about it and you want to jot your number down well you can, you know, and... once people start seeing the word HIV and AIDS again, it kind of goes in your head and it's in your mind. Like it's... you know, if you see it, you're washing your hands, then you're going to think about it rather than if you're... you know, you don't see it. You see the word, you know, and if it's in a woman's washroom or something like that, I mean at least it's getting in people's minds a little bit..

But I'm not saying like you know... it's just crazy like they don't... it's not... like everything else in this world is advertised to the max, but the issues that should be advertised all the time and more and more and more aren't being advertised. When you go to a hospital you don't see a single sign about AIDS anywhere.

The general consensus with the single mothers, however, was that the message would have to be particularly shocking if it was to have an impact on other women.

P: Oh, yeah, in the commercials where they have all them bodies piled up into one pile, this is how many people were killed last year. Why don't you do that for AIDS and stuff.

P: Yeah (agreement)

P: Or are you going to wait until it's too late.

P: Yes.

F: So you think people need to be shocked more then?

P: Yes. (agreement)

P: Scare their ass.

P: Scare them.

P: People need to be scared.

These women also felt that women needed more information regarding the risks of casual sex. Many women expressed concern for women who frequent bars and have sex with men about whom they have no information.

I mean it's also got to go with people, you've got to have yourself well to say to yourself, well, okay, I'm thinking about this, having sex with this man, maybe it's not a good idea because I don't know too much about him. But I mean not too many think about that. You see some of the women down the bars, they'll be all over people not even thinking. They're not even thinking about well tomorrow I could wake up with AIDS. They're not thinking about the consequences.

Just tell women to be more cautious about what they're doing because you really don't... don't jump in the sack with a man that you met the first night just because you had a couple of drinks.

The discussion around the issue of bars was an introduction to a subject which was addressed at length; the challenges of offering HIV prevention education to women influenced by alcohol and drugs.

Challenges When Women Are on Drugs or Alcohol

While it can be difficult to present information on HIV prevention at the best of times, women in all of the focus groups emphasized that being under the influence of alcohol or drugs can make women less likely to absorb the messages as well as put them into practice. This topic was the most heavily discussed in the focus groups with the sex trade workers. The sex trade workers focused on two major issues: women who became addicted to drugs after they began working in the sex trade and those who entered the sex trade to support their addiction.

Even within the addicts there's another group. There were women who were in the sex trade and then became an addict. So they have already had the opportunity to learn all of the good health things, you know, we had already been in this and myself included as far as like I had learned all the healthy ways of taking care of myself prior to being an addict. And then there's women who are addicts that turn to the streets who work totally a different way, okay, because they never had the opportunity to really to learn about safety and to know that like condoms, condoms, condoms, like you know, this kind of thing. They didn't have that before. What happened was they went out desperate, so it was about just getting the money and it was about doing whatever, you know, and so they didn't have that mechanism that clicks in.

You know for the women who were prostitutes... into prostitution first and then developed an addiction we had that opportunity whereas the other women who went out desperate... it's a whole nother story, you know. And they're not going to worry about HIV because they're going to think you know, I just want my dope right now. HIV ten years down the road, you know, and right now my immediate... I was an IV drug user also for many years and at that time it was about Hepatitis. But if there was four of us there and one syringe and one of us had Hepatitis, it didn't mean that the other three didn't get high. I mean you'd like to... you know, I was also blessed that I didn't contract Hepatitis either. I mean big time, right, but we didn't think about that stuff.

Yeah, the dope is there. I want my dope right now, you know. Worry about HIV, Hepatitis ten years when the time... you know, they say it stays in your system 13 years, you know, I mean we're talking immediate. And when you're a person that went to work on the street because of an addiction, like if they went out there without having that first time to learn about safer sex practices, you know, and things like that, you're not going to think about that stuff.

I think the reason why they're not fully using their head is their addiction that's calling out to them. It's their addiction. It's not that they don't know better. And it's not that they want to do it, it's their addiction telling them to do it.

Oh, well yeah, myself I have knowledge but my addiction gets the best of me at times, you know.

Yeah, and especially I guess too if someone's addicted to a drug, you know what I mean and they want their fix or whatever, then they're not... you know what I mean.

Yeah, like I say it's people's addictions, they will just do things because of their addiction, they want that fix right.

One woman gave a particularly poignant reason for why women with addictions may ignore safer sex advice: a lack of self-worth arising from their poor physical and mental health.

Right. I mean you know you have to... you have to keep your body well like you said... there's so many people out there that just... they don't give a shit. You know, they're dying from their addiction anyway so what's the sense? That's the way they look at it. You know, they're dying one way or another so... that's how they look at it. And it's not right but it's just that their mind... that's where their mind is.

The single mothers also mentioned the complex issue of drugs and alcohol, but more as it related to risk-taking and the youth in their community.

I think that drugs and alcohol have a lot to do with it. I think that it's very easy accessible... you could teach them at home to have moral... then you know, oh after university and all this stuff. But when they use it with friends and they have joints... and you know what, it happens. And it's out there on the street and the Ecstasy is there and the drinking is there and you know... and soon as they get a few drinks into them, how can they have a clear judgement. How do they know what they're doing. So you know even just the pills that are accessible to the teenagers and the drinking and stuff like that, it's so easy for anybody to get it. And then once you're under the influence like really, and how can you even think straight and anything could happen and I think that has a lot to do with it.

Concerns about their children and youth in general actually became a recurring theme with the single mothers, and it did at times become difficult to get them to focus on their needs as women as opposed to what they saw as the needs of youth. Their roles as both mothers and caregivers for the community's children were obviously of great importance to them. The sex trade workers and African Nova Scotian who participated in the focus groups also expressed concern about the youth in their community.

Reaching Youth

Although the purpose of this study is to examine the HIV prevention needs of diverse communities of women, the issue of protecting their community's youth was extremely important to the participants. For this reason, their thoughts on the subject are included in this paper. For the sex trade workers, their ultimate goal was to help keep youth out of the sex trade. They believed that the lure of money and low self-esteem needed to be addressed to reach this goal.

Yeah, but it always has. It's always started young. You know, because when I was a kid I lived in the Johnson House in the Coloured Home and I was like 13 or 14 when I lived in there, you know, and oh, you want to drive in town, or you want to this, or you want to... and then it's like oh, well, you know, I've done all this, now you're going to do something for me. Like go away. What's that? You know what I mean. I mean I... my decision was my decision and as crazy as it's going to sound, I'm glad I got with my kids' father and not anyone else because it was never, you got to go out there, and you got to... it was always... actually when he first saw me out there, he smacked me, took me home to my mother. But you couldn't stop me by then because I got a little taste of money and I liked it, you know.

F: So it's a real different story then when you're talking about teenagers as opposed to when you're talking about adult women.

P: Yeah, because they want that affection, you know. They think by, you know, oh, well, you know...

P: Yeah, he'll buy me a new suit or something.

P: Yeah, you know, we're going out to dinner or any... you know what I mean, like they're not thinking on the same level as an adult.

That's where we need to focus on too, you know, is the kids because you know, schools yes, but personally I feel group homes. Group home kids, you know what I mean. You need to go in because those are the ones that are looking for affection, somebody to love them, and they're not looking for it in the right way. You know, they're looking... oh, so and so took me to McDonald's and you know... so personally I think it's... like the teens, boys and girls, not just girls. Boys and girls. So they're looking for the same thing, affection, no matter how they get it.

Some of the sex trade workers had already made an effort to reach youth at risk; they believed that youth needed to be confronted with some of the grim realities of the sex trade to keep them out of that line of work.

I went to the Ray Allen Centre for the first time, I told them, don't ask me anything unless you want the truth because I'm the one and I'll scare your behind off, you know, and them girls ask questions, and I was... and I thought to myself, well, I haven't even told you half of it. You know, wait until you have a gun held to you? Wait 'til he has a knife to your throat? You know, wait 'til you got to go identify one of your girls' bodies in the morgue then, you know, then you're getting a real taste of that life.

The African Nova Scotian women discussed how the youth in their community seemed to feel invincible when it came to HIV. They stated that until the youth were faced with another youth with HIV, they would refuse to believe it could happen to them.

P: It's unfortunate but it seems like for the young kids of today, it's almost like they don't believe anything until they know someone of their own age that has it.

P: That's right. It's not right in their face.

P: And it's unfortunate because that may be what has to happen before it really clicks into them that, you know, my buddy is actually going to die kind of thing, you know.

P: Because often times you hear them say that, you know, that's not going to happen to me.

P: Oh, all the time.

P: Like I know who I'm sleeping with, they say. How often do you hear them say that?

P: Young people believe that they're untouchable.

P: Oh, yeah, they do. (agreement)

These women also have seen evidence of young women using oral sex as a method of avoiding pregnancy, without considering the potential health implications.

P: And you know there's a new philosophy with young girls now you know, it's a new philosophy, I don't know if you guys heard it yet. They do not lose their virginity, they're into oral sex.

F: Yes. Yes, thank you, thank you, yes.

P: They won't get pregnant, they don't think anything will happen to them.

P: Yes, you've got it. That's it. Thank you.

P: They don't think it's sex. So oral sex is big time now.

P: Yeah, they allow the guys oral sex.

I mean not all girls are like that but you know if you're with a guy and you really care about him and you know very well your parents talked to you about coming home pregnant, that's

something that I won't tolerate but they want to satisfy in some way so that's how the kids are thinking today.

The single mothers emphasized their belief that teachers need to be well prepared to talk about HIV and safer sex, as parents did not always have time to address it themselves.

I think that a lot of parents, especially single moms that are working and stuff, you just don't have the time that maybe they may have had in the past. But in the past they were ashamed to talk about it. So I think that it's really important that after school programs where our children are going after school where they have the time and they should have access to the information maybe somewhere privately they can go and talk to somebody...

While the women felt a need to inform their youth of the need to protect themselves against HIV, they seemed to have greater difficulty when it came to talking to the men in their life about the same issue.

Issues With Men

When asked about their relationships with men, most women expressed that this was an area of concern. Some were able to verbalize their safer sex needs to their partners, but others did not feel that they had control over this part of their life. The sex trade workers who participated in the focus groups were generally quite comfortable in asserting themselves. However, they were quite aware of the challenges that women may face on the job, such as pressure from men to not use condoms.

A lot of men they think with their dicks, excuse my French, but that's what I think. They don't think with their head, they think with their dicks. And, they just don't... they just don't care. If you're willing to do it (have sex without condoms), they're willing to do it.

And they don't got a condom... they don't care. You tell a guy and he's saying okay you go to work, I don't got no condoms, what do you mean condoms, get out there bitch. You don't need no condoms. They don't care.

You know, they ain't worried about what they're going to give you and the women aren't worried about what they may catch from the guy, all the guy's thinking is you know, I'm not going to...and then when I try to explain to them, listen there's all kinds of things you can get orally if the woman has it in her throat, you can still get it. They don't want... they don't hear that. You know, the clients don't want to hear about it and the girls don't... they'll just leave me... "Yeah I'm using condoms". Just to leave them alone, but we know they're not.

Because there's a lot of them (men) out there now will argue with you black and blue and tell you, well I'm clean, my answer to that is if you're so clean, you and everybody else who tells me that, where do AIDS come from. Where did the disease come from, everybody's clean. Somebody got something.

The guys will say, oh I'm clean, I'm clean. So if you're telling me you're clean okay, then there is someone else out there that you use without a condom because you told that girl the same thing that you're telling me. Right, and you don't know where she's been. You don't know if she's clean. And she can say, you know, oh well I'm clean... and that's the whole thing, and they will

say, I'll give you extra money. Well, guess what? No, it doesn't go like that. If you can't... if you can't accept it the way it is, then you know...

I don't know where their (men's) heads are at. Because I always say to them, if you're not afraid of what you're going to catch from me, then you must already have everything. You know what I do. You know what I do and if you don't have a little fear there, then you must be trying to give me something then. You know, because that's how I think about it.

Male clients may also indirectly influence a sex trade worker's safer sex practices by encouraging competition amongst the workers. By offering extra money to those who agree to have sex without condoms, this places added pressure on those who typically insist on condom use.

P: No, you just want to show yourself you're better than all the other girls and make more money than them.

P: Yeah, so it's different things for a lot of different...

P: It's competition.

P: Yeah, even if it's not the fear of getting your behind whopped, it's just all different things for a lot of different people so... it's a competition, so like if you were to say, no I'm not going to have sex with you unless you wear a condom, but then the woman next to you says, well I'll do it regardless.

P: That's the competition.

P: Well, that's like the other night I'm out there and there's other girls that are doing it and see I don't have like a drug addiction or anything, I just do it because I've been doing it for a long time and I'm out there (laughing). No, because this other girl out there, like she's doing it without the condom and I tell her like you know uh uh, you know what I mean, well I have to do it with the condom and they're like well I can do with another ten dollars.

There's more of them out there that don't care about that (HIV), I'll give you extra if you don't want to use (condoms).

P: You know, now I'm mad because I have to stand out here all these hours and like... we used to laugh and say the better you look the longer you stand, you know, so make yourself all dirty and scruffy and you'll get a date. That's the way it is now.

(Laughter)

F: And is that like sort of maybe that desperation thing?

P: That's what the clients want.

P: It's the look. It's the look.

P: When you're out there and you're all dressed because I used to dress all the time when I went out there but it got to the point that I started wearing just shorts and t-shirts and sneakers... that's the girls they seemed to be picking up was the girls with sneakers, shorts and t-shirts on, so I was like I've got to try this on. And as soon as I started trying that, I started making money again.

P: Yeah, so... and then you know I'll go and I'll say listen, now you'd better be using condoms with this client because I'm getting pretty mad about... you know what I mean. No, you're not, and I know you're not and that's why they went by me for you, because look at you and look at me and I know that's probably the only reason. Either that or you want this ten dollars for your pill, so now it's gone to the point where they're doing ten dollar dates now.

Sometimes it gets frustrating for me. I'm standing out there, four guys come by that don't want to use a condom, know that I use them and they'll stop for so and so because they know she doesn't.

P: What's the good of having HIV, you're not saving my life.

P: That's what I'm saying... money can't...

P: You can't put a price on life.

P: Yeah, so... you deal with that all the time. I can't go for that.

I mean even if as an addict you know you're... some guys come along and they're saying, look... and believe it not, there's still a whole bunch of clients that will still try to offer you extra money not to use a condom...
(agreement)

And you know they (some sex trade workers) don't (use condoms) because they know that they're going to get their money faster that way...

The challenges faced by sex trade workers weren't limited to their clients, however. They recognized that their personal relationships could at times be as risky as their professional relationships.

Sometimes women trust men more than they should. And I'm talking about on a personal level. Because your man is straight, don't think he don't run around because he does. Because all men run around, I don't care who owns them... straight up. And I think that has an effect on people not protecting themselves sometimes if they want to try.

P: Well, yes, but you see other girls, you know what I mean. And they're like, oh... I can't leave, I've got to stay you know what I mean. And so I think that runs down their safety level too.

P: Oh, hell, yeah. They're living in fear of their man.

P: Yeah, you know, being able to go home you know with this when they should have had this. You know, so then they might take a little more to do without or... you know what I mean, because I've seen a lot of shady things...

P: That's what I'm saying...

P: That would be double scary, a man and the job. You know, because they're a bad combination.

F: So what you're saying, it's not just the men on the street, it's the men back home that...

P: Yes.

F: So is that usually the case, you find some women are more likely to protect themselves on the street than they are to protect themselves at home?

P: Yeah.

P: A lot of times the women that work will use condoms with their clients all the time but then...

P: Forget about it.

P: Forget about it when you get a lover. Because you know, I mean it's kind of like... the condoms will make you think more of work whereas you want to have a personal sex life too and it's hard, you know, there's a whole lot of other issues there too. You know, but unless one of those factors are present, why bother?

P: Yeah, that's what I would think too. Why bother?

P: You know what I mean, I'm using condoms, you know what I mean... they're looking at the fact well... or at least hoping in the back of their mind, well you know, my man don't mess around and... you know, well you want to think that. I mean you know I don't want... like people say to me about being a scarred woman because I think all men mess around if they get the opportunity and they can get away with it, ain't none of them going to say no. That's how I think. But then, you know, I mean, you know, I've got my own issues around this but I honestly believe that there's... if the opportunity is there, and they figure they can get away with it, you know, because the thought don't come from (pointing at head) that's where all the brains is down there (pointing at groin). So, you know. (laughing)

While the previous statements implicitly suggested a lack of safety in their intimate relationships, some women talked about a more explicit sense of danger.

Yeah, something else too like... because I worked in a lot of bigger cities too and I found that a lot of girls were, you know, worrying about their safety less because they were more worried about the ass whupping they were going to take if they didn't have so much money to come home with.

Some women from the African Nova Scotian communities had concerns about the fidelity of their partners, but were afraid they would endanger their relationships if they insisted upon condom use or HIV testing.

F: So, the question again is what kinds of things make it difficult for women to protect themselves? What is it?

P: Fear of the man leaving them basically. I mean...

P: Fear of rejection.

P: Yeah, exactly.

P: And if you're not... you know, if you don't break down and say okay, you know, just this one time (to not use a condom) or whatever, then they go away. And then of course you're faced with the dilemma of feeling frustrated because your sexual needs are not being met. So that's a very big issue. You know... in terms of the protection and the pressure that's put on you, you know.

P: Yeah, the pressure yeah.

P: (a man would say) Why are you all of a sudden asking me to wear a condom?

P: ... wear a condom, you know, you're the only woman I'm with...

P: That's right, you know...

P: Oh, Hon, you know you're the only one.

P: And interjected into that relationship is almost an issue of mistrust you know, because we can't deny the fact that our men have many interests too, you know, and if you, you know, give them any kind of little inkling that you suspect that they're cheating or whatever, that raises a whole bunch of issues. And for many women, they'd rather not go there. Even if they want to be tested to even know, you know, those are issues that are no joke.

P: Yeah, they're either afraid of losing the man... and that's what's going to happen. They'll say, you know, I mean normally that's what the man will say, well fine if you think that I'm out there cheating well, you know...

F: ...so when you talk about condom use and not protecting yourself, why is it that women are afraid to use condoms?

P: Well because some of the men... if you have a man that's... that's not something that he wants...

P: Or you know they always come up with different kinds of excuses not to have protected sex.

Some of the African Nova Scotian women expressed the possibility that their partners may be having relationships with other men. The taboo of talking about same-sex relationships in their community made it difficult to discuss this with their partners.

F: What kinds of things might make it difficult for women in your community to protect themselves against HIV?

P: Not knowing that your husband or your boyfriend is hetero... I mean bi-sexual.

P: Yeah, I was going to say lack of knowledge.

P: Lack of knowledge. Your boyfriend could be sleeping with another man for all you know.

P: Exactly.

F: Why is it? How come we don't talk to our partners about condom use?

P: Because first of all they wouldn't even be thinking about the Downlow Brothers being in my house.

P: That's true.

P: Number two is that if you talk to some of the Black men around here, you would never catch them at no AIDS Forum around because you know why? They walk out there, they're going to be labelled as having AIDS. You've got to realize that we live in a very small community and the people that don't understand what's going on when it comes to HIV and AIDS are still being misinformed and those who want to participate in these kind of sessions may be labelled as well.

P: So, You've got to watch out for things like that as well. I mean some... you're talking about a lot of young Black men out there.

The single mothers had similar concerns to those of the African Nova Scotian women; some felt that their partners would accuse them of infidelity if they discussed safer sex within the relationship.

Maybe start talking to some of your men, it's like well, you've must have been with somebody if you're talking like that. Like who have you been with? Not because it's a protection thing, it's like, well, you must have been doing something. Because I know in my mind if I said that to him, that's the first thing he would say, well, I know I haven't been with anybody lately, well why are you asking me? You must have been with somebody else. You know, it's always the negative point of view that you must be asking because you must be guilty. So that's why women are more comfortable talking with each other about it than they are... well, at least me with my partner because that's just the way he is. He'd figure that I'd been up to something if I asked him about whatever.

The majority of the single mothers, however, expressed that they felt comfortable insisting on safer sex practices, and would not tolerate infidelity from their partners. They made strong statements supporting their strong belief in standing up for themselves.

P: You decide when you feel comfortable enough because in society today... I mean all of us are women and we all know that a lot of... you get a lot of pressure from guys and men to have sex...

P: Without a condom.

P: Without a condom and it's... and like they pass you these girl lines, oh baby you're looking so fine, you're the only woman for me... like HELLO.

P: Yeah, you know, you ain't exactly Prince Charming.... No, no, no, you ain't getting me...

P: What's your man going to be doing when you ain't looking? Everybody goes, my man ain't doing nothing. But you really don't know about it. It's just like they don't know about you, you're not with them.

P: But I think a lot of it has to be... the women got to change a lot of attitudes towards that as well.

P: Trust your man.

P: If you feel that your man is out there diddling somebody else...

P: Use a condom.

P: Get rid of him.

P: No, no, don't even bother coming in that door. I mean you have to be the strong one in the relationship and say, look, you're the one that did wrong.

And like you say, he won't be bringing something home to me and he won't be bringing something home to my kids. There's the door. You know, you want to be sleeping around with everybody, then obviously you're not ready to be in a monogamous relationship.

You know, they say a man is made to ask and a woman is made to refuse...

Unfortunately, these women also indicated that they were perhaps more outspoken than many other women in their community; they believed that it was not unusual for their friends to look the other way when it came to their partner's indiscretions.

P: And I think what you have to do is, you have to sit down and be open with them. And you have to let them know, you get caught doing something you're not supposed to be doing, you're out of here. You're like yesterday's newspaper.

F: Do you find a lot of women do that though?

P: No. (agreement)

P: No, they keep letting it happen.

When discussing their intimate relationships with men, this subject was heavily entwined with the issue of negotiating condom use. While it is difficult to separate the two topics, the women did present some discussion on the unique challenges with the use of condoms.

Condom Use

For some women, the decision to use or not use condoms is not only dependent on the level of their partner's acceptance but on their own level of comfort. Some sex trade workers stated that some women are still embarrassed when it comes to condom use.

P: But this is a woman who said to me, you got one of them things? One of what things? I knew what she wanted but I was going to make her say it. Because there's another whole group of women out there who are say over the age of 30 that are now back in the dating scene, you know, or whatever that... I mean condoms weren't an issue then. They can't even say the word. They can't say condom, rubber... they won't go to the drugstore.

P: A lot of people are embarrassed to go to the store and buy them.

Other women, however, presented very creative methods with which they introduced condoms into their work. They believed that if they could use condoms without the men being aware, there was less chance that a man would have the opportunity to refuse to use one.

P: Yeah, I just don't discuss it. I just put the condom in my mouth and do it. Ain't no discussion. (Laughter)

P: You know, like while he's digging his money out, I'd be putting the condom, you know, so we don't even have to talk about this because it's done.

P: They'll say, oh, I'm some glad you didn't make me use one of those things. Look honey, what's that? Oh, my, you're some good. Right.

The sex trade workers noted that mental health issues were increasingly influencing the women's decisions of whether or not to use condoms on the job.

There's a lot now where there didn't used to be (mental health issues). There didn't used to be like there are now. There's a lot of women with mental health issues that are out there and you know, they're just like victims in a sense because the clients... those are the ones the clients are going to take because they can get away with not using condoms and doing all kinds of nasty things and making them spin on their head for 20 dollars, you know, because they know... they don't care, you know, and getting it to these... making the women understand, they don't care. I mean the guy could say to them, look I really like you and I trust you and ordinarily I make all these girls use condoms but I really like you and, you know, I want to have real sex with you. And they fall for it.

The African Nova Scotian women also verbalized the embarrassment that some women feel when it comes to discussing condoms.

Let me tell you something, I bet you... you know what it is, it's nine times out of ten that women feel embarrassed by telling a guy to wear a condom.

These women also stated that when it comes to condom use, it tends to be easier to negotiate their use earlier in the relationship but then increasingly difficult as the relationship progresses.

P: Well it's different if you're just starting to go into a relationship. I mean I think it is. If I'm starting just going to a relationship, then personally if we're going to be together, you use a condom, it's just that simple.

P: All right.

P: Going into it. To have to go and discuss it with a partner that you've been with it might be a little difficult.

P: Yeah, that could be difficult.

P: But going to a relationship that...

P: Oh, definitely, yeah.

P: That wouldn't even be an issue.

However, with respect to condom negotiation, several of the African Nova Scotian women admitted that this practice was easier said than done. They strongly believed that many women were not taught how to communicate that need.

P: As long as you take your relationship to the next level, the next step and that's something you're doing together.

P: But women have to be taught that. We have to be taught that, how to communicate, right, so that we can do the right approach.

The single mothers saw embarrassment as less of an issue, but felt that they had to contend with the men's belief that condoms diminished sexual pleasure.

F: Now what do you think might be preventing women especially from protecting themselves against HIV?

P: Because they're (men) good talkers.

P: All wrapped up into the man, oh well he don't want to... he doesn't want to use it because it don't feel good. Too bad for you.

While men and condoms present two concrete examples of the challenges women face in their efforts to protect themselves against HIV, some challenges, such as the myths and misconceptions surrounding HIV, are more subtle but just as difficult.

Myths and Misconceptions

Many myths and misconceptions continue to surround HIV. The sex trade workers were aware of many misconceptions, both within their circle of workers and also within their clients. They observed that many people still believed that if they weren't homosexual, using injection drugs, or working in the sex trade, they must not be at risk.

P: It's out there, you know, and I think straight people that are... and when I say straight people I mean people who aren't in the sex trade or aren't caught in the drug world, they need to be woken up a little more than we do. They really do.

P: They're in hard core denial.

P: Yeah. They need to realize that you guys are at risk too.

I think a lot of straight people that have never worked or have never been in the drug trade, I think they feel that they're above it. I can't get that. But what they don't understand is your husband, yeah, you may have been married to him for 10 years, but okay he's 40 years old, he show up with everybody he slept with in the last 30 years, you know, how do you know they didn't have it.

But people don't look at the big picture like that. That's why I say, that's where the ignorance and the fear comes in because they think they're above it so it scares me... "I'm a straight guy, I work in the bank, I won't catch it." So a lot of them... you know.

You know, and I think things like, you know, people have a certain... still have a certain thought of what AIDS look like. I think that the fact that there is more... there's more ethnic type pictures as opposed to the middle-age... like most people think, it's a middle-age white business man who's gay who has AIDS. Okay. They... you know, they're not looking at... you're not seeing the face of AIDS as, you know, Black, Aboriginal, you know, a woman, you're not... they're still not seeing that as the face of AIDS.

The women also discussed how, at the height of the AIDS scare, there was also an assumption among clients that they would be able to tell which sex trade workers were infected simply by their appearance.

P: Yeah, that's true. Because I'll tell you during that... during the big, big AIDS scare, the chunky girls were making all kinds of money.

P: Yeah, they were.

P: It's because people take it because you got a little bit of weight on you, you don't got the AIDS.

P: You know, that's what the assumption was, that as soon as you get HIV you're going to get all skinny and shriveled up, you're not going to look healthy, where, you know, during that time... clients didn't want no thin girls. Do you have any girls that are, you know, healthy, chunky, whatever, you know what I mean because they figured chunky and healthy means no AIDS.

Another common statement was how, although HIV has existed for several years, many people still are unclear as to how easily and in what manner HIV can be transmitted.

And the thing is, and they're not quite 100 percent about who are you either because they say AIDS is contracted through a body fluid. Saliva is a body fluid. They're not 100 percent sure of that either.

You know, and then I kind of like you know all the myths, like if you use the same facecloth whether they're washed or not, you use the same towels... but I mean I lived with that man off and on for several months while he had, you know, the AIDS virus and I'm still negative. So, you know. He got me over my fear of it, of being around people that are positive.

Because I know when my... my son's father died in '91 okay and I've lost a few very good friends of mine to complications due to AIDS and I remembered like... if you sit there, I don't mean to be rude but you know, when you guys come over and you leave, I got to tell you because somebody else is going to tell you... like you know, when I make coffee or something, I throw the cup out, or... and then the assumption that my partner was positive so automatically I had to be positive. There's no, how could she not be, you know. But they didn't know at what point in his life that he contracted the virus whether we were still having sex or not.

One sex trade worker voluntarily disclosed her HIV positive status. Yet, she had some misconceptions regarding the testing process for HIV and the window period during which a person may have a false negative test.

I was a carrier of the disease for almost eight years before they told me "you're positive". During that eight years, I was always negative. Every time I got tested they always told me you're negative, you're negative, you're negative. And then eight years later, they come back and they told me, I'm positive. So you know, you don't know how long you can be a carrier before they tell you that you have it, you know what I mean.

The women from the African Nova Scotian communities had some similar thoughts regarding the misconceptions surrounding HIV in their community. The disease was seen as being one that only affected certain groups of people, giving some women a false sense of security.

Thought it was a white disease. It wasn't a Black disease.

P: At that time, the people that died were people that were known, you know, homosexuals, but Magic Johnson, you know, he wasn't.

P: No, he wasn't, no.

P: Therefore, we have to... we have to focus on the fact that it's not just a gay disease anymore.

P: Well, I think that's when reality focused in that when he caught it, that's why it hit home that people realized that, okay I guess non-gays can get it.

I'm hearing it. Not a lot, what I hear is negative and it's usually a homosexual disease and in the gays...

P: And first of all, married women think, I don't need that testing done.

P: (agreement) Yeah, that's true.

Okay, we've got to look at the big picture here. Why is somebody going to go for HIV tests when they don't know nothing about HIV? Right? I mean Black people here are misinformed. They don't know a lot about HIV. So it goes way back to the number one question, they have to be educated first.

When Kim was working on that project, I can remember that Kim, and I remember you doing some callouts in the community to discuss AIDS and... HIV and AIDS but like she was saying... my understanding of lack of education about the topic, I automatically felt that it was a homosexual disease, it didn't affect me so what did I want to know about it for?

These women also indicated that some people in their community had concerns regarding the ease of HIV transmission. Some individuals still believed that HIV was more easily transmitted than it has been proven to be.

One more other thing too is that if somebody was diagnosed with HIV, for the lack of education within the black community, there's a negative stigma around it because people really don't know how... how it can be contracted. So they got these fallacies in their head that even breathing on somebody with an open scar automatically transmits the HIV virus. So that is another thing too, is lack of education that stops us from talking about it because I mean if was diagnosed tomorrow with HIV, then of course I would have to be celibate, but I'm telling you something, I wouldn't tell anybody.

I've only ever heard of once at... I can't give any names but it being at a meeting somebody said, well this one person that she had HIV and they said they... the person said something about making sandwiches or something and they said, well I won't be eating any of her sandwiches, you know, but it's not something that is out there.

Among the group of single mothers, many misconceptions were revealed. There was some discussion of level of risk among certain groups of people, but the topic of how HIV can and cannot be transmitted became a very contentious issue.

Well, like how to catch it. People seem to think that if you've got HIV, like that person, you can't hug them, you're going to catch it, or you kiss them you're going to catch it. They...there's not enough information to sort of put it at rest.

Well, the fear of, you know, somebody who's got it, well, my main thing is that if you're homosexual, well you automatically either get it on your first time, don't eat off your plate you know even if it's been washed, or...you know, you'd always want to throw away the dishes. You know, and no physical contact.

P: You can't get it from a water fountain or anything else like that, I mean that's ridiculous.

P: Yes, you can.

P: No, you can't.

P: Yes, you can.

P: I think sometimes women still... and you know women are quite shocked, at least some of the women that I've encountered that may be, you know, if they're in a heterosexual relationship and they were surprised to find like you know, that they...that they were (HIV positive).

P: And then they're sitting there worrying, well, how did that happen?

P: And so she ends up with something and it's like, oh my God, how did that happen?

P: That's how the talk of toilet seats and all this comes into play. Like, you know what I shook hands with a possible...because they were home, they didn't do anything and somehow they got something.

F: So they don't want to believe that it's the men in their lives that could have done...

P: Yeah.

F: So it's easier to believe the more extreme things?

P: Yeah. Oh, they're... a lot of their men are doing it and they're just too scared to say anything and they just sit back and...

P: Take it.

The participants in this group have also observed how there seems to be a sense of invulnerability among their community's youth in regards to HIV.

P: They're thinking that because they're very young, they could be 12 or 13, they think they can not catch it.

P: They just think that they can't. They can sleep with 25 of them. But when they're 14 I'll say to about 17 before they get a brain on, they think that they can't catch AIDS. They think that these children, all the sex that they're having among each other, they think they can't catch AIDS. They think that they've got some miracle thing going on because they're young, they're not going to catch it.

These women indicated that the media's portrayal of HIV has influenced how this illness is viewed in their community. They believed that some people relied on the information presented by less than accurate media sources.

TV. Sometimes... like a lot of times it doesn't portray the truth. It's sort of made to entertain you. So it's either up here when it should be down here and... and it depends too on who's watching it. You and I could watch the same program and come out with different concepts. It's just the way you interpret things and I interpret things.

But perhaps the fieriest debates were saved for the issue of who should be notified if someone in the community has HIV, and how this notification should be carried out. Many women had voiced the strong opinion that HIV positive individuals should be identified, with the belief that this would help curb the spread of HIV. The response to this issue may be related to the earlier quotes in which many women identified gaps in their knowledge of how HIV is transmitted.

Yeah, parents should be informed if a school made a... if the children going to school that has it... I mean I have no problem with my kids hanging out with people that have AIDS but I would be concerned if they got cut around the child. I mean they could hang out with them no problem but I would be concerned if they got cut and I didn't know when...

I think people too that know that... like find out they got AIDS and they're in the earlier part of their pregnancy, they shouldn't be allowed to keep the child. Because that child is only going to live for so long and then die.

P: No but I believe that...

P: They should have to carry like...

P: AIDS card.

P: Like a blood... Red Cross card, saying you know that they have it because I mean it's not the people... it's not so much the women's fault for sleeping with people, it's the men that know they have it that aren't saying.

P: But they should be made to get tested. Like everybody should. That's what I think, there should be a law.

P: I agree with that, yeah.

P: Exactly.

P: AIDS is like the plague that like is going to kill everybody off because eventually... like she said, everybody is going to have it.

I think... they say that pedophiles have to be announced in the news to let everybody know, I think that there should be a program where people when they find out have AIDS have to report to a program too.

These misconceptions also led the women to have erroneous beliefs regarding what they may do to protect themselves against HIV. Some women believed that seeing the results of tests, or being with a man who took care of himself, would offer them degree of safety.

P: I want to see papers.

P: I want to see papers that are saying HIV test, negative.

P: Yeah, but that paper don't even matter...

P: You should go get tested both of you.

P: You also should be seeing them for a while...

P: It don't even matter.

P: And find out their mannerisms like how often they take a shower, how often do they clean themselves, like just general hygiene. Because that will tell you a lot about a person.

However, when that comment was probed further and the women were asked whether they would automatically believe a man who had a negative test and appeared clean and healthy, they emphatically replied no. But the initial comment could still point to an ingrained belief that a healthy appearance implies HIV negativity.

Stigma

The myths and misconceptions held by the participants and by individuals in their communities have led to incidents of stigmatization. In the case of the sex trade workers, however, stigmatization seemed to occur more in conjunction with their occupation than with HIV itself. In relation to HIV, many sex trade workers felt that as they became more knowledgeable they also were able to keep the diseases in the proper perspective.

Well, I can't speak for others but myself I found the more people that I knew that was positive and stuff, I've learned to accept it more. I'm not... don't get me wrong, yes, I'm afraid of it but there is precautions you can take of it. But I think that's a big thing that... like I said, it's been talked about so much and people have it now and things that it's... people are accepting it more today. Before it would be like, looking at you, oh she's HIV, I'm not going around her. I did it myself. Like, you know, but now it's... you know, I'm no better than you if you have it, right.

I agree with her because my old boss in Moncton, that's what he died of. And I mean for like months upon months I went down there and he lived in the same household as us girls and... like

we only found out like probably about two or three months before he passed on, but like I didn't stop going there or nothing, you know what I mean.

But like this was a businessman, heterosexual, older man, you know, I mean he might have been a client, who knows, but he was honest. He said... you're not the people that I would want to talk to which would be sex trade workers, you know, gay and lesbian people, street people. But he said, but when I lost my wife, you were the only people that were there for me. All those other people... because there's a difference. When you lose someone to cancer, people hug you. You know, if you lose a partner to AIDS, people go, oh, I'm sorry dear, geez, I'm really sorry. Because they just automatically assume that if this was a partner, you're... like you must have it and if I hug you...

Yet, because of the stigma associated with the sex trade, some women acknowledged that they have taken risks when it comes to sex. They stated that, at times, they avoided people or agencies that provided condoms or other safer sex services to escape being labelled as a sex trade worker.

P: Like I said, there was some girls that just... like they don't want people... like they're hiding the fact that they're working so they don't want anybody to know and they don't want to accept condoms and stuff.

P: Because they're ashamed. They're ashamed of themselves. By putting themselves out there, they're ashamed.

P: Yeah. But they're putting themselves at risk.

P: Yes, because there's some women I know that won't go to see Stepping Stone on Thursday nights, they'll come to me afterwards because they know I'll talk to them.

P: Because they're nervous, yeah they're in the closet.

P: Right, I mean like it... I mean I haven't worked the streets in a long time but when I did like I get chills and I mean I did it... but I mean I always had to be... like do you know what I mean, like so secretive and stuff. But I mean it always gets out. It doesn't matter how secretive you are and I mean... but you can be still secretive and safe at the same time.

For the women from the African Nova Scotian communities, the church was seen as having a major influence on the attitude of the community towards HIV. However, they admitted that to date, the church has not been very open to the concept of discussing HIV.

Because it's not a discussion that people talk about around their kitchen table or talk to the children about because the majority are homosexual... homosexuals. And that is like a forbidden word in the black community, not every family, but I'm just saying those who are really connected to the church... I'm not saying anything negative about the church but those who are connected with the church still go back to Adam and Eve, not Adam and Steve. So that's why they don't discuss these kinds of things or be open about HIV because there's no need to be.

P: And then when they get to the church, because I mean the church community too is that... it's just such a no, no in terms of gays, you don't openly talk about the things or the consequences or whatever, which I think is a shame. I don't think it should be a hidden thing, I think we need to talk about it because it's a reality in the world.

P: And everyone thinks it a gay disease but it's...

P: It's not.

P: it's everybody's disease nowadays.

P: And I don't know if this is getting into one of your questions, I think until you break down the barriers with the churches, because our Black churches are very strong. You know, as soon as you talk about HIV or you talk about homosexuality, which HIV does not necessarily come from homosexuality, I think that there has to be an education, but you need to unblock these churches.

P: People would not even listen. They would close their ears to it. They wouldn't want to hear it because it's so embarrassing to them.

P: Well the first thing they see it... they see it as sin and you got to... you know, you have to go into the theological theories and tell them... I mean you would have to into a whole Biblical thing to say listen...

P: How would Jesus deal with this? Jesus is not going to block it off, you know, he's going to find a way to reach people, so you just have to open them up because our churches are very closed.

Even outside the confines of the church, stigma around homosexuality has affected how HIV is perceived and dealt with inside their community.

The community still hasn't come to grips with homosexuality so like I was saying earlier, I know guys that are gay but don't want anyone to think that they're gay, so they're sleeping with women too. Do you know what I'm saying?

It can upset your position, it really can. So, and then on top of that, dealing with your employment, then you have your community that is not educated with AIDS, that talks negative about HIV and AIDS because they automatically think it's a homosexual disease, then you're going to be stigmatized as a homosexual, everything... so to me, personally, I mean more... hats off to you, if you did that but me personally, I wouldn't go out. No, I wouldn't...

In the end, many women were concerned that their place in the community would be threatened if they were diagnosed as being HIV positive.

I would die with that and the... it wouldn't come out until after the fact. And no, people are not educated about the disease and I know that I would be shunned.

Also I think too, I think the stigma around it. I think people are... stigma around even being able to speak about it or even working with people who have HIV or have, you know, close friends or family or partners who do. There's such a stigma and that's what I found very heartbreaking with folks you know around that.

Within the group of single mothers, there was a common understanding that much work needed to be done to remove some of the stigma that surrounds HIV in their community.

Yeah, they have to see it (to destigmatize it) or you know even... I mean okay I have... I have a relative who died of AIDS. I have friends who have died of AIDS okay. So I'm... I've done my homework and know, you know, so, you know, I treat them... they're friends, I'm just a little bit more cautious and it's... so it's... you know, people just need to know and learn.

P: But could you imagine if they told you well you have AIDS, what would your life be like then? Because I mean people look down on it so badly.

P: They do.

P: Like it's like you're a plague, you know, and you'd be cast aside and.... I mean and that's how a lot of people look at it, they won't let your children play with other children because they have it, and you know they're afraid to drink off water fountains.

The fear of stigmatization leads into the next issue, the fear of gossip in the community.

Gossip

Testing for HIV holds significant benefits for an individual's health. However, given the misconceptions that can lead to the stigmatization of those with HIV, it is not surprising to note that some people are hesitant to seek out testing. The sex trade workers did not indicate that they had those concerns, but in the focus groups with both the African Nova Scotian women and the single mothers, there was a notable fear of gossip within the communities. The tight-knit nature of the small African Nova Scotian regions was of particular concern.

P: Yes, and that's the thought that goes on... gets around.

P: And if one person in the community gets around.

P: Yeah, the news gets in the wrong person's hand, travels through the little neighbourhood and then everybody's whispering and going on.

P: And like I said, just...

P: How do you stop the gossip in the neighbourhoods because that's how it all starts by the gossip, so they have to... have to be educated.

P: They have to be, that's right, so how are they going to get educated if they're worried about gossip?

F: What would be brought into the community?

P: Like a mobile...

P: Unit?

P: but would you have it labelled as HIV testing or would you just have it test... women testing?

P: That's what I'm saying, yeah.

P: But you know very well word flies... word flies fast in this community. Oh there's a mobile unit coming in here and test people for AIDS.

P: and then they'd be sitting there, oh, did you know we saw so and so, and so and so in there.

P: And watching people who's going there.

P: But ... yeah, but still if we did a mobile thing (for HIV testing) it's not too confidential if you're seen walking in there.

P: They don't know what you're walking in there for.

P: Oh come on now, we live in a Black community.

P: They're just assuming they know.

P: Yeah, but that's enough for our people not to go.

Well, I think just the stigma of it getting out there that they're trying to protect themselves. You know what I mean, like I mean if you were all of a sudden decided that you're in a relationship and you're now thinking and being more focused on the fact that the AIDS is out there and you ask your partner to wear a condom when you might not have for the last five years. I mean if that gets around the community and people start... you know what I mean...

The single mothers echoed similar concerns regarding gossip in their community. As with the African Nova Scotian women, they indicated that they would prefer having their testing done at a site that offered several services to avoid the "finger pointing" that may occur if they were seen entering an HIV screening site.

They don't want anybody to see them. It needs to be more private. If it's just a certain kind of a clinic that... let's say the STD clinic that basically specializes in that, no one will go because then if she met me and I met her, well we know what we're going there for. But if it's something that offers something else, then you don't have a clue what I'm there for and I don't have... if it's something that's specifically for... then you know, and I'm not going to... when I go there, if I see her first, I'm out before she sees me.

Gossip in the community was but one of the factors influencing the women's decision of whether or not to get tested. Fear of the testing process and of the results also affected that decision-making process.

Fear

The fear felt by the sex trade workers who participated in the focus groups can be broken down into the fear that they may be placing themselves at risk due to their occupation and the fear of the results should they choose to get tested. The women described some of the fears they had a result of their work.

I worry about it constantly. Myself. Because I'm in the sex trade business and it's... you know what I mean, but I don't worry too much about it now because I don't have sex with nobody (chuckle) ... you know what I mean like a long time ago I stopped having intercourse just because of that. It scared me enough to stop in my line of work.

Now you know, thank... thank the creator that I was negative you know, and was tested 3000 times. I was scared to death. I still believe that you guys are missing something, you know, but...

However, the women also verbalized how the knowledge they acquired as a result of their work helped to dispel some of that fear.

The fear is, you know, you still don't want it but like the fear... like a terrified oh fear, you know... it's just not... that's not so prominent because we take the time to know... to learn about these things.

I think... not that people is not worried but it just... she spoke about like when it first came out it was this big issue, it was frightening and now I find there is a lot of people out there that's positive and it's talked around... it's talked about so much it was and stuff so, it's there but... they don't dwell on it as much. It's not, okay, she got AIDS, I'm not going around her, you know.

Okay. I'm not saying that people don't worry about it any more than they do, but people will take the precautions... it's like years ago if you had Hepatitis, it was the same thing. Now everybody got Hep C, so... (laughing) It doesn't make you complacent, you still don't want to be... and you'll do the precautions to stay away from those things, but it's not like the fears...

Regarding testing, one of the women described how frightened she was as she debated whether or not to get tested. The fear of the unknown consumed her for a year.

Like I said I went through it with an ex of mine, he was diagnosed you know, so for a long time it was a scary... that was the scariest year of my life.

When asked about testing, the single mothers also admitted that fear often prevented them from being tested.

F: Well, what do you think is preventing women from getting tested right now?

P: I think they're scared.

P: Afraid or scared yeah.

P: Because you just never know.

P: I wouldn't want to be the person sitting on the other end of the phone for somebody come tell me I have AIDS.

However, once the women were able to overcome their fear of testing, the issue of access to testing became a contentious issue.

Access to Testing

The women who participated in the focus groups revealed useful information regarding how and where testing should take place. For the sex trade workers, past experiences with testing in traditional health care settings, which were less than positive, gave them great insight into what they did not want in terms of testing.

I have scars from my IV drug use, I was an IV drug user for many, many, many years and I have scars. And when I go to get just blood work done, you know, I'm watching them and laughing okay, because they're doubling up the gloves and I'm thinking unless you're wearing steel honey, it ain't going to matter if the needle is going to prick through all that latex, but... you know, and I'll say to them when they... because I see how they look at me right and now I'm not actively using but when I was at the time, people would see the tracks and you're going for another test, they embarrass you without saying anything. Just the way they look at you, by the way that they... you know, even you're handled in a way differently...

I think some people would actually (get anonymous testing) because a lot of people that go to Stepping Stone, like you can only go to your doctor so many times before they tell you that they're not giving you another one, right.

P: I don't feel comfortable when I go for mine (HIV test). I never do, never. And I think it is the surroundings at the clinic. I know them people and they've known me for like my whole life but still I just don't feel comfortable you know, going into the... saying oh, you know, can I get a... I find they kind of look at me strange or something.

P: Yeah, like why would you want an HIV test? Like you know, really, you know.

P: Because like they don't really know what I do and really it's none of their business so I'm not going to tell them, but I just... I don't know, I just... that's the feeling I get is that they're looking at me like, why are you doing this?

P: Yeah, they're not going to... they don't have to go somewhere (if testing were offered at Stepping Stone). They don't have to go and look for it...

P: Or look a certain way to get cleaned up to go down to the hospital so they'll take your blood without wearing 42 pairs of gloves, you know.

The location of the testing site was very important to the sex trade workers. While some indicated that they would be willing to come to Planned Parenthood

Metro Clinic for testing, the majority felt they would be more comfortable if testing were offered at Stepping Stone.

P: Stepping Stone because...

P: Yeah, a lot of girls...

P: A lot of the girls, yeah, that's where we're all used to going. You know.

P: That's a way to open up the fridge.

P: They bring us into the Centre because like it's like a house. It is a house and we feel comfortable there. You know.

P: Well, maybe we should set... like you said about a safe place, maybe we could set up something with Stepping Stone or maybe like once a month we could sit down, you know, and just have a lunch or something and talk about this and see how people feel, and you know, just the girls getting together for... you know, trying to learn something to protect ourselves.

P: And just like you had at Stepping Stone with a table with a number or whatever, it's amazing. You come in here and you see all that on the wall and everybody reads everything, and if you don't then the staff will say, did you see that? This is what's going on girls, check that out. So, if you were coming, say September 28th, they'd have it up and a few days before they'd be like don't forget such and such is happening this day and...

I just thought like what she was saying and H. was saying that would be good if somebody... like if you were getting them up here, that way at Stepping Stone, they're going to... well, they know we go there everyday anyway and then some day I didn't... what if I wanted to go for that meeting...

P: Yeah, I think people would like that better instead of going into the (doctor's) office and you know, okay we're going to do this confidential. We can go to Stepping Stone, we can get this test ran, and then if you know, if I'm positive then I'll have to deal with it and do something.

P: Yeah. Yes, I think they'd feel a lot more comfortable, like to set up a little clinic somewhere.

P: Stepping Stone's already built up a lot of trust.

P: Yes, there's a lot of trust there.

P: Okay, within the sex trade community, you know, people go to Stepping Stone, they feel safe, they feel safe that what they're going to talk about is basically in there... you know, I mean you're going to find a few other dynamics where people go to things you know, things may slip out here and there. But basically between the staff and the house itself, it's been established there for a long time now and when you're looking at a whole lot of women who have trust issues anyway, trust is a big thing. You know, and feeling that this is really going to be anonymous, right, however it comes out. You know. And I think... and then you're also looking at the fact that people, you know, that usually... a lot of the people in the sex trade, everything is immediate, right now, so if you get them on a day when they was at Stepping Stone and having a coffee or something like that, and then you just came in and said, guess what, I'm doing the anonymous HIV testing today, anybody that was interested, come on up and get a test done. You know. You're there. Well, hell, I'm here anyway.

P: (agreement) Yeah, exactly.

P: I'm here anyway, I ain't doing nothing.

Like who wants to go and like the clinic there's like all these... sometimes it's so full, you know what I mean and you know why you're there and you don't know why anybody else is there but you know why you're there right and you're sitting there, and you're waiting for these people to call you and I mean you wait an awful long time and all this shit is going through your mind... and I don't... I don't like it. Like whereas at Stepping Stone, I could go there and there... I mean there's going to be somebody I know, you know, if not even just the outreach workers, but I go there and I feel comfortable so if I'm in there and you know, you were to come in and say oh, well, you know, we're doing anonymous AIDS testing, right... I'm going to be like, well, here, I need

one done. Whereas I don't want to go through the hassle of setting up the appointment and going through the clinic and having these people look at me like I've got two heads.

One woman, however, liked the idea of coming to Planned Parenthood for testing as she felt that it would offer an extra measure of confidentiality.

Yeah, I think here (Planned Parenthood) wouldn't be too bad either (for testing) though because Planned Parenthood, you know, it's... who knows what you're here for. Everybody that walks in that door could be getting birth control anything you know, so...

The participants also believed that offering flexibility with appointments would encourage sex trade workers to get tested. They stated that it was not only important to get testing in a comfortable location, but also in a timely fashion.

P: Right there, it's just right there. I don't got to go someplace where I have to make an appointment...

P: (agreement)

P: Yeah, you have to make the appointments and stuff at the doctors and sometimes you can't get in to them doctors for like a month later, and if you're feeling not right and that, who wants to wait, you know what I mean. So if there was something set up for like a couple of times a week or something, I think that people would go to it.

F: Well, and the thing too, it's hard to get yourself psyched up like you said. Often when people call here, it's by appointment so it might be two weeks before you get an appointment. So do you think that would discourage people then?

P: (several people) Yeah.

P: If I want to call you and say, well I want to get tested tomorrow and you said I got an appointment... I can't get you for another two weeks, I probably won't come.

P: You know how scared and freaked out you're going to be in two weeks.

P: Yeah, I mean it was hard enough for us to make that call anyway.

I: So you need a lot of flexibility.

P: Oh yeah. See, and a lot of thing with working girls, they don't like waiting.

Another factor that some of the women took into consideration was the opportunity to have their HIV test done anonymously rather than confidentially.

F: Like is that a big deal do you think like total anonymity versus just confidential?

P: Yeah, that's great.

P: Like cause it's a step above confidential.

P: yeah, it is, yeah, big time step.

F: So that would be a big deal for somebody.

P: Yeah.

When the women from the African Nova Scotian communities were asked for their ideas regarding accessing HIV testing, they frequently commented on the importance of incorporating other health services along with the HIV testing. They felt that this would provide the women with more privacy and avoid the stigmatization they would encounter if community members knew they were getting tested for HIV.

P: But it's (mobile testing unit) a good idea but it might not just have to be testing on HIV.

F: That's an idea.

P: The other thing to think about...

P: Your pap smear, the blood screening, pap smears...

P: Blood screening.

P: We've got all kinds of health problems in our community. Come in and have your blood tested for everything. Blood screening.

(Agreement)

P: Free blood screening.

P: So maybe if there was more mobile blood units, people would go.

F: Now that's interesting...

P: And not because it was mobile HIV unit, but mobile blood unit.

P: Exactly. You'd have to incorporate it with something else.

I had another idea. If there was like a woman's clinic, like say on a Saturday morning and incorporate that like at the end of... like that would cover women's issues and then at the end of the morning, say well now it's open to anybody that wanted to be tested for AIDS or whatever.

P: Well, they might... back in the day, remember when Sickle cell was going around and they had where everybody could go and get tested. Remember that?

P: Yeah.

P: And people did go... a lot of people did go and get tested.

P: But that's a different combination of...

P: That's right, there's no stigma.

P: No.

However, the women stated that one of the biggest deterrents to accessing HIV testing in African Nova Scotian communities was the fear of a positive result.

P: I think that's a hard task I'll tell you right now to get people to go and get tested.

P: Because they're afraid.

F: But let me ask you this question. Why is it that women are not getting tested for HIV and AIDS? Let's start with that question, why aren't we getting tested?

P: Because just like everything else, they don't get tested for anything else either.

P: I was going to say that, they don't get tested for diabetes, or...

P: It's not just AIDS.

P: It's fear.

P: Yeah, it's a fear of having something and how are you going to live with it?

The single mothers indicated that a lack of transportation and flexible childcare can prevent them from accessing services that are not located within their immediate community.

P: As long as they have childcare.

P: And child care, yeah, that's a big thing.

P: We can do anything as long as we have childcare.

It did become clear that if the women were to access testing for HIV, they had to recognize the important effect that testing could have on their lives. Yet, the women all indicated that to achieve this, they needed to be presented with HIV information that was relevant to them.

Need For Relevant Information

Both the sex trade workers and the African Nova Scotian women had specific concerns regarding the information presented to them about HIV. They felt that some of the messages did not address the realities of their lives. The sex trade workers wanted to see more heterosexual couples in HIV messaging, as well as more people of colour.

Like if I'm seeing a poster and it's just two white guys on there, oh yeah. You know, I might not even really pay attention. But I were to see a picture with a woman, you know, or a picture with an ethnic male, you know, or a heterosexual couple as opposed to a gay or lesbian couple, I'm going to pay more attention.

These women also pointed out that much of the HIV information they see comes from a more Central Canadian perspective. They felt that the needs of Atlantic Canadians were sometimes ignored.

All the research, everything comes to the Eastern Provinces last. You know, it's like, you know, we all wear rubber boots and fish for a living so we don't need to know that stuff anyway. You know, because we're always the last to get whatever, whether it's right from information... from funding to information. We get it last... if we don't have the information, you know, the up-to-date information, you know, not like.... I don't care about what happened in 1989 because I'm right now here in right now. I want up-to-date stuff...

Within the African Nova Scotian women's focus groups, the main concern was the lack of statistics reflecting the prevalence and incidence of HIV within both the African Canadian and African Nova Scotian communities.

F: Okay, so is there any information you think women in your community need to have to protect themselves against HIV?

P: Stats.

F: Stats.

P: We need some numbers. We're fighting against something this deadly, we got know what the numbers are.

P: Because I think that's the only thing that's going to hit home.

P: Yeah.

No, what I'm saying too... what I'm saying that even if it didn't cost anything, it's just that they have open information. They're dealing with numbers. They know that it's an epidemic. Whereas us as Nova Scotians not having any information like that, don't consider it as important and still think about the negativity that people would feel if they see them being tested by this mobile.

F: People are talking more, there's a concern with respect to the high rise (of HIV infections) within the States, if you don't know North Carolina, South Carolina, but the best statistical stuff is a buy-in, remember you have to be able to equate up here for our people. So that kind of stuff, if we don't have it abroad, maybe...

P: Yeah, give them some numbers.

P: Especially, it's something to be able to zoom in and make the connection with.

P: Just let them know that the Black that are...

P: With the Black community are the ones at risk.

F: And what I did was, I didn't really give information about sex, but what I did was I basically did a summary of what HIV and AIDS look like in our community. Because I didn't have no statistics...

P: Yeah, that's what the problem is.

P: No Canadian statistics...

P: Because we're not really here, you know. (laughter)

Beyond statistical information, the women also stated that locally produced media would get the attention of the women in their community more than media produced outside the region.

F: So besides that, is there any other information that you think that you would need?

P: Yes. Some commercials.

P: That are Canadian.

P: Yeah, Canadian, Halifax.

P: Locally based, even...

There was also a common perception that there were few community agencies that dealt with the issue of HIV in the African Canadian population.

F: As a matter of fact, now to this... as I speak we have nothing in Canada except for I think one organization in Toronto that's doing HIV and AIDS education with Black people in Canada... all of Canada.

P: And we have nothing in the Atlantic provinces except for the time when we had the Black Outreach Project and that was covering all the Atlantic provinces, you know what I mean. So we have nothing, we really don't.

When asked about methods which could be used to get across the relevant information that the women felt was needed, the women had some useful suggestions.

P: ...another way too to get it out... what would be really nice is if we had a hot line.

P: That's true, yeah.

P: And their calls are all anonymous.

P: Yeah.

P: And the teenagers, anybody that wanted any type of questions answered about HIV or AIDS or any place to go to get tested, anything like that, that's what we should have on the help line.

I still say though I like the issue of a page like this in the form of a flyer with not a whole lot of words on it, okay, but just a few bullet points circulated in the communities, get somebody to just go door to door with them like how we used to help people to know about community meetings that would come about and if it's not too wordy, you know what I mean, people will look at it quickly and they'll see the messages that you're trying to deliver. I think that that is another vehicle to help the African Nova Scotian community to recognize that this issue of AIDS is not going away.

When discussing the relevance of the available information, the African Nova Scotian women had several strong opinions related to the role that race plays in the dissemination of HIV prevention education. This issue had enormous significance for them.

Issues With Race

As was mentioned in the previous topic, the African Nova Scotian women felt that there was a lack of statistical data on their community. However, some women felt that the reason for this dearth of information was that there was a common perception that people of African descent were of less importance.

P: Well, they have stats though because they have... they have stats, you know what I mean. I just think it's a lack of concern. And I hate to say it, I don't want to call it the race card, but it is.

P: It's a form of genocide.

P: It's a lack of concern. I mean... a form of genocide, right, if this is happening over here with those Negroes over there, why are we putting our tax Canadian dollars in it, you know. It sounds sad but that's what it usually is.

The women in the focus groups also emphasized the importance of the church in spreading the HIV prevention message in their community. They believed that the ministers in the churches would be good vehicles to spread that message, as they already had credibility in the eyes of many community members.

But at least some of the newer ministers are progressive. You know, they're doing that. You know, they're talking for the day, right, it's out there and its... where some of the older ministers are just sort of, well yeah I know it's there but I don't want... you know, it doesn't belong in the church or I don't want to talk about it, but it's... you know, I think the pulpit is a great place for it because Black people go to church.

P: and that's why I said church because a lot of the Black women attend church. And I think at least for the older women, to me it seems that the messages coming from the man in the pulpit is something that they... they have more of a connection with.

F: So you feel that that's the biggest influence, in the church?

P: I do.

These women believed very strongly in the idea that if women in their community were going to "buy in" to HIV prevention messaging, they needed to hear from other individuals of African descent.

P: But you know what, I've got to tell you the truth. From my experience, people need to see their own colour on their story, you know what I mean.

P: Yeah, and that's true.

P: I'm telling you it's the truth.

P: And they need to see someone they know.

P: They're still not making a connection, a Caucasian or white person, whatever you want... is sitting up there...

P: Right, but I think that you need to see our faces. We need to be telling our stories from a person that is HIV and Black.

P: That's what I was saying about personal testimonies.

...So it would be kind of good to see in 2004 something implemented even if it's a hotline... if you had just one person employed, one Black... it would have to be an African Canadian person in my mind's eye, one person... even one person employed with Planned Parenthood to start putting these things into action.

The women agreed that the issue of monogamy was a contentious one in the eyes of some of the men in the community. However, for some women, this issue was difficult to address with the men in their lives, as they believed that this put their relationship at risk.

P: No, but that's... that's monogamy.

P: That's difficult.

P: And this is a big issue in our community.

P: It is yeah, that's right. (Laughing)

P: Because I... we cannot ignore the fact that this whole issue of AIDS and because it's a sexually transmitted disease, it's multi-faceted. And in order to... in my opinion, to deal with the problem that we're faced with in the community, you have to also look at those other factors. And the fact of the matter is with that, we've already earlier determined that communication is a big problem in our community and that does not escape the ten-year marriage, right.

P: Exactly.

P: It could be worse in a ten-year marriage.

P: So forced monogamy for our men... some of them, can be a big issue.

P: Oh, definitely. Definitely.

P: And there are less of our men than there are of our women. So forced monogamy would just change that.

P: Exactly.

P: Yeah, and for some women, they would have to decide, do I deal with the issue of condoms and safe sex and stuff with my husband, or I leave it alone and stay married.

The African Nova Scotian women had lengthy discussions about the tight-lipped nature of their community when it came to the topic of sexual health. They stated that this inability to address anything of a sexual nature could be traced back in the historical context of their family and community relationships.

P: What I was going to say is similar to that. With the Black culture, I think that we need information sessions to make us aware of it more and more whereas I think Caucasians or whatever and that, they don't need as much as we do. I think they are aware. But...

P: Well, somewhat

P: Yeah, but they're not as naïve as we are on these things. I mean... no I think we are... we're hidden... we hide behind these things and we don't bring them out.

P: ...we don't come home and share our stress with our family. We're not able to communicate properly with our friends because we have to hold it in because we've been oppressed for so long. You know, we're not supposed to break down so we want to be able to talk to our children and it's happening in small doses that women are able to open up to the children and open up to themselves... So I think it goes way back.

P: Oh, yeah, it does. I think so too. Yeah, I agree. Way back. And you know it doesn't matter how much you spell it out, you know, really, we're still suffering from that, you know, we have to get beyond that. We do.

P: Because we don't want to face reality. We don't want to talk about it.

P: A history of denial.

P: It's just way back... it goes... stems way back from when we were all young. Nobody wanted to tell you about having periods, you know. It's basically the same thing.

P: No, it is. It stems from all that. They don't want to talk about it.

P: Lack of education.

P: Lack of communication.

P: It is to a degree, yeah, lack of communication.

The African Nova Scotian participants were not the only ones with a unique perspective on the needs of their community. The sex trade workers also had insights that addressed their specific needs.

Emotional Aspects

The sex trade workers expressed the dichotomy they perceived between the men who were “tricks” and the men they were in relationships with. While they were aware that they could potentially be at risk of infection with HIV in their romantic relationships, they verbalized that this did not necessarily translate into consistent safer sex practices.

Or personal life. In fact they (sex trade workers) might not even be in a relationship with a particular person, where they go out to date by choice instead of by money. Okay, then you use condoms. You know, but that's not the case a lot of times. You know, I mean I was guilty of that my ownself. You know, I'm working, I'm making these men use condoms, then I'm going down to the Derby so I can meet a sailor and going to the hotel with him and ain't even thinking about condoms, you know, because I want real sex too. You know, it's crazy, and putting... and you didn't consider it high risk because this is a boyfriend considered... you know, I'll get AIDS with tricks but I won't get it from a boyfriend.

F: So some people are seeing their boyfriends, lovers or whatever as being like cleaner and not having to worry about it.

P: Yeah.

P: You know, tricks is business...

P: In some cases it's not always true.

P: No, but... no, people do think like that though.

P: Well, you want to.

P: That's right.

P: Because you want to believe that.

P: You know, you want to be able to live too.

Work on the streets may also provide some women with a sense of emotional fulfillment and connection. While they recognize that these feelings may be based upon an artificial sense of reality, the emotional response itself is still very real.

That's what I'm out there for. I got out there because I'm not with nobody but when I go there I just want to feel like.... I know they're lying when they say they love me and stuff, but I just feel the emotion, and I feel good after. I know people say I'm crazy but whenever I go have a trick I feel good sometimes, you know what I mean. But then I feel like, okay if I'm not going to get it here, I'm going out there and getting it. And I will get it. You know what I mean.

When I'm out there and yeah, I like that too, but I find the tricks, or johns or whatever you call them now, like they even beat you up too but you go right back out there, I find I do and that's why I find connected more... I'm more connected on the street than anything.

Another subject that was uniquely expressed by the sex trade workers was the importance of support from other sex trade workers and community workers.

Support

The sex trade workers, at various times, defined support in terms of emotional, psychological, financial, and material. In the end, however, all this support was perceived as being very important in their effort to more consistently engage in safer sex practices. The outreach services offered to the women working the streets were seen as particularly useful.

P: So I find when I'm out, I'm out every night, on Thursday nights they go over Dartmouth and they go over there and they talk to you, they give you condoms, usually juice and a bar sometimes, and I mean they give you the bad trick list, like who... you know, what I mean, got hurt and...

F: So in every way, they're trying to keep you safe.

P: Yeah, as much as they can without standing next to you kind of thing, you know.

F: So that makes a difference...

P: Oh, yeah. Big time.

P: Because I mean you could probably... you could maybe be out there and could be all messed up or something and didn't have a condom and then they're coming by with condoms.

Stepping Stone does the strolls too so they go out and meet new people. It's not just those of us who come to the Centre. They go out and you know will introduce themselves and give out bread. They don't even have to know you, just as long as you're there, you'll you know...give you condoms, needles, whatever, so it's not just for those of us that know who they are because they'll introduce themselves to you. And then it's up to you to take their help or not.

P: Okay say they don't use services like here or Stepping Stone or whatever, okay, they might not see Stepping Stone but I mean I've ran into people that doesn't have condoms right and I say here, you know, have a couple... have a couple... and all of a sudden this girl, I say have you got any condoms, no here. Right, you know, like I'll carry condoms with me too.

P: That's like me out there every night, I'm out there every night, right, and there's girls there every night, K., you got any condoms? I give them to them all the time, no matter if it's two or three or if I have to give them a couple...

P: Oh, never I'd never deny.

P: Because, yeah, that's like me. I always give them the condoms, bad trick list and here's a number, call them, they'll come meet you and everything like that. Because I see different ones all the time, but I always... I never, ever say no to them. Even if I'm down to my last two, here's one, at least I can make one trick, then I'll go home.

The women all praised Stepping Stone for the unending support they received there. Along with the multitude of services offered at this organization, the women were all very grateful for the non-judgemental and safe atmosphere. Many expressed how they felt at a loss on the days that the organization was closed.

You know, so then you're thinking of, where am I going to get the money? I've got to go back to work. I've got, you know... But one of the people that worked at Stepping Stone also worked at the shelter I was in, so she was like, don't make any drastic decisions. Come to Stepping Stone Monday morning, I won't talk. And if it wasn't for me starting to go there in October, I'd have been working again. So it's support in all kinds of ways. It's just... it's like... because they don't stop you from doing what you want to do but if you don't want to, they help. So it's never judgemental, ever.

Yeah, I go there every day and I miss it on the weekend when it's not there. I feel safe there when I go there. When I'm there I'm not out tricking or I'm not there, I'm out tricking. Because I go out every day, but I feel so comfortable there. And the people that's there... because they're there for the same reason I'm there.

But still everybody has a different background, why they started to work, maybe they were forced, maybe you just started, you have guilt, whatever, but you never really hear a whole lot of beef going on in the house.

You still are respectful while you're in the Centre, you know, and that's something else too. You couldn't walk down the street and see something happen to one of us that we've been around all the time without one of us saying something. You know, because we're all there together all the time and it's just... everybody kind of blends in no matter what.

P: But then see with Stepping Stone, only for them, I tell you I don't even know where I'd be at right now... I mean truly, if it wasn't for them people there, like... I know it's only an organization and stuff but I hooked up with them and I got connected to them. I met girls there and everything and it's like...

P: It's where you feel comfortable.

P: I just... I feel good when I'm out of there right, when they're closed the weekend, I do not like it.

The issue of support was perhaps best summed up in the words of two of the participants.

P: It's good to know that somebody cares.

P: Yeah, as long as one person cares, there is hope.

However, the women stated that the realities of their work could be quite different from that of women who work in the sex trade through escort services.

Escort Services

While many sex trade workers eagerly agreed to participate in this project, none of the participants were currently working in escort services. Yet, from the past experience that some of them had with escort services and personal contact with women they knew who currently worked there, these participants were able to offer insights into the HIV prevention needs of these women, as well as the challenges that may be present. One of these challenges would be resistance from the owners of the businesses.

P: You could always call and say, listen I want to send you something... could I get your address?

P: That's right.

P: I just want to send you a pamphlet.

P: Or poster, they can you know display it...

P: But you know what, as crazy as this is going to sound, at the same time they may not want to put posters or pamphlets though because they may think they're going to scare the johns away.

P: Yeah, that's true.

P: They're more about making money than caring if the girls they got working for them are safe.

P: Yeah, because I answer calls for an escort service, right, and I don't go telling all that. I just give a price and I'll send a lady out.

The business owners do not present the only challenge, however. The participants expressed how some of the women who work in the escort services perceived themselves to be invulnerable to HIV infection.

P: No, they think they're a little...

P: They think they're a little higher class.

P: Maybe we should send them some pamphlets.

(Laughter)

P: they think they're high because they're in a house, they live in a house, them house prostitute, bawdyhouse.

P: Yeah, and there's AIDS in there too.

P: You're right.

P: And a lot of the women that work at escort services think they're better than the girls that work on the street.

P: Yeah, and they do.

P: Right, I'm an expert, I'm not a 'ho. But do you fuck and suck for a living? Then you're a 'ho, you know what I mean.

According to the participants, some of the women employed at escort services may also be experiencing a sense of shame regarding their work.

A lot of the women at escort services they work much more closetedly. Okay, and they know that if I go to Stepping Stone, so and so may see me and then she'll know I'm working and people don't know I work.

Regardless of their place of work however, the sex trade workers felt that none of them could ignore the legal aspect of HIV as it relates to their work.

Legal Ramifications

The sex trade workers were also the only participants to address the legal issues that may arise as a result of their job. Testing for HIV can be problematic for them, as a positive result could have an impact on their perceived ability to continue working, from both a legal and an ethical perspective.

When you do go get tested, okay, which to me is a good thing, but then I've heard other people say okay, what if I get tested and I'm positive? Does my own moral responsibility fall in the fact that I should stop working because I am positive which makes me a higher risk not only to clients but to whoever else that they associate with or... you know. Even with the condoms because we do know, you know, condoms do break from time to time, you know, there's things like that. So... and also because of the legal stands of it, like are the cops going to mess with me more, oh there's that one with, you know, with AIDS. So they're going to mess with them more and they've seen that from past experiences with some of the women who are already positive.

With so many issues arising from these focus groups, it was interesting to hear what the participants currently perceived Planned Parenthood Metro Clinic's role to be within the context of HIV prevention.

Knowledge of Planned Parenthood Metro Clinic

Considering that Planned Parenthood Metro Clinic is in a unique position to provide services to the women in this study, many of them were unaware of what the clinic could offer them. Certainly, they had very little knowledge of the HIV prevention and testing services provided. When making the initial telephone contact with the single mothers and the sex trade workers, I discovered that many of these women were surprised to find out that an anonymous HIV testing program was in existence at the clinic. The facilitator with the African Nova Scotian groups expressed a similar finding. This topic was raised again during both focus groups with the sex trade workers. Many of these women said they only thought of Planned Parenthood Metro Clinic in relation to the contraceptive and pregnancy options provided.

When I think of Planned Parenthood I think of, okay, I can go out... if I ever got pregnant, which I'm 50 so that ain't happening, but you know that I could go there and feel comfortable that I have pro choice as opposed to pro life people. Right. That's what I think. I think Planned Parenthood, I think pregnancy.

To be honest, if I were out working and you came by, Hi, you know, I'm Anita from Planned Parenthood... hey honey, I can't have no more babies.

I hear, you know like I think that if you went out and said what's the first thing that comes in your mind when I say Planned Parenthood, most people would say either babies or abortion. Simple. So if it's going to be going into or being more involved in the sexual health, maybe they should look at making that a more prominently known type of thing.

The themes that emerged from these focus groups arose as they were verbalized as being significant to the women in this study and provide an insight into the daily lives of these participants. In the next section, a summary of the findings and recommendations for future HIV prevention education possibilities and testing strategies will be examined.

Summary and Recommendations

As this research progressed, it became clear that there existed a gap in the understanding of women's experiences with HIV prevention. To help bridge this gap, this report concludes with a summary of the research findings and recommendations for the health professionals, community agencies, and governmental departments who work with women.

Summary

External forces impact upon the ability of women to protect themselves against HIV.

Even when women wish to protect themselves against HIV, their efforts may be limited due to outside pressures placed upon them. These pressures may appear in the form of financial pressures, power imbalances within relationships, geographically inaccessible HIV prevention services, and a perceived lack of "visibility" of women with whom they can relate in existing HIV prevention messages. Specifically, here are the issues as they arose within each group of women.

Female sex trade workers:

- Male clients may offer sex trade workers more money if they perform sexual acts without condoms;
- Male clients may threaten violence if the sex trade workers insist upon condom use;
- Male partners in the home may become violent if the women do not take home an adequate amount of cash following a day's work, therefore making the women more likely to not insist upon condom use with their clients;
- Male partners in the home may discourage condom use in their relationship to differentiate their "romantic" relationship from a "working" relationship;
- Addictions may make women less likely to use condoms or to absorb safer sex messages;
- Mental health issues may make women less likely to use condoms or absorb safer sex messages;
- Negative reactions by health care professionals may discourage sex trade workers from seeking out HIV prevention services and education, such as HIV testing;
- A perceived lack of heterosexual models in HIV prevention messages may make these messages less relevant for sex trade workers.

African Nova Scotian women:

- The women may not feel comfortable addressing the issue of unfaithfulness within their relationship;
- The women indicated that they would be even less likely to address the possibility of their partner being involved in same-sex sexual acts outside of their relationship;
- The negotiation of condom use becomes more difficult the longer the women are in a relationship;
- The church can have a powerful influence upon the ability of women to talk about risky sexual behaviours and safer sex issues;
- African Nova Scotian women in outlying communities may find it difficult to access sexual health services and HIV testing;
- A perceived lack of African Nova Scotian models in HIV prevention messages may make these messages less relevant for African Nova Scotian women.

Lower income single mothers:

- Schools and teachers are sometimes not prepared or willing to address safer sex issues in the classroom, making young women especially vulnerable to putting themselves at risk for HIV;
- Negotiation of safer sex practices may be difficult in a relationship, as the men may then accuse the women of infidelity;
- Single mothers may not feel comfortable addressing suspicions of infidelity within their relationship;
- Issues such as child care restrictions and a lack of transportation may make it difficult to access sexual health services and HIV testing.

Women's perceptions of their risk for HIV infection may not match the reality of their risk for HIV infection.

As indicated in the information gathered from the focus groups, women may have misconceptions surrounding their risk for acquiring HIV. Some women believed that women were less likely to get HIV than men, specifically gay men; others believed that they were not vulnerable to HIV if they were currently in a relationship; yet others thought that they could tell by looking at someone whether or not that person was infected. A few women also overestimated their risk for HIV by thinking that they could contract HIV from casual contact. The following is a summary of the perceptions of the women from each of the three groups.

Female sex trade workers:

- Some women may believe that they are less likely to contract HIV from the men in their romantic relationships than from the men in their working relationships;
- HIV is still sometimes seen as a disease of middle-aged gay men;
- Women who work in escort services may perceive their risk for HIV as being lower than that of women who work on the streets;
- Some uncertainty still surrounds which fluids may transmit HIV;
- There exists some confusion as to the difference between the time to seroconversion and the time to the development of symptoms.
- There exists some confusion as to the difference between the time from infection to seroconversion.

African Nova Scotian women:

- HIV is still often not seen as a disease that affects women;
- HIV is frequently seen as a disease that afflicts only gay men;
- Married women may believe that they do not have to be concerned about protecting themselves against HIV;
- There is sometimes a lack of recognition of HIV in the African Nova Scotian community;
- Youth in the community feel invulnerable to HIV and do not recognize some sexual activities (such as oral sex) as potentially putting themselves at risk for sexually transmitted infections;
- Some women may not believe that the men in their community would engage in same-sex sexual activities;
- There is a not uncommon belief that HIV can be transmitted through casual contact.

Lower income single mothers:

- There is still a perception that HIV is a disease of gay men;
- Some women may not believe that they may be at risk for HIV in their romantic relationships;
- There is a not uncommon belief that HIV can be transmitted through casual contact;
- Some uncertainty still surrounds which fluids may transmit HIV;
- Youth in the community feel invulnerable to HIV;
- Some women believe that publicly revealing the names of individuals with HIV would help stem the spread of the disease;
- There also exists a belief that mandatory testing for HIV would slow the spread of HIV.

The emotional context that surrounds HIV may affect women's decisions to seek out HIV prevention services or to engage in safer sex practices.

The decision to seek out HIV prevention services is not a simple or straightforward one. The women in these focus groups indicated that they had to consider many possible negative emotional outcomes, such as a loss of status or the damage to their reputation within their community. At other times, the emotional effect may be more internal and personal, such as the fear associated with not knowing and possibly not wanting to know one's HIV status, or the need to feel an emotional attachment to a sexual partner. However, the perception of having satisfactory emotional support from individuals or agencies may also encourage women to access HIV prevention services. The details of these emotional experiences for each group of women follow.

Female sex trade workers:

- Some women use denial of their risk for HIV infection as a coping mechanism;
- For some women in the sex trade, a diminished self-esteem may lead to substance use and risky sexual activities;
- Some youth may turn to the sex trade in an attempt to receive acceptance and affection;
- Fear of their partner at home may lead women to engage in risky sexual practices both at home and in their job;
- The need for an emotional connection may lead women to engage in risky sexual practices both at home and in their job;
- The embarrassment of talking about condoms can be a barrier to condom negotiation for some sex trade workers;
- The shame that some sex trade workers may feel regarding their job may prevent them from seeking out supportive services;
- The fear of knowing their serostatus may lead some women to avoid getting tested for HIV;
- The judgemental reactions from health care providers may discourage some sex trade workers from receiving sexual health services;
- When provided with a respectful environment, sex trade workers are more likely to access sexual health services;
- The emotional support provided by other sex trade workers encourages individual sex trade workers to protect their health;
- The range of support services provided by community organizations, especially Stepping Stone, helps give sex trade workers the incentive to protect themselves.

African Nova Scotian women:

- The fear of being rejected by their partner may make women reluctant to insist upon safer sex practices;
- The embarrassment of talking about condoms can be a barrier to condom negotiation;
- The embarrassment created by church teachings around sexuality may make it difficult for women to discuss sexual issues;
- Some women fear that if they were diagnosed as having HIV, they would be shunned by their community;
- The fear of being the target of gossip may prevent women from seeking HIV testing and other prevention services;
- The fear of knowing their serostatus may lead some women to avoid getting tested for HIV;
- Some women feel that racism has led to their safer sex needs being neglected by the scientific community and the government;
- A history of oppression has sometimes led to the inability of African Nova Scotian women to discuss their needs.

Lower income single mothers:

- The fear of being rejected by their partner may make women reluctant to insist upon safer sex practices;
- Misguided trust in their partner may lead some women to believe that they do not have to protect themselves against HIV;
- Some women fear that if they were diagnosed as having HIV, they would be shunned by their community.

When developing HIV prevention education programs and services, health professionals and community agencies must look beyond the simple mechanics of “safer sex” and include content that addresses the contextual issues of women’s lives.

Clearly, many issues must be taken into consideration when planning HIV prevention services to meet the needs of these diverse communities of women. These issues can be categorized using the determinants of health framework as a guide.

Income and social status:

“Health status improves at each step up the income and social hierarchy... higher income and status generally results in more control and discretion” (Health Canada, 2002a, p. 1). Given that the ability of the sex trade workers to bring in an adequate income may be inversely related to their ability to protect themselves against sexually transmitted infections, and that the single mothers repeatedly stated that a lower income limited their choice of health care services,

it is no wonder that these women indicated that their income and social status has an influence on their health. Compounded with the negative connotation that society can place upon working in the sex trade or receiving social assistance, this determinant is a significant one.

This determinant was brought up many times as an important issue for both the lower income single mothers and the sex trade workers. For the single mothers, who sometimes do not have access to a vehicle, the cost of a bus or a cab to access services may be prohibitive. If agencies providing HIV prevention services cannot be located in or near lower income areas, staff should consider outreach services. For the sex trade workers, putting safer sex practices into use in their work may actually negatively impact upon their ability to make money. These women must be given the safer sex information needed for them to make informed decisions, but in the end health care providers must realize that they should not be judgmental should the sex trade workers choose sexual activities that are less safe. For all three groups of women, there was also a fear that if they insisted upon safer sex practices in their relationships at home, the men may choose to leave them, thereby affecting the income of the family. Again, the health care providers should be empathetic and informative, and also be prepared to refer the women to organizations in the community that offer support and/or emergency services. It is also helpful to provide free condoms whenever possible.

Social support networks:

“The caring and respect that occurs in social relationships, and the resulting sense of satisfaction and well-being, seem to act as a buffer against health problems” (Health Canada, 2002a, p. 1). When considering the HIV prevention needs of women, health care providers can include aspects of these social relationships into their program planning.

The importance of social support networks was observed during the focus groups themselves, as the women all appeared to enjoy discussing their experiences with other women and drew strength from one another. This would indicate that informal groups can be a well-received and efficient method to disseminate HIV prevention education to women. The sex trade workers also emphasized the importance of social support in their lives. Specifically, they discussed the positive influence that other sex trade workers had in their efforts to protect themselves against sexually transmitted infections. They also indicated that Stepping Stone, as the only organization in the city whose mandate is to provide services for sex trade workers, provides them with the kind of support that they need in their efforts to stay safer. This not only demonstrates a need for Stepping Stone to continue to receive support and funding, but also for other organizations to form a strong partnership with this agency to facilitate the provision of HIV prevention education and services to sex trade workers.

Employment/working conditions:

“People who have more control over their work circumstances and fewer stress related demands of the job are healthier and often live longer than those in more stressful or riskier work and activities” (Health Canada, 2002a, p. 1). The sex trade workers made it clear that each time they go to work, they have multiple stressors to contend with. Giving these women the tools they need to help in their decision making process on the job can go a long way in keeping them protected from sexually transmitted infections such as HIV.

This determinant is especially significant as it relates to the sex trade workers. When designing HIV prevention education programs and services, the challenges sex trade workers face due to their occupation must be considered. Rather than focusing on stringent safer sex rules, health care providers must offer harm reduction measures. Sex trade workers can be offered the opportunity to discuss methods of negotiating safer sex. Health care providers must be willing to have frank and explicit discussions regarding sexual health practices and testing for sexually transmitted infections, and should have knowledge of other community agencies that could provide support to sex trade workers such as Stepping Stone. Health care providers must also realize that violence, both sexual and physical, cannot be written off as just an “occupational hazard”, and must be dealt with in a sensitive and thorough manner.

Social environments:

“...social stability, recognition of diversity, safety, good working relationships, and cohesive communities provide a supportive society that reduces or avoids many potential risks to good health” (Health Canada, 2002a, p. 1). This determinant implies that while women may be given the best HIV prevention education possible, their ability to put this information into practice is influenced by the structure of not only their community, but also societal conditions as a whole.

When considering this determinant, we must all remember that affecting someone’s health may not just mean working with the individual herself, but also working to affect changes in society. While Planned Parenthood Metro Clinic has a long history of working to improve conditions within which individuals may put into place healthy sexual practices, we have not worked in isolation. It is essential to form strong community partnerships with agencies with various strengths. The same principles would apply in this situation; while we at Planned Parenthood Metro Clinic may not have the expertise to speak to issues related to, for example, inadequate funding for women obtaining social services, we can offer our input regarding how limited income may affect sexual health. It is also important to remember that any input used to formulate a strategy necessarily must be based upon the perceived needs of the women affected, and must include their feedback and involvement in the entire process. Therefore, community and governmental agencies must maintain and develop partnerships

to ensure that the needs of those who may not otherwise have a voice are being heard.

Personal health practices and coping skills:

“Definitions of lifestyle include not only individual choices, but also the influence of social, economic, and environmental factors on the decisions people make about their health” (Health Canada, 2002a, p. 1). It is very important for individuals who design HIV prevention education programs to remember that, embedded within the decisions that women make regarding their HIV prevention practices, are the expectations and pressures imposed upon them by society.

As discussed with earlier determinants, societal pressures may influence a woman’s ability or motivation to put into practice HIV prevention methods. While women may be presented with the best, most current HIV prevention education, it may not always be a priority in their lives. It may conflict with their ability to provide for their children. It may conflict with their desire to maintain a relationship. It may also conflict with what they have been led to believe is behaviour and treatment they must accept from their intimate relationships as well as their relationships with their health care providers. Individuals involved in HIV prevention must take into account women’s past experiences and realize that simply because a program is well designed, it may not have immediate effect upon a woman’s practices.

Health services:

“Health services, particularly those designed to maintain and promote health, to prevent disease, and to restore health and function contribute to population health” (Health Canada, 2002a, p. 1). Therefore, understanding the importance of quality and representative health services becomes crucial when providing HIV prevention education to women.

Health professionals must consider the ability of women to access the services being provided. First, on a geographical level, the services can be located in an area that the women can reach easily, preferably on foot, or alternatively on a major bus route. Not all women have access to vehicles, and the cost of taxis can be prohibitive. As many women are the primary caregivers for children, the health services could also be offered at a site that is child-friendly. Again, as the cost of childcare can be prohibitive, women must feel as though their children are welcome. The services should also be provided by individuals who are non-judgmental and unbiased. While considering the qualities of the service providers and the information in these offices, it would also be worthwhile to make an attempt to reflect the diversity of the clients. Efforts can be made to hire qualified individuals who understand the issues of the clients, and, specifically in the case of African Nova Scotian clients, who preferably are from the community.

Posters and pamphlets in the office should include information that is relevant to the clients and models that reflect the diversity of the client community.

Culture:

“Some persons or groups may face additional health risks due to a socio-economic environment, which is largely determined by dominant cultural values that contribute to the perpetuation of conditions such as marginalization...” (Health Canada, 2002a, p. 1). While culture was clearly an issue with the African Nova Scotian women, culture is not limited to ethnicity. The sex trade workers and single mothers had a unique culture themselves, which emerged during the focus groups.

The term “culture” in its broadest sense seemed to have an impact on all the women who participated in this project, but perhaps most affected were the African Nova Scotian women. This observation is not only based upon race and their position as a visible minority, but also upon the information that the women shared about their community regarding the effects that the church, attitudes towards sexuality, and lack of anonymity have upon their ability to seek out HIV prevention services. However, when reading the information from the focus groups, the impact of external forces remains especially significant; many women believe that services and information are being withheld from their community based upon stereotypical racial views. Yet, these stereotypical influences are not exclusive to the African Nova Scotian women; the sex trade workers and single mothers also have suffered at times due to a lack of understanding of their culture. When designing and implementing HIV prevention services, agencies should consider how their values might be seen as the values of the dominant culture. If programs are being developed for specific groups of women, their input can be sought to ensure that the programs are meaningful and address the realities of the women in the target audience. Service providers must realize that some women may have faced marginalization in their previous encounters, which may make them hesitant to access services if there is any perception of oppressive programming.

Gender:

“Gendered norms influence the health system's practices and priorities. Many health issues are a function of gender-based social status or roles” (Health Canada, 2002a, p. 1). Gender was a thread that ran through the discourses of all the women who participated in this project. On a daily basis, societally imposed definitions of “who” these women are and “what” their roles should be influenced the decisions these women made.

This determinant of health embraces all that has been said earlier in each of the other determinants. The impact that income, status, employment, support, culture, health services, coping skills, and social environment have in the lives of

these participants is magnified due to a patriarchal construction of gender. As the proportion of women diagnosed yearly with HIV continues to increase, this reality must be reflected in current HIV prevention education programming and services. That means that there is no “cookie cutter” solution to this issue; programs designed for a specific group may not necessarily be transferable to another group. This presents a challenge for service providers; however, it is a challenge that must be met if HIV prevention education and services are to be meaningful to women.

Recommendations

As this research project progressed, it became clear that each of these three groups of women had unique needs in terms of HIV prevention. Strategies that would be appropriate and accepted for one group may not necessarily work for another group. As discussed earlier, Planned Parenthood Metro Clinic currently takes the needs of certain diverse groups of clientele into consideration when planning the direction of the anonymous HIV testing program through outreach testing services, but the program presently has no services directed specifically at women. The information gathered from the focus groups will, however, have a direct impact upon programming in the near future. This section discusses in further depth how Planned Parenthood Metro Clinic can address this issue and also how other organizations and agencies may play a role.

Recommendation #1: That Planned Parenthood promote the scope of its services and its mandate more actively in the community.

As outlined in the description of the program at the beginning of this report, Planned Parenthood is in a unique position to provide HIV prevention and testing services to women due to our long history of providing sexual and reproductive health services to women in the Halifax region. We also have a reputation for providing non-judgemental, unbiased, and client-focused care to all our client population.

The women were generally quite aware of the contraceptive and pregnancy options services provided at the clinic. Unfortunately, however, many of the women who participated in the focus groups were unaware of the anonymous HIV testing program. This is a lost opportunity in terms of reaching women who are at risk for HIV infection. While Planned Parenthood Metro Clinic is not in a financial position to develop numerous promotional materials, past experience has proven word of mouth and a reputation for the provision of quality care to be a powerful method of promoting our services. Most of the youth who access our services found out about us through friends or schools. Therefore, reaching out to women and the agencies that are currently providing them with services would be an efficient way of informing them of our services. These methods will be incorporated into the recommendations that follow.

Recommendation #2: That Planned Parenthood Metro Clinic begin offering anonymous HIV testing and related services at Stepping Stone, an agency that supports individuals actively or formerly involved in the sex trade.

Based upon the comments of the sex trade workers who indicated that they have established a high level of comfort at Stepping Stone, I have already begun discussions with Stepping Stone to initiate the process of making their organization an outreach site. I will be able to provide anonymous HIV testing, non-nominal hepatitis B, C, and syphilis testing, hepatitis A and B vaccinations, and/or group educational sessions on a biweekly basis. My presence at Stepping Stone will also allow me to promote some of Planned Parenthood's other sexual and reproductive health services, thereby assisting in meeting the needs in the first recommendation. As outreach testing has been a part of the anonymous HIV testing program since its inception and I already have a partnership established with this agency as a result of this project, this will be easily accomplished.

The sex trade workers who participated in the focus groups were very open and honest in their belief that my presence would be well accepted at Stepping Stone, and they all stated that they would be glad to share their positive experience in the project with other sex trade workers. I have also developed a good working relationship with several staff at Stepping Stone. The one drawback is that as we currently only have funding for one staff at the anonymous HIV program, there is a risk of spreading myself too thin and having less time to spend with clients at Planned Parenthood Metro Clinic.

Recommendation #3: That Planned Parenthood Metro Clinic begin offering anonymous HIV testing and related services at a centre which serves single mothers, such as Bayer's Westwood Family Resource Centre.

The single mothers in this project expressed an interest in accessing the services of Planned Parenthood Metro Clinic and the anonymous HIV testing program. However, due to limitations related to childcare and transportation, they emphasized a need for these services to be in a more convenient location. I have spoken with the director of the Bayer's Westwood Family Resource Centre and discussed the feasibility of providing outreach testing at this agency. However, I would not limit my sessions to testing. During the focus groups, the single mothers expressed an enjoyment of the group dynamics that occurred. They found that the sharing of information and experiences was a meaningful process for them. Therefore, I intend to include group educational sessions prior to the provision of testing. This will allow me to dispel some of the predominant myths that the women held while providing them with the support of other women. The women will be able to discuss their concerns surrounding HIV prevention, such as relationships with men, misconceptions related to HIV, and condom negotiation skills. This would allow the women to address some of the

issues that were brought up in the research and summarized in the literature review by framing HIV prevention within the context of empowered decision making as opposed to solely focusing on reliance upon men agreeing to use condoms. It would also provide me with the opportunity to inform the women of the services available at Planned Parenthood Metro Clinic.

Recommendation #4: That Planned Parenthood Metro Clinic consider methods to make HIV testing and related services more accessible to members of the African Nova Scotian community.

This recommendation will present special challenges. While I have the ability and the inclination to provide HIV prevention education and anonymous testing in a region such as North/East Preston, the question that cannot be ignored is whether or not my presence would be welcome. The women in the African Nova Scotian focus groups were astoundingly clear: they believed that HIV prevention services should be provided by someone from their community. Upon completion of this report, I intend to present the findings of this research to the members of the African Nova Scotian community; the facilitator of the African Nova Scotian focus groups has agreed to assist me in finding a location in which I can make this presentation and also to be present with me to assist in answering questions which may arise. Her presence will be extremely important as it will provide me with a way “in” to this community; considering the focus groups’ statements on the importance of having this information presented by a member of their own community, I may not be successful in reaching this community otherwise. While the sharing of the research findings with the community will be important, this meeting will serve a dual purpose: I will also encourage questions and comments from the audience and incorporate this information into the decision-making process. The possibility exists that, after being introduced into the community by a well-respected individual and sharing the results of the research, perhaps I may be seen as a credible provider of needed health services. If not, any outreach services in the North/East Preston area may have to be put on hold until the clinic receives more funding to train an individual from the community.

Another theme that was made clear was that any outreach services should not only be HIV related. The women in the focus groups indicated that, due to the easy spread of information in their community, many individuals would not go to a mobile clinic that only provided HIV testing and education. Again, this would provide the opportunity to promote Planned Parenthood Metro Clinic’s other services by including information on such reproductive and sexual health issues as Pap smears, testing for other sexually transmitted infections, and birth control. It may also be possible to provide supplies such as emergency contraception. Again, this will all hinge upon the feedback I receive regarding who should be providing services in these communities.

Recommendation #5: That Nova Scotia's Department of Health provide an increase in funding for the anonymous HIV testing program, based upon the increase in workload necessary to meet the previous recommendations.

As the first four recommendations indicate, there exists a great opportunity for Planned Parenthood Metro Clinic to further share its expertise and services within these communities. However, we presently do not have sufficient staffing to provide all these extra services while still maintaining the current level of service provided to our clients. We also do not have the funding to professionally promote our services in the community. Past client evaluation forms have indicated that word of mouth is by far the most frequently cited form of promotion of all of Planned Parenthood Metro Clinic's services, but this method may exclude members of the communities we are currently trying to reach; if we are not already reaching African Nova Scotian women, female sex trade workers, and lower income single mothers, how can word of mouth reach them?

Earlier in this report, Planned Parenthood Metro Clinic was described as a clinic that, due to its long history of providing quality sexual and reproductive health services to women in the community, was well positioned to offer HIV prevention services to the communities of women involved in the focus groups. The clinic also has the ability to offer these services in a very cost-efficient manner. As discovered by Heath and Pyra (2003) following an evaluation of the anonymous HIV testing program, a comparison of the cost of anonymous HIV testing through Planned Parenthood Metro Clinic with that of a similar service through a family physician reveals that the service at the clinic is less costly (e.g. \$30.80 for one hour and fifteen minutes of the Counselor's time versus \$130.20 for an hour and fifteen minutes of physician counseling). Given the time pressures faced by primary care physicians, it is highly unlikely that physicians would engage in an hour pre-test counseling session and fifteen minute post-testing counseling session as is done through the anonymous testing program. Comparing the HIV Counselor's fee to two fifteen minute counseling sessions with a physician (pre and post counseling) reveals that the anonymous testing program service is still cheaper (\$30.80 versus \$52.08), and the client would receive a more comprehensive service through the anonymous testing program in this case.

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