Listen Up!
Women Are Talking About….

Women's Health Research Project
Phase 2 Report

The social determinants of women's risk for HIV infection and illness progression in Lower Mainland British Columbia

Examining Community Based Strategies and Solutions
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Summary

All too often when women get sick we get blamed for it as though we did something wrong (or failed to do something right) by becoming ill. One of the hopes of the *Listen Up!* project is to stop blaming individual women and examine instead the social determinants of health – in particular how these put women at greater risk for HIV infection and the progression of the illness. In the process of doing so, we hoped to shift the focus of research on women and HIV/AIDS away from, what we saw to be, an increasing emphasis on the voices, ideas, and experiences of various professionalized "experts", to those of women in communities themselves.

We built on the findings of Phase 1 of the project, which explored, with women, the social factors they saw as affecting their risk for HIV infection and illness progression. In this second phase, we worked with a community-based *peer* research model to discover what women wanted to see done to reduce or eliminate some of the barriers identified in the previous phase.

The women who worked with us as peer researchers were recruited from the communities we had originally worked with in Phase 1. After a two-week training course in community-based research methods completed in November of 1999, a group of nine women completed a series of 44 interviews and six focus groups in the following communities:
- Women living with HIV
- Care-givers, family, and friends of HIV+ persons, alive and deceased
- Professional women
- Aboriginal women
- Women with dual diagnoses
- Women living in or frequenting Vancouver's Downtown Eastside (DTES)
- Current and former substance users
- Young women living in Langley, BC, a small rural community just outside of Vancouver

The peer researchers and project coordinator worked for five months to group, collate and analyze our findings. We broke this analysis into six sections, according to the questions that had formed the bulk of our initial interview guide.

Other Barriers Identified
As suggested by feminist research principles (Nielsen, 1990), we wanted to check back with women in the Phase 1 communities about the accuracy and completeness of our initial analysis of the social determinants of health. As we did so, women mentioned two factors that they felt were missed in the first phase analysis:
- discrimination against young women; and
- issues around childhood sexual, physical, and emotional abuse.

They also identified four issues which they felt deserved greater prominence or development in the initial analysis including:
- issues for women parenting children living with HIV
- issues for women working in the sex trade
- women's safety in public spaces and

- discrimination against women with mental illnesses.

Past Solutions
In discussing the social factors that determine health, we asked women how they had overcome or changed barriers in the past. In doing so we hoped to celebrate with them their past successes, as well as share success stories and instances of creating change with others. What we found was that women often mentioned connecting with other women, community organizations, or agencies of like-minded or similarly identified people, who offered services such as support groups, medical care, the basic necessities of life, and the opportunity to reach out to others, as having helped them overcome barriers. However, many times women had found that the only way out of a situation was to walk away from it. In this vein they mentioned changing jobs, changing doctors, and leaving an abusive partner as remedies to past problems.

Help Still Needed
A question asking women about barriers they were currently facing or help they still needed to overcome long-standing barriers was added to the initial interview guide by the peer researchers. In talking to women about solutions and strategies for change they wanted to see implemented, it was deemed important to also ask what situations were particularly in need of solutions.

The issues women most commonly identified were experiences of poverty, such as being unable to afford adequate food, housing, transportation, health care and money to live on. They also identified needing help to:
- find a knowledgeable, compassionate doctor
- eliminate experiences of discrimination due to race, gender, class, and HIV status
- leave an abusive relationship; and
- negotiate imbalances of power within intimate, romantic relationships.

Necessary Social Changes
When women were asked what they thought would need to change in society so that they, or others, would not experience the same kind of situations again, women focused on two basic changes
- increased awareness through educational efforts and
- increased communication across various locations of "difference".

Women wanted to direct educational efforts to those in various positions of authority and the general public regarding:
- the realities of living in poverty
- the nature of "abusive" relationships
- the effects of discrimination of various kinds
- the reality of living with HIV/AIDS;
- gaps in the social service system; and
- the uses and potential benefits of alternative and complementary therapies.

Women wanted better communication between
- doctors and patients,
- health care providers of various modalities,

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- those in authority (such as government officials) and
- those who are effected by the decisions of authority figures (such as recipients of income assistance).

Finally, they called for a re-distribution of resources to increase availability to people living outside of the City of Vancouver and to projects and research (such as the development of microbicides) done in women's interest.

Strategies to Make Changes
Women suggested a myriad of differing strategies to create the many layers of change they saw as necessary to address the social determinants of their health. Just a few of these include:
- developing a series of HIV/AIDS Resource Centres for women in rural and suburban locales across the province
- lobbying for increases in income assistance rates
- developing a 1-800 line for health care providers working in different modalities to access information about treatments their patients may be receiving
- actively seeking out more opportunities for people living with HIV to speak in schools
- teaching life skills courses in schools, which would include information on healthy relationships
- encouraging car-pooling; and
- lobbying to increase respite care and support to people *affected*, but not living with HIV.

Priorities
In the next phase of the project we will be moving to implement action and community mobilization around some of the strategies and solutions for change that women suggested. In order to help us focus our energies on the things that women saw as most important, we asked our participants to identify what they saw as the three most important issues to create action around. While the diversity of the priorities women mentioned was very wide, the three most commonly identified ones were: increasing income assistance rates; increasing funding for and access to complementary and alternative therapies; and increasing the amount of clean, safe, and accessible subsidized housing.

We are now looking forward to moving on to Phase 3 of the project. In this phase we will be focusing on disseminating the results of our research and mobilizing communities to create meaningful change in a respectful and sustainable manner. We also hope to craft a Women and HIV/AIDS Action Plan that can be used to guide and coordinate the provision and development of HIV/AIDS related services available to women in the Lower Mainland.

Introduction and Background to the Project

This document reports on our experiences of being involved in the second phase of the community-based research project *Listen Up!: Women are talking about…the social determinants of women's risk for HIV infection and illness progression.* It also reports on the results of our research and lays out the directions and recommendations we have developed for future action.

The *Listen Up!* project was originally conceived by AIDS Vancouver and the Positive Women's Network with the goal of:

> Developing the local knowledge of health agencies and interested women, about how the social determinants of health affect women's risk for HIV infection and the more rapid progression of the illness to AIDS.

Initially, the project was mandated to look at three specific health determinants:
- poverty
- power in intimate relationships and
- relationships to health care providers.

However, due to feedback and responses from women participating in the first stage of the project, this list was lengthened to include
experiences of discrimination from other social institutions, and
problems with AIDS services and service organizations.

The guiding principles of the project were as follows:
Health is defined in a holistic fashion that takes into account social factors, such as gender, race, and class, and the effects they have.
The experiences and ideas of the women who participate in the project inform and determine both its shape and the use of its results.
To be community-driven through the use of a community-based, action-oriented research method.

The need for the project was first identified when a literature review, done for the project (Kong, 1998), found no published Canadian research that looked at the impact of women's social, economic and political realities on HIV infection and illness progression.

The effects of social factors -- such as women's economic inequality, poverty (including access to quality food, housing, etc.), and experiences of violence -- on women's health *generally* have all been well documented in the literature (e.g. Doyal, 1995; Duvall and Booth, 1978; Gabe and Williams, 1987; Nechas and Foley, 1994; Payne, 1991). Additionally, the effects of power in intimate relationships, violence, sexism, poverty/classism, racism, homophobia, and ableism on women's ability to protect themselves from HIV infection and illness progression have all been discussed internationally (e.g. Christensen, 1990; Morrill and Ickovics, 1996; Sobo, 1998; Weiss and Gupta, 1998).

However, the way in which these social factors effect health is different in every place and time because the way in which they play out – what they look like, the implications that they have, how they concretely effect relationships between people – is different. Therefore, it was determined that a local research project, to help AIDS service organizations and other women's equality and health advocacy groups to better understand and respond to the ways in which social factors effect women's vulnerability to HIV infection and illness progression in Canada (and particularly in BC) was needed and the project was born.

Phase 2a of the project took place from May – October of 1999 when a series of 6 focus groups was conducted to examine the question of what socially determined barriers women perceived and experienced as affecting their own risk for HIV infection and illness progression. The six communities of women we worked with at this time included those who: were living with HIV or care-givers to HIV+ people; had sex with women; were diagnosed with a debilitating mental illness; were Aboriginal; were current or former substance users; were Spanish-speaking refugees and immigrants. Results from this first phase are discussed in detail in the report *Listen Up!: Women are talking about…* Phase 1, which is available through both sponsoring organizations.

However, while identifying barriers to health is an important first step to health promotion, it is not, in and of itself, enough. As many of the women who participated in the project said,

"We know what the problems are. Can we move on to working on the solutions, please!!!"

No one knows better what the best solutions to particular problems are than those who are experiencing the problem themselves. In Phase 2b of the *Listen Up!* project we returned to communities to continue our discussions with women. This time we focused on what changes women felt would help reduce or eliminate the barriers that had been identified in Phase 1.

This second round of community discussion also provided us with a valuable opportunity to check back with women about the thoroughness of the analysis of the findings from the previous phase and to identify additional barriers and determinants.

The main goal of Phase 2b was to develop local knowledge, of health agencies and interested women, about women's preferred strategies and solutions to reduce or eliminate the socially determined barriers to their best sexual health, as identified in the previous phase.

How the Research was Conducted

by Gina Kjar

This phase of the Listen Up! Project was funded by the Vancouver Foundation. An advisory committee was set up consisting of members of AIDS Vancouver, Positive Women's Network, Drug and Alcohol Meeting Support for Women (DAMS) and BC Children and Women's Hospital. The coordinator was a woman experienced in feminist health research issues.

Twelve peer researchers enrolled in the training and nine completed it. These women were chosen through an interview process by the project coordinator and the trainer, based on the criteria that they be members of the communities the project was focusing on. They also demonstrated a genuine interest in the goals of the project and basic literacy skills.

Peer researchers held forty-four one-on-one interviews in various locations with women from different communities in the Lower Mainland, and included women who:
- are living with HIV
- are care-givers of people living with HIV, both paid and unpaid
- are current and former substance users
- are Aboriginal
- have a dual diagnosis
- are living in or frequenting the Downtown Eastside
- are living in Langley
- identify as professional women

Also, six focus groups were held at the following locations:
- Positive Outlook (a drop-in at Vancouver Native Health Society for HIV + people)
- British Columbia Persons with AIDS Society
- DAMS (Drug and Alcohol Meeting Support for Women)
- Downtown Eastside Women's Centre
- with a group of professional women from Vancouver
- with a group of young women living in Langley.

The interviews and focus groups have provided the Listen Up! Project with strategies women feel would affect changes in their communities, making them healthier places to be. The results of the project will be made public partly through the release of this document, which was complied and written by members of the peer research team and the project coordinator.

The findings were discussed by the peer researchers and project coordinator as a group. Each woman then chose a section to write up, then bring back to the group for more discussion and final approval. We would like to acknowledge the work that everyone contributed to this process. We also wish to express the gratitude of those who were unable to do the actual writing – for various reasons, including the effects of living with HIV – to those women who took on this extra task.

Findings: Additional Issues Identified

(written by Stephanie Kellington)

One of the purposes of the second phase of the project was to take the analysis of the results from Phase 1 back to the women in the communities we had originally worked with. We wanted to check in with them about how thorough and true to their experience they felt the analysis to be. This step has been identified as a key aspect of good feminist research (Nielsen, 1990). Although we were not always able to work with the same women as we had in Phase 1, speaking to other women in the same communities provided a valuable opportunity to collect additional perspectives and insights that might have been missed or neglected in the initial phase of the research.

Women in this round of focus groups overwhelmingly endorsed the analysis of the findings of the first phase as presented to them. They did however, feel a number of issues weren't addressed, or were not clearly enough separated out from others in the analysis of findings of the first phase.

Discrimination Against Young Women

One of the issues women identified as missing was discrimination against people because they are young. Young women discussed experiencing problems such as:

not having their medical concerns taken seriously by health care providers

not feeling empowered and unable to talk about experiences of childhood sexual and/or physical abuse with those in positions of authority

being treated with suspicion, rather than respect, by those older than themselves

the feeling that because they are young it is sometimes assumed they have no serious problems, or that life is automatically care-free and good.

Two women explain:

> Even now [my doctor] doesn't treat me like an adult.
>
> [I]t makes me feel bad because I know I haven't done anything to deserve it...that whole attitude of being watched because you are young.

Women also called for the addition of a sub-category to the information on power in intimate relationships.

- One place where power is often abused is between parents/older relatives and their female (and male) children.

Participants in the group of women living with HIV were particularly adamant about the effect that these past experiences of abuse had had in shaping their consequent experiences, as well as who they are currently.

I think that at least for me a lot of it has to do with how you grew up, so if you grew up being poor, if you grew up in a single parent family and say there was abuse in the family and stuff,

you grow up and you don't know that there was anything else, you don't know…and you're not sure and you end up having problems when you're older, like say maybe you turn to drugs or you're not [inaud] [T]hat's where a lot of the problems start, not just having your family broken apart but problems within your family like abusive parents or sexual abuse.

Other issues were touched on in the first phase report but participants wanted more information on, or more weight accorded to these:
- issues and concerns of women who are parenting HIV+ children
- issues and concerns for women who are working in the sex trade
- violence against women that does not take place within the confines of intimate relationships, i.e. violence on the street or in other public spaces such as on transit, or in service organization waiting rooms and
- discrimination against women who have serious mental illnesses.

In discussing their experiences of discrimination two women who experience serious mental health concerns made the following comments:

> Other individuals are able to maintain a certain lifestyle because of medication they take, but once they're off [the medication] they're totally different people [and] have been harassed by the police. Or people say 'ah, you're crazy, get away from me'.
> I have a dual diagnosis…but I don't like to tell people because you start getting the 'Oh, she's a nut job. Oh, she's a nut case'.

First, we presented the outline of our initial analysis of the nature of the socially determined factors that increase women's risk for HIV infection and illness progression to participants and asked for their feedback on it. We moved on to talk more in depth about the social determinants that participants saw as most important to focus on finding resolutions to, and how they would ideally like to see these resolutions come about.

Findings: Past Solutions
(written by Monique Desroches)

Unfortunately it was difficult to keep the women we talked with focused on talking about solutions and strategies that had worked for them in the past, instead they tended to wander off to other problems that they needed to voice. Also, some of the answers do tend to have an individual focus rather than a social focus.

Poverty
Women agreed that the best way to face to poverty was to be gainfully employed at a job that provided an extensive benefit package and a fair enough wage to be able to save money. Some women had returned to school to complete their education to better their chances of securing such a position or to receive a needed promotion. Others began selling drugs or engaging in prostitution to offset poverty.

Women took advantage of community services available to them such as the food and clothing bank, needle exchanges, street nurses and free condoms. If need be they rationed cigarettes or even quit smoking altogether.
One woman talked about how going to her doctor daily for methadone helped her to establish more healthy spending patterns, by addressing her physical addiction she was less likely to blow her money on cheque day. Another woman found that writing letters was an inexpensive way to correspond with friends and family.

Power in Intimate Relationships
The overwhelming past solution to abuse in an intimate relationship was leaving an abusive situation. As difficult as this move is women had found support from transition houses in the downtown area and from safe houses in the suburban/rural areas. Once a woman is placed in one of these houses she learns new skills such as recognizing a healthy vs. unhealthy relationship and also receives counseling to overcome grief and fear.

Women found being able to recognize a healthy relationship and being celibate addressed issues around intimacy. Although through discussion between the Peer Researchers we discovered that celibacy could be a double-edged sword. On one side the woman is in control by maintaining a no sex zone in her body; the other side (as voiced by two HIV+ Peer Researchers) is that celibacy can be a place of denial and rejection of intimacy.

One woman spoke of learning to say no to a partner who often forced sex on her as a very powerful place to be, as was, for other women, telling their partner to wear a condom or any other barrier. And of course women found that having a loving supportive circle of friends and family went a long way in helping to maintain their health.

Discrimination

Living in a racist society with economic discrimination, and social and political disadvantages to people of colour and First Nations people, women may self-medicate with drugs and alcohol in an attempt to alleviate these pressures. Learning to say no to this was one woman's solution to past difficulties.

Accessing services through agencies that were specific to First Nations' people gave some women a sense of community and identity, which strengthened their esteem and helped them to face discrimination.

Relationships with Health Care Providers and Institutions

Women expressed that asking for help is by far the best thing that they can personally do to positively impact their health. Two practical solutions women found were changing doctors and growing their own medicinal herbs. Daily visits to a doctor for medications was also mentioned.

Visiting a street nurse was a past solution to health care. Women were able to receive Tylenol and other over the counter medications that were otherwise unattainable due to cost. Also, many women found street nurses to be more educated about their circum-stances, more compassionate, and less intimidating than a doctor. One huge benefit of street nursing is that they will come to your residence to administer care and any needed medication.

AIDS Specific Issues

Personal solutions specific to HIV/AIDS were growing medicinal herbs, being celibate, and educating others about HIV/AIDS. One woman talked about her experience of working as a peer educator on HIV/AIDS issues as follows:

Where I live in the Fraser Valley I go into schools, starting at grade 8 and up into high school and talk about my HIV status and what it's done to me and how it's effected my life. They seem to listen to me because I'm actually living with HIV and I'm a girl so that helps.

Surprisingly only one woman said that accessing free condoms and telling her partner to wear one was a solution. Also expressed was an experience of a workplace union being supportive of people who are affected by HIV/AIDS.

Other Issues

The women covered many topics in the focus groups and interviews; some fit into our five categories, however others needed separate recognition. While a few women expressed the attitude of "fuck them all, I have control", the majority found that they depend on others and that talking to another person is extremely beneficial to maintaining health.

Other women found that by making sacrifices and having a faith-centered belief system they were able to overcome challenges.

Women spoke of taking care of themselves by getting more rest, receiving bodywork, trying complimentary therapies and remaining abstinent. Services that they found helpful were going to the Downtown Eastside Women's Center, Street Kids in Distress (when it was still in existence), First Nations agencies and assorted government programs.

Findings: Help Still Needed
(written by Monique Desroches and Stephanie Kellington)

Women were also asked to identify problems in their lives that they had been unable to find solutions to and identify help that they still needed around these issues. This question was added to the original interview guide by the peer researchers. Researchers felt that in light of our focus on identifying potential solutions and suggestions for action, it was important to give women an opportunity to air on-going problems that had proven particularly difficult and were perhaps, therefore, particularly in need of solutions. The following summarizes some of the discussions we had on this topic.

Poverty
Affordable Housing
Access to low-income housing or subsidized housing was one of the most pressing poverty-related issues that women identified needing help with. As one woman asked *"How are you supposed to live a clean, healthy life when they're sticking you in dumps like [the hotels in the DTES]?"* Women identified a lack of subsidized housing spaces available in the province as having created lengthy waiting lists and a difficult period for those on the lists. The limited number of locations for subsidized housing, as well as the clustering of such housing in urban cores (and subsequent lack of availability in rural areas) was a related issue.

Economic Options Needed
Increasing the number of viable financial options for those living in poverty was another pressing problem. Some women felt pressured into prostitution or selling drugs as a way to make enough money to feed their children or pay for their own (complementary or alternative) health care. To this end they called for:
- increased educational opportunities for poor women
- increased flexibility from financial institutions regarding debt re-payments
- increases to government income assistance levels
- increases to the levels of child tax benefits and the elimination of policies regarding minimum income requirements prior to receiving "working mother" bonuses from the child tax office.

Change In Banking Policies
The peer researchers themselves also noted related issues regarding the inaccessibility of savings and chequing accounts at banks to people on income assistance. This is a result of banking policies regarding minimum deposits and account balances in order to open and keep open accounts.

The city of Vancouver does have a bank – The Four Corners Bank – specifically oriented towards those living in poverty that does not adhere to these policies. However, this bank has only one location, right at the corner of Main and Hastings, in an area that many former drug users find extremely difficult or dangerous to go to due to the possible triggering of addiction issues and experiences.

Women, both in the focus groups and amongst the peer researchers, felt that *not* concentrating banking and other services geared specifically to low-income people in the Downtown East Side would increase service accessibility to a variety of women.

Transportation Problems
Some women wanted to pool their resources to organize a carpool to help with transportation problems. Others focused on getting bus passes made available to those with long-term disabilities, such as HIV.

Universal Day Care
Other women called for universally accessible child-care, available on demand, which they saw as particularly crucial when job hunting.

Power in Intimate Relationships
The problem of searching for and not being able to find a compassionate, knowledge-able doctor was one that many women noted not having been able to solve.
Having increased and easier access to counseling, especially (though not exclusively) for those living in the DTES, was also a common concern.
Issues that women mentioned wanting this kind of help with included counseling to help recognize healthy relationships and to work through grief after a death of a loved one.

For us as researchers talking about women's concerns in these areas proved contentious. As a group we had some discussion about how to categorize these concerns. The project coordinator wanted to put them under the category of "Relationships with health care providers and institutions". A number of the peer researchers argued however, that there are few people with whom one has as intimate a relationship with as with one's doctor or counselor, and few people who have as much power over you as your doctor or counselor/therapist. Therefore, issues around finding appropriate doctors and counselors/therapists are mentioned under "Power in intimate relationships" as being one place where this kind of power may be abused.

Many women find that the mere fact of engaging in an intimate sexual relationship with a partner creates vulnerabilities and relationships of power that can be difficult to negotiate. One woman described her understanding of this dynamic as follows:

> If you're beginning a relationship it seems like after you have sex with them you become more vulnerable … because you feel more or because you just are. And sometimes you'll be pressured into having sex, or the person won't be safe, refuses to, and then you feel like 'I still have to'.

Some women therefore mentioned still needing help regarding what to do when their partners were demanding sex and not taking no for an answer, despite the woman's own desires. Women felt very vulnerable saying no because of fears that doing so might lead to the partner leaving and potentially taking with him/her an important source of income (particularly if children were involved in the relationship) or to their partner becoming violent or emotionally abusive. Women are often taught to equate sex with love, and some had believed that if they said no they would be open to accusations of "not loving" their partners.

Some believed, as one of the peer researchers put it, "*If I fuck him enough, then I love him enough, then maybe I can change him*". As a result they could feel very controlled by what went on in the bedroom and at least one participant had become pregnant against her will while living in this kind of emotionally abusive situation.

It is also important to note that while there are particular gender dynamics, social roles and expectations that inform and shape how these situations play out between men and women, women also experience abuse within intimate relationships with other women.

As one of the peer researchers pointed out, many of the services and resources available to women leaving abusive relationships with *men* are not accessible when leaving an abusive relationship with a *woman*.

In a situation where a partner, of whatever gender, was requiring sex on demand and not being able to express their own desires puts women at risk for both HIV infection and illness progression in a myriad of ways. Among these include:
a much lower likelihood that condoms or other barrier methods of sexual protection will be used in these kinds of relationships leading to possible (re)infection by a promiscuous partner (who may, or may not, also be forcing other women into similar situations)
the possibility that the partner may become physically abusive, landing the woman in hospital where she is vulnerable to infection through medical procedures, as is explained by one woman:

> My husband beat the snot out of me and blew my spleen out. I had to be rushed to the hospital and have my spleen removed – which is the blood processing part of my body – and have four bags of blood given to me [one of which was infected with HIV].

Relationships with Health Care Providers and Institutions
Encouraging a move towards the health care system and its practitioners increasingly taking up a disease model for addiction (as opposed to a moral failing model) was something one woman mentioned needing help with.
- Others focused on the need to be treated as individuals rather than discriminated against as members of a sub-culture or group by their health care providers.
- They also wanted help so that they themselves would be less intimidated by health care professionals, including, and especially doctors.
- They wanted to be able to question their doctors when they felt they were making a mistake, or not passing on correct or sufficient information but often felt over-whelmed or intimidated to do so. Help to do this more frequently was something many women called for.
- Many women mentioned needing help to access alternative and complementary therapies as one of their biggest priorities.
- They also wanted help to pay for dental care and treatments and called on MSP (the Medical Services Plan of BC) to cover these costs.

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Discrimination
A number of the younger women who participated in the project felt that discrimination against young people had negatively impacted their lives in many ways.
- They mentioned needing help around identifying or establishing support services geared particularly to young women.
- Many participants also wanted increased help to access counseling services and support groups in order to receive support in dealing with the effects of belonging to a group that is discriminated against.

In discussing this issue many of the peer researchers were fully in agreement with this tactic. The project coordinator however, was disturbed by the focus on helping individual women to "conform to the conditions of their own oppression", rather than changing these conditions, while some of the peer researchers felt this belief to be naively idealistic.

In order to alleviate discrimination women also called for help in being acknowledged as an individual and not seen merely as a member of a sub-group or culture. One participant specifically mentioned feeling uncertain about what to do to end the discrimination that she felt had impacted heavily on her life.

> "I don't know what to do...'cause its just all over. People know you're positive and you get shunned, or being Native and a woman...you get shunned. I mean, you give [other people] pamphlets or whatever to read and some won't take the time to read it".

AIDS Specific Issues
Many women mentioned wanting help accessing support services specifically for women living with or affected by HIV/AIDS as well as increasing prevention education regarding HIV/AIDS for both school children and adults living in suburban areas. Similarly, the peer researchers themselves also focused on the lack of services for people affected by, but not infected with, HIV/AIDS – especially services geared towards young people who are perhaps no longer young children but are also not yet adults. They called for help to create and implement services oriented to this particular population.

HIV Specific Education For Doctors
Lacking an open and trusting relationship with one's medical doctor is an obvious social determinant of HIV infection and illness progression.
- If a woman is not receiving full, correct or honest information from her doctor about either precautionary measures to avoid infection or treatment measures to avoid illness progression she is increased risk of experiencing both of these.
- Factors that impede these kinds of relationships – such as discriminatory attitudes on the part of health care professionals, as well as differing communication styles and issues around dealing with authority figures – can all put women at increased risk.
- Also very important: not having access to a full range of proper treatments for general health maintenance.

- Women living with HIV frequently mentioned needing help to improve the quality of their relationships with various health care providers.
- Women also wanted help to educate doctors about the risks that young women face so they would *not* be told that AIDS is not an issue for them.
- They also wanted help to increase the HIV/AIDS specific resources in suburban areas, such as knowledgeable doctors and support groups for women living with HIV/AIDS.
- The peer researchers also identified a lack of availability of the female condom through ASOs as an issue that needs further attention.
- The peer researchers also noted the importance of overcoming discriminatory and differential treatment of women living with HIV within the AIDS community. Some of the women had experienced this kind of treatment and one of the peer researchers noted*:*

> Women who get the virus are seen as 'less than'. It seems that men who have the virus have more power, they are looked upon as 'poor victims', but women somehow created the virus by themselves, went out and got it on purpose. [This attitude] is apparent in many services.

Help in combating and overcoming these kinds of subtle, yet pervasive attitudes, was another identified need women had yet to have met.

Other Issues
Other issues that women mentioned still needing help in addressing ranged from the very specific to the very general. One woman simply noted that she had found no solutions yet and still needed help with "*everything*". Others spoke very specifically of needing help dealing with the courts in regards to the trial of her daughter's rapist, while   another wanted help dealing with the hospitals and the police around the treatment she had received, as an abused woman, accessing their services.

Safety Issues
Safety issues were another common concern that women still wanted and needed help in dealing with. Among these issues that women mentioned were:
- improving access to public transportation, especially for those living in suburban or rural areas; and
- increasing other kinds of resources to women living in suburban and rural areas, including the creation of a Women's Resource Centre in Langley.

Findings: Social Changes Women See as Necessary
(written by Gina Kjar with Stephanie Kellington)

The question posed to participants was "What do you think would need to change in society so that you or other women would not experience these kind of situations again?" Due to the very nature of the question almost all of the respondents had many answers to it. However, there was only a limited space to say them in. All the answers women gave were very clear in what needs to change, and again the answers had a lot to do with communication and education. Some overlap of topics with the answers to other questions will occur due to the interwoven complexities of the issues covered.

Poverty
Women said having access to better housing, more housing co-ops, and more low-cost subsidized housing – all of which should include adequate women-only options – would be a good start to preventing the same problems in the future. Two women explained their positions as follows:

> "If we had more adequate housing, then cleanliness would follow and self-esteem."
>
> Subsidized housing [was] my saving grace. I mean I live in it now, I pay $360 per month for my place. I couldn't have [gotten off welfare] without it."

Other social changes women suggested were to
- reassess the poverty line
- educate the public and those in authority on what poverty is, and
- increase government spending on single parents, women and children.

One woman suggested that those living on government-sponsored income assistance should have more options about how they receive this assistance including:
the choice to opt in to a method of receiving financial support that would see women have accounts at a variety of stores (such as grocery stores, drug stores, clothing stores, etc.) for the necessities.
In this way, potentially destructive spending patterns would not be repeated until new ones had been learned. She explained her thinking as follows:

> I'm my biggest enemy, I want the extra money but I'll spend it on drugs because I want to forget, I do…. What I'm saying is that I think programs should be set up at the street level to be given…for the food, not given a voucher because that's demeaning…but an account so that you actually have to get the food. …I think something set up like an account so there's some dignity. You just go in and pick out whatever [you want].

Relationships with Health Care Providers and Institutions

Better Communication
Women want to see better communication between doctors and their patients, and better networking between professional caregivers – especially caregivers working within different models of care (such as allopathic, naturopathic, homeopathic).

- "Better communication" in this context should be taken to mean firstly more respectful communication, so that patients do not feel talked down to or belittled by doctors
- More open and complete communication so that patients are enabled and empowered to be actively involved in their own medical care and decision-making.
- Women noted that we, as a society, should stop putting doctors on pedestals so that patients would feel more comfortable challenging prescriptions and diagnoses.
- Additionally doctors need to feel more comfortable saying "I don't know, let me ask someone else and get back to you".

Health Care Plan Funding of Alternative Therapies
Participants also argued that the funding structure for alternative therapies needs to be changed in order to make them more accessible to women living in poverty. Specifically women wanted:
- to increase the range of alternative therapies that are funded under the provincial health care plan, to make the coverage of those that are partially funded more complete, and
- increase awareness about alternative therapies as effective forms of preventative medicine. As one woman said:

> I've been studying these things since I was 14 years old. I'm 41 now [and] before I couldn't even talk to people about that stuff without them being like 'oh, get out of here!'. It's only starting to come back now, which I'm very grateful for…and that's my idea of preventative medicine.

HIV Medications and Clinical Trials
- Participants wanted to see changes in the ways in which current HIV medicines are being regulated, supplied, and distributed.
- The peer researchers added to this that they felt doctors should be less reluctant to prescribe useful and appropriate HIV cocktails to people living with HIV who are also intravenous drug users (IDUs).
- They also felt that women and children need to be included more often in clinical trials that develop new drugs and determine appropriate dosage levels.
- Finally, they called on doctors working as HIV specialists in particular to see their patients as more than the total of their HIV-related symptoms.

A very specific change one participant suggested was to have medical doctors work with psychologists or counselors before a patient's surgery in order to help better prepare patients for the experience as well as for potential after- or side-effects. Some women stated that an increased number of spaces available in clinics for chronic pain management would be a positive change.

AIDS Specific Issues

Again, the answers seemed to point in the direction of more education for the general public on having HIV as a woman.

Participants felt there would have to be more research done, and attention paid to the realities and particularities of women's experiences living with HIV/AIDS.

Education
The peer researchers who were living with HIV themselves felt particularly strongly
- the need for a greater awareness of, and sensitivity to, stereotypical assumptions about how women become positive (assuming they were sex workers or use injection drugs).

Not only are these assumptions sometimes false
- greater educational efforts need to be made towards convincing people that how you became positive doesn't matter, it's the fact that you are living with HIV that does.

Other suggestions that participants brought forward included having a particular peer researcher (whom the participant knew personally and who had spent many years living in the country) go out to rural areas and teach people about HIV/AIDS.

They also suggested
- increasing educational efforts directed to the police and the justice system on women and HIV, and
- educating men on proper condom use.

> The peer researchers would like to add that " all people [need instruction] on the proper use of all barrier methods of safer sex practice".

Power in Intimate Relationships
The answers women presented to us had a lot to do with how people treat others in intimate relationships -- things like being able to refuse to have sex with a partner without fear of retaliation and being able to ensure the practice of safer sex measures without fear of retaliation. Other suggestions put forward were
- teaching our sons to hear the word "no',
- increasing men's awareness about what constitutes abusive behaviour and
- encouraging them to take on greater personal and collective responsibility for such behaviour.
- Participants said that men need to hear the word "no" not in terms of women's health issues, but of their own as well.

Women felt that a necessary step in accomplishing all of these goals would be to build a greater awareness in society regarding the effects, realities, and impacts of sexism and patriarchy on women's lives currently. Children need to be taught about sexism as a concept, while inculcating in them the belief that women and men are equals.

The development and enactment of laws that would better protect women and children, such as stiffer laws for pedophiles and rapists, were also suggested, in both the focus groups and the interviews as something women thought would have to change to make things better for the next generation of women as well as our own.

Women also called for the further development of female controlled methods of birth control that they would be able to take without having their partner know. As one participant explained:

> Some women who are in a relationship don't have a choice on if they want to have sex. Their spouse or partner may come home at 2AM in the morning and wake them up to have sex. It would be good if they had an option to protect themselves from further infection.

Discrimination
Unfortunately this topic did not raise a lot of discussion or answers in the groups and interviews. The answers we did get from respondents included:
- for society to be more open to helping Native people and more aware of issues specific to First Nations cultures
- increase educational efforts to reduce homophobia
- teach people that men and women are equal to each other; and that differences, of all kinds, are not a bad thing.

Other Issues
This section of the findings was the most interesting as it brought to the table so many other issues that were not covered in the analysis of the first phase findings.

A few concerns had to do with women's issues around safety on the street, including: implementing changes such as
- having childcare, transportation, and safety precautions for women living and working on the streets
- having better transit systems at night in both urban and rural areas
- increasing services to women in rural areas
- monitoring and legalizing prostitution
- having "more community involvement", in terms of building stronger communities; and
- creating more non-profit societies and support services.

Many of the peer researchers disagreed with this last idea and felt that there are already too many redundancies in the system and wanted to focus on increasing the efficiency and accountability amongst currently existing agencies before creating new ones.

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Findings: Strategies to Make Changes
(written by Gina Kjar with Stephanie Kellington)

We found that women's responses to the question " How would you make these changes?" tended to be outcome-based, rather than process-based. This was a problem because of how we phrased and presented the question. For instance, if the change in question was to increase access to women-only subsidized housing, participants would respond that they would "eliminate waiting lists", rather than talk about the work and the steps they saw as necessary to either reduce the number of people on the lists or to implement alternative ways to access/create women-only housing). Of those women who did answer in a process-oriented fashion, many did so in a very personally directed way. For instance, if the issue in question was living on government sponsored income assistance, women responded that they planned to quit smoking in order to have more money for food, rather than, for example, that they would get together a group to start a letter-writing campaign or organize an awareness campaign. This was also a problem in how we phrased and presented the question.

Some women did present suggestions that were both process-oriented and community-focused however and they had a lot to do with community-based action and education. We have chosen to focus on these answers for the purposes of this report as they take us most closely to being able to fulfill our original goals and objectives.
In this vein, women spoke of being loud and noisy so that they would be heard.
They spoke of frustration with government services and organizations, and wanting to take back their power.

The level of frustration and anger women were experiencing is reflected in the response of one participant who replied to this question with the simple answer *Kill the bastards.*

Relationships with Health Care Providers and Institutions
Improving the delivery of health care to persons living with HIV
Women expressed their views on a variety of issues regarding this point. In order to facilitate better communication and encourage information sharing between practitioners of differing *models* of care, the peer researchers suggested:
- establishing a 1-800 phone line with an extensive data-base.
- Doctors and care-givers working within differing models could call up and get information about herbs or medications their patients might be receiving from those working in other models.
- increasing the number of clinics that work according to integrated models of care and involve professionals from a range of disciplines working within a variety of different models.

Better Communication between health care professionals and patients
In order to facilitate better communication between health care providers and their patients, participants suggested the development of a Women's Health Resource Centre, at the community level. Women could get basic information about:
- health care issues as well as learn medical terminology
- how to talk to doctors
- how to protect themselves from abuses and intimidation by the medical profession; and

- education about the training that health care providers do have in order to de-mystify and de-mythologize doctors as all-knowing and all powerful.

They expressed strong views on relationships not just with physicians but with other professional caregivers as well.

Women also wanted to further the education doctors receive regarding not just HIV issues but those around being female, as well as poverty and addiction.
- They suggested implementing "sensitivity training" around these issues for doctors, counselors, and other health care providers as a mandatory part of professionals and paraprofessionals training.
- They also wanted to increase the number of female doctors, and doctors knowledgeable about HIV working in the DTES.

Finally, they suggested that as part of a strategy to de-mythologize health care and make the experience less frightening and intimidating for women, doctors should be more forth-coming about what medications do to people's bodies, how they work and what side effects people can expect to experience and which ones they should worry about.

> Doctors and other care-givers should not assume that all patients can read *written* warnings or directions that accompany prescriptions.

Issues such as basic dental care were brought up with suggestions on
setting up a preventative and maintenance dental care fund by reallocating existing funding that is used for emergency dental care. Women suggested creating opportunities for increased accessibility to complimentary and alternative health care, such as, herbal medicines, massage therapy, hydrotherapy and options for their mental health.

AIDS Specific Issues
Education Needed

> The wide range of answers we received from the respondents was overwhelmingly one of education for communities and society alike on the issues of HIV/AIDS.

- For example, women felt if the police and others in positions of authority had a better understanding of the disease they could better communicate with those living with it – and consequently, treat them better.
- If there was a speaker who was positive to go into the schools and talk about what HIV is and how it affects all of us it would be beneficial to society. This speaker should always be age and culturally appropriate for the audience.

The peer researchers suggested that if it is difficult to receive school board approval for this, potential speakers could make arrangements through public health nurses or individual counselors/teachers. They also emphasized the need to talk to very young kids – *before* they are sexually active. As one peer researchers noted:

> What is age appropriate?
> When the kid is asking the question it's age appropriate!

Younger participants especially were keenly aware of the need for this kind of educational work in schools

> Just at our school on National AIDS Day I had a red ribbon. It's really creepy to see people's reactions to that. Because some people will just look at you and 'whoa', or just them assuming you may have [HIV].

Another solution we heard that falls under the rubric of "education" was to open community-based resources centers for HIV information in locations outside of the West End in Vancouver. Women wanted to:

> ...have a safe place for people [to go] to know the explicit way on how AIDS and HIV, or any STD, is transmitted, [some] place for information.
>
> ...and [to be] able to talk in your own language, that you are comfortable with
>
> And not told your time is up, time for you to leave now, but to stay until you understand.

Safe Places to Access Information
To accomplish this they called for the development of more "safe spaces" to access information regarding HIV as well as
an increase in the amount of community-based knowledge regarding HIV positive women available in these spaces.

A safe space in this context was also one where women wouldn't be hassled or asked why they were wanting this kind of information and where they wouldn't feel the need to be secretive. It would also be a space where confidentiality was guaranteed but where you didn't have to prove you are, or may be, HIV positive to access the services.
Finally, it would also be a space where women could be guaranteed to be safe from assault and physical violence, as well as from unwelcome pick-up attempts and come-ons.

Women also suggested that some thought be accorded to how people would get information home from these spaces afterwards – such as a plain kraft envelope or paper bag that was *not* adorned with red ribbons or agency logos. Communities that were specifically mentioned by

participants as in need of such a space include the DTES, Langley, Burnaby, and most small communities in rural areas. One possible use for this resource center, would be to host women's suggested "open houses" on HIV/AIDS. The point of these open houses would be to show the public how those living with HIV live, as well as that living with HIV is hard to deal with but also in many ways the same as everyone else's lives.

The peer researchers added: A high profile, high impact media campaign needs to be initiated, to lobby the government to create funding for respite care for people who are caring for HIV+ people, as well as those living with other life-threatening illnesses. For some people living with HIV, some of their most pressing concerns presently revolve around the fact that those who are their *informal* care-givers are usually simply not able to access any formal respite care at all. Furthermore, many ASOs restrict their services to those who are positive. Services for respite and support for those *caring for* people living with HIV/AIDS, as well as those immediately affected but not infected need to be not only increased but made easier to access. Women were aware that current difficulties arise from a lack of funding for particular agencies and felt that the only way to change this situation would be public campaigns to pressure the government into freeing up more money.

Finally, participants emphasized that there needs to be more communication about what services ASOs and other community-based agencies do offer. Agencies need to do a better job of advertising their services and making potential clients aware of them. As one woman said:

> There are gaps in services…I've lived in the Fraser Valley for four years now and…I am very vocal about my status. People who know me know I'm HIV+. I just found out last week there's a support group in Langley. I didn't know that because nobody told me….And I've looked.

Poverty

Although the strategies to combat poverty were varied and quite extensive the top three answers for the majority of the participants were on issues around housing, having access to enough money, and altering how poverty belittles a person.

Most women we spoke to said they did not have adequate housing or access to it. They felt that if there was better housing that they could afford then they could concentrate on other issues such as feeding themselves and their children. Women told us that they did not think that wanting a clean safe and cheap place to live was asking a lot. One suggestion women had for increasing the amount of affordable housing stock, specifically in the DTES, was to take over and refurbish some of the existing hotels and turn them into safe, clean and adequately-equipped self-contained units.

> "…some of these hotels, instead of tearing them down, just re-do the inside and furnish them with a fridge and a stove".

They suggested eliminating guest fees to enter hotels as a way to increase options for shelter as well as possibilities for informal care-giving to those living in hotels. One woman noted:

> "My dad's 80 years old and he couldn't come up to visit me [when I was sick, because of the hotel "guest fees"] He traveled 800 miles".

One issue that would have to be addressed in lobbying for this change is the fact that for many of the people who work as front desk clerks at hotels in the DTES their only source of payment for those jobs comes from whatever guest fees they are able to collect. The peer researchers also added in discussion about this item that increasing the number of safe houses, transition houses, and detox facilities available to women would go some way to alleviating many women's housing crises.

Women told us the current welfare rates were not enough to live on and wanted to see changes made to these. They wanted to petition the governments to raise these rates and give people living on income assistance an opportunity to have a decent standard of living. One woman suggested the following strategy to make this happen:

> "I would like to see [ASOs] set up meetings with people who handle the money [for the government], set up meetings and workshops with these people. To me, that's what the government is there for – to listen to the people, that's why they're there in the first place…I'd like to see people in your positions go in and say 'listen, we'd like to set up a time to meet and talk and this is where our clients are coming from and this is what they'd like to see, so what can you do?' And then you come back to us and say this is what we've been told.

As well as raising the rates of income assistance, women proposed strategies to make it easier to access additional benefits such as Disability Level 2 (Permanent Disability) benefits and Schedule C benefits.

> "Whether I go to level 2 or Schedule C it's that you have to go through such a struggle, such a fight. It's like they wear you down….I'd like to see the steps made easier. I'd like to see it so it's not such a struggle.
>
> I'd like to see it so that women have an advocate so that they can go right to whoever is responsible for this".

Finally, women were also concerned with ways to make it easier for those who were capable of working to get off welfare. They suggested making it easier for low-income women to access

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entrepreneurial loans to start small businesses and increasing opportunities for on-the-job training and hands-on skills development.

Part of the solution women felt at present was to help people who have little money to cook and eat healthy on the money and resources they do have. One woman suggested giving recipe books to people who are using food banks.

> "Sometimes they give you dried beans or whatever [so] they should maybe have a recipe or two to tell you what you can do with that sort of food to make it last longer".

Another suggested developing a barter system or "trading post" where women who had bought bulk goods (because of the lower cost) could trade with each other. *"If I were buying 4 lbs of sugar I should be able to trade it off with [another participant] for 2 lbs of flour that she might have."* Women also wanted to see food banks open for more days out of the week, give out more perishable items, solicit donations from organic food producers, and institute a home delivery system for those too ill or elderly to stand in line.

More options for free legal advice, transportation and childcare were also among solutions women felt were viable. Also, the development of public education and awareness campaigns coupled with more intensive awareness training for those in positions of power and authority such as government workers, health care providers and policy-makers to make people understand that, in one woman's words:

> "Just because we are poor does not make us bad people".

Power in Intimate Relationships
Women wanted the power to say "NO" to persons forcing them to have sex, both within and outside of intimate relationships, without fear of retaliation. To create this change women suggested increasing counseling opportunities for women and couples in abusive relationships to either change the nature of their relationship or empower the woman being abused to leave. To facilitate identifying instances in which this service might be of use the peer researchers suggested educating doctors and dentists to recognize the signs of an abusive relationship – and giving doctors the right and/or responsibility to report these signs.

Participants also felt tighter laws regarding child molestation and adult sexual and physical abuse would work towards helping the regain their power. In order to accomplish this the peer researchers suggested that women's organizations should form a sector-wide lobby group and lobby all levels of government for these kinds of changes. They also suggested pursuing more high profile rape cases in courts in BC and doing more work to encourage women to press charges in instances of sexual and domestic assault.

Women indicated that another way of giving them back some control over situations where they had felt powerless, would be if they were able to choose a form of birth control they wanted and one they were able to control and use without the knowledge of their partner, if necessary. The peer researchers suggested accomplishing this by lobbying the government to increase funds for research and development of microbicides. They also wanted cheaper and more wide-spread access to other female controlled methods of birth control and safer sex practice – such as female condoms – which already exist. This, they felt, should include free distribution of female condoms by ASOs, such as is currently the practice with male condoms.

Economics and financial difficulties are other factors that can make it difficult for women to leave abusive situations. To alleviate these kinds of situations participants called for increasing government financial assistance to women left by or leaving their partners. One participant in particular also wanted better access to financial and legal support for those who had been left in debt by a former spouse. To this end the peer researchers suggested that every organization should have a legal advocate. This person would research law and disseminate information, such as the fact that one way to deal with being left responsible for an ex-partner's debt would be for the woman to take out notices in papers announcing that the couple had separated and that she will not be held liable for financial debts incurred by her partner.

Participants also suggested ways to try and avoid these kinds of relationships occurring in the first place by explicitly teaching about "healthy relationships" and skills for independent living and self-awareness in schools so that girls would be able to better recognize, and hence avoid, abusive relationships.

> I think there should be more programs in schools for young people, both men and women, so that they can later be independent and not have to depend on someone. Say they meet some guy and they sort of end up living with him and this guy says he's providing for them so they sort of have to have sex with him. I know that sort of thing happens, [in] whatever kind of relationship – …you owe something…[If you're taught life skills] you'll be independent and you'll be confident and you'll be able to make the right choices about having someone influence you or control you.

"I also think that young girls even in school need to be taught what healthy relationships are. They might not know, depending on how they grew up or depending on what they see on TV, they might not know what a healthy relationship is – equal, balanced, trust[ing] – stuff like that. That's important too because they might get into something and not know how to get out because they don't even know what they're into in the first place".

Lastly, given that many HIV+ women experience abuse and manipulation in relationships related to their HIV status, some women called for increasing educational efforts to partners of people living with HIV/AIDS so that partners would have a better understanding of the illness and more compassion regarding what it is women are going through.

Discrimination

Women had ideas for changing the way they are dealt with in society, including teaching people to value women's role in society. Some participants felt that to accomplish this it was important that women first empower each other through, for example, consciousness-raising groups. They felt this would enable women to insist on our own value and to not feel dependent on male spouses for value and worth in the world.

Participants also called for more opportunities for cross class communication to alleviate classism. They also wanted specific help and agencies for Native people. In regards to this point, some of the peer researchers discussed their preference for encouraging marginalized communities to work together with dominant communities, believing that communication between groups is the only way to enable power and not lose the voice of the collective. Conversely, the project coordinator and others of the peer researchers argued that, often groups who have been historically marginalized and oppressed need to be given space to work separately and empower each other. In the end we realized that both strategies could be used together and complement each other.

Participants also felt if more people knew about what it was to have HIV they would not be so discriminatory toward those who have it. To accomplish this they suggested that more doctors and others in positions of authority be better educated about persons living with HIV.

Other Issues

This category surprised the peer researchers in the degree of answers provided to them. In speaking to this question some women focused on the importance of their own realizations that they do have power, it's just a matter of acting on it.

> I have one [solution]. Realizing that there's not such thing as can't. And no one's going to come along and do it for me and that I have to get out there and find my own information. To realize that we have to do it [inaud] – it's a series of events, thoughts and then words and then actions. You gotta do it.
>
> It means so much to me to take my power back for me because I've never had it. When I was a child my father had it, when I left home everybody else had it, everybody else seemed to have it, you know? And what I've learned too is that I've always had it, I just haven't realized it but now I'm learning how to use it.

Speaking of community-focused strategies, most women said the louder they were the better it would be for them. They wanted to see a lot of community action such as groups of women getting together to voice their frustration and to make changes in their lives. Women were saying if they rallied together they could effect change for all of them.

> "[T]he more we back each other the more we can do. Society, to me, is teaching us to isolate".

Some of the methods they spoke of were:
- getting as many people as possible to partner with big, loud organizations to speak in one loud voice
- lobbying and petitioning governments
- creating local steering committees
- creating a mission statement
- having social gatherings like tea parties to raise awareness of various issues
- putting ideas on paper; and
- creating support groups for women.

Another more specific idea was to organize a series of meetings at the Downtown Eastside Women's Centre to identify local issues and out of this to create a network of community resources for, by and of women.

Participants also suggested conducting good quality research in an ethically and legally sound way by finding funding and then publishing the results and having them available for free as a way to increase women's access to resources for change. They also wanted to have conferences, speaking events, and a newspaper to publicize these changes. All of this, they felt, could and should be achieved at the grassroots level.

The peer researchers felt it is important to recognize here that much of this work – and certainly work employing these strategies – is being done, with varying degrees of success, on a grassroots level, already. They noted two implications of this fact.

One implication is that very likely, many of the women we talked to were not aware of many, if not most, of the efforts that are currently being made, or have been made in the past, to promote women's equality and end racism, homophobia, ableism and AIDS discrimination in Canadian society. They felt in some instances this indicated a need for the people and agencies organizing these efforts to better promote and advertise their initiatives. The project coordinator further adds that it also points to systemic and structural inequalities in how information is disseminated and the fact that those who have access to information about various efforts to end inequality are often those who are relatively privileged to start with.

The second point the peer researchers made is that it will be important for us not to reinvent the wheel in our efforts to create social change. We should not replicate work already being done but rather look to successful models of change that have been fought for and achieved in other communities (for example gay men and AIDS services).

Findings: Priorities for Action
(written by Stephanie Kellington)

After asking women to lay out the range of issues which they felt had affected their ability to be healthy, remedies successful in the past, proposed solutions for situations with no remedy as yet, and strategies for effecting those solutions, we asked women to prioritize the potential changes they had identified. Given the broad range of issues and problems identified by the project, we felt it was important to be able to focus the limited resources and energies of our advocacy and mobilization efforts in those areas that women themselves had identified as priorities.

However, when asked to list their top three priorities for action the 44 women we interviewed nominated 101 different priorities, demonstrating the incredible range of barriers women face to establishing and maintaining their optimal health. There was little over-lap between their priorities! Once we began to group priorities according to the issue they addressed, the following patterns emerged.

Poverty
By far the most frequently mentioned priorities for action of our participants were strategies to improve the conditions they faced living in poverty.

Income
Twelve women in the interviews and many more in the focus groups, more so than for any other single strategy, wanted an increase in income rates for those living on all forms of government assistance. This is one of the three most important things that could be done to help them lead healthier lives. Anti-poverty advocates, health promoters and social activists of all kinds have been arguing for years that falling levels of income assistance and the dismally low levels to which they have sunk have institutionalized poverty and put people's health and well-being at empirically proven risk (Doyal, 1995; Evans, Barer and Marmor, 1994; Gladwell, 1990; McCulloch, Howards, and Ivan, 1999; Payne, 1991). Women living on income assistance are also clear about these links.

Housing
The next most commonly mentioned issue was increasing access to and availability of safe, clean and affordable housing for those living in poverty or on low incomes. Increasing the amount of low-cost housing as well as the number of housing co-ops were the strategies suggested to address this issue.

Transportation
Improving the public transportation system and access to public transit for those
living in poverty was another common priority. Women living on government assistance often experienced difficulties in merely accessing the public transportation that does exist. The mere fact of being able to get around and do the kinds of things they knew would enable them to be healthier or to escape difficult situations was an important priority for women.

Food Quality and Availability

Increasing access to better quality, nutritious food was a final common priority to do with poverty. Some women felt that there was adequate food (through food banks, free meal services etc.) available to those living in poverty, but that there were problems with the quality of the food in terms of nutrition, variety and freshness. Others felt that there were problems of quantity, accessing what was available, or storage and preparation difficulties.

Other priorities women had that broadly addressed the theme of poverty included:
- increasing financial resources to suburban and regional women
- increasing the number and kind of support services available to those living outside of the Downtown Eastside (DTES)
- increasing dental benefits to those on government assistance
- fighting back against government cutbacks
- increased funding for childcare
- advocating for welfare to provide better assistance around the costs associated with going back to work
- lessening the restrictions on welfare that make poor people powerless
- increasing the number of small business and entrepreneurial loans given to people on income assistance
- "poverty issues" generally and
- increasing respect for low-income people and particularly low-income people living with HIV/AIDS.

Relationships with Health Care Providers and Institutions

Increasing funding for alternative and complementary therapies was the most commonly mentioned priority in relation to the health care system.

Women expressed much interest in and desire for alternative therapies but even those who were living above the poverty line were often not able to afford the kind of therapy or the frequency of use they felt would be most beneficial. Those living in poverty, especially those living on government assistance, were simply not able to afford to access many treatments which prior experience or informed advice told them would be of help. Women felt strongly that they should have the option to choose which kinds of healing treatments worked best for them and found it particularly frustrating in situations where they might have used a particular herb or other therapy in the past and found it to work, but were currently unable to access it because of cost.

In fact, we heard and are aware of many stories of women taking prescription drugs given to them by doctors, selling them on the street and using the money to buy the herbal or homeopathic remedy that was the woman's first choice. Making these types of remedies more readily available in the first place is an obviously preferential situation.

Physician education to alleviate problems of discrimination or inadequate/inferior treatment was the next most commonly cited priority. As with the first phase of the project, women reported many instances when they felt they were not listened to, disrespected, or when their problems were not taken seriously, as a result of some aspect of their social identity.

Another commonly cited priority to do with health care pertained to increasing the number of appropriately trained and culturally aware counselors and hence increasing access to counseling services for women. This was particularly an issue for some of the women living in the DTES, though it was mentioned as well by those who were living with HIV and/or living in suburban or rural areas.

Other priorities that women mentioned in relation to the health care system included:
- increasing the availability of medically prescribed marijuana
- stricter confidentiality policies
- increasing government regulation of HIV medications and doctors prescriptions of such medications
- increasing the number of spaces available through chronic pain clinics
- providing women with resources and knowledge to be less intimidated by doctors and take a more active role in their own health.

AIDS Specific Issues
Women also cited a number of priorities dealing with AIDS specific issues.

> The most frequently mentioned of these was increasing respect for people living with HIV/AIDS, particularly low-income people who are often not able to protect themselves from the effects of discrimination to the extent that those with more money might be able to.

Alleviating discrimination in regard to housing issues of all kinds was identified as a particular priority. This issue cut across class lines but may be especially difficult for low-income people who have fewer housing options as a result of a severe lack of adequate, affordable housing.

Women felt that increasing the number of opportunities for people living with HIV to speak out and be recognized in their own communities, and educating children about the realities of HIV/AIDS in schools should be addressed as AIDS-specific priorities. People would not only be less likely to discriminate against people living with HIV, but be better able to understand the disease and protect themselves.

Women identified remedying the lack of information particular to women and HIV/AIDS as a priority. They called for increased funding to be allocated to research specific to women and HIV/AIDS both in regards to treatment and prevention. Other priorities included increased public education about women and HIV/AIDS and the creation of additional drop-in centers where both positive and negative people could go to get information about HIV/AIDS, both in the Downtown Eastside and in rural areas outside of Vancouver, such as Langley.

A number of the women who participated in the study in Langley were from strong Christian backgrounds and felt that increasing both HIV prevention and support services that were sensitive to the needs of and explicitly open to those of strong religious affiliation was an important priority.

Finally, increasing the services and support structures that were available to care-givers, family, and friends of people living with HIV was a clear priority for a number of the women. Particularly identified as problematic was the severe lack of support structures available to family members (including children) after the person who had been living with HIV had died.

Discrimination
Most of the priorities women identified in this area addressed either discrimination due to being HIV+ or discrimination from health care providers—topics that are discussed above. One woman was clear that her one and only priority was to *"help our Native people"*.

Other priorities identified included decriminalizing and implementing state monitoring of prostitution, and increasing services to working girls. While discrimination against sex trade workers is by no means the only reason these steps may be necessary, it does form an important contextual variable that makes them desirable.

Power in Intimate Relationships
Women's priorities in regards to themes of power in intimate relationships were overwhelmingly centered around increasing resources to women to help them leave abusive relationships, after leaving, while in or to avoid experiencing these kind of relationships altogether.

Priorities included:
- increasing resources to suburban and rural women attempting to leave abusive relationships increasing long-term support to women who have left abusive relationships
- teaching men to hear no; and
- decreasing family violence against women and girls generally.

One woman also talked of her own difficulties in attempting to leave an abusive relationship and being held financially responsible for debts incurred by her ex-partner even after she had left him. She felt identifying strategies to eliminate this type of situation were her top priority. Another set of priorities for women related to power in intimate relationships was increasing information to both HIV positive and negative women in relationships about HIV/AIDS. Finally, some HIV+ women noted that their priorities would include identifying ways to make it easier for them to establish social and friendship contacts outside of the community of people who are HIV positive.

> [Y]ou can't even find friends, nobody wants to talk about it unless they're HIV+. You can't find friends...

Other Priorities
Another set of concerns that were priorities for a few of the women dealt with questions of governance, crime, and policing. Issues included:
- increasing government accountability
- eliminating international cartels
- decreasing crime
- increasing community involvement in "cleaning up" the streets, and
- decreasing police harassment.

Directions for Future Action

Or "Where do we go from here?"

(written by Stephanie Kellington)

Throughout this report, we talk about how working on this project has effected all of us who came to it as researchers. I think it is fair to say that it has taken far more work and hours of sweat than any of us had originally anticipated to produce this slim volume and caused all of us many moments of uncertainty, anger and extreme frustration. But these hours were engaged in voluntarily and with great enthusiasm. Throughout this time we have also been inspired, taught, and enabled to grow in our understanding of the issues and as individuals.

What we hope and intend to do now is use our own growth and our own experiences to reach out to and inspire others; others in our lives, in our communities, and in positions of authority and/or power over our lives and communities.

Community-Based Research is not truly "community-based" if the reports that come out of it sit on a shelf gathering dust after the project is done (Barnsley and Ellis, 1992). The point of doing Community-Based Research is to create "knowledge for action" (Tussler and Marchand, 1998). We intend to create action based on the knowledge generated through this project in a variety of ways.

In Phase 3 of the project, we intend to focus on two simultaneous "streams" of activity: report dissemination and community mobilization in the lower mainland. Dissemination activities will include community forums, the development of a web site, street outreach, pamphlet distribution, report distribution, the release of results to the media, conference presentations, and publications in professional and popular format magazines and journals. Additionally, one of the peer researchers has already begun organizing follow-up meetings with women in her community to check back with them about this analysis and to solicit additional solutions and strategies for action.

As part of community mobilization activities, we anticipate running a second training session for peer researchers in workshop facilitation, and community mobilization. Peer researchers and the project coordinator will then organize a series of workshop presentations on the project and its findings with service providers, health care professionals, government officials, and those working in the field of HIV/AIDS in the Lower Mainland area. These presentations will focus on the priority areas women identified in the course of this phase of the project and will attempt to find a means to bring women's own voices regarding the issues and proposed strategies for action to those in positions to act on them. Through these workshops, and the series of community forums, we will develop a Community HIV Action Plan for Women in the Lower Mainland and work to see that this Plan is implemented in cooperation with local Coordinating Committees.

In Phase 4 of the project, we anticipate broadening our work beyond the Lower Mainland area and reaching out both to the rural regions of BC and across the country nationally. Women who participated in the project repeatedly stressed to us that as difficult as the situation might be in the Lower Mainland, that the resources to help them avoid HIV infection and/or illness

progression were even scarcer in rural and suburban areas. We see a potentially useful role for the project in networking to open up a dialogue about these issues with ASOs, women's organizations, Native Friendship Centres, and youth groups in these areas. We will initiate a process of community consultation, bringing to these communities the kind of resources that would be most useful and important to them in order to allow work of this nature to continue.

Doing research at the community level can be an immensely challenging and wonderfully rewarding experience. It is, by its very nature, bound to be challenging, more diffuse and more multi-faceted than academic or institute-based work.

> Yet one of the true strengths of Community Action Research is the deeply rooted commitment that all of the participants have to creating the conditions for change and action based on the results of the research.

We remain committed to the process of creating "action through knowledge" and anticipate with great pleasure the opportunities and challenges that will arise from seeking to do so.

Reporting on the Project as a *Project*

As part of maintaining accountability to our funders (the Vancouver Foundation), the Foundation provided us with a list of questions that could be used to guide the writing of our final report. In order to incorporate these concerns into this report each peer researcher took on responsibility for 1-2 sections of questions. In taking on this responsibility the woman led a discussion with the other peer researchers at one of our weekly meetings on the topic of her section. She then went home and wrote up the results of that discussion in a short paragraph or two. These summaries appear below with edits and additional comments by the project coordinator (with the women's permission) where appropriate.

Results, achievements, factors influencing outcomes
Discussions facilitated by Freda Lockhart and Monique Desroches,
Stephanie Kellington writes:

The peer researchers identified three groups of factors that they saw as contributing to the success of the project.
1. The first of these was the quality of the staff people involved with the project – both the community based educator, who was their initial contact with the project and whose teaching and inter-personal style was universally praised as inclusive, accessible, and key to the initial bonding of the group, and the project coordinator.
2. The second factor was the women's early decision, facilitated by the educator, to trust each other regardless of their cultural or racial background and to approach the project in a success-oriented fashion that encouraged them to focus on the project goals and objectives and allowed them to care passionately about doing the work and doing it well. The peer researchers felt that their commitment to the project and their decision to take it and their work for it seriously, contributed to the project's success.
3. Finally, they felt the structure and organization of the project – that the research was done using peer researchers who were familiar to the women in the communities they were working with – made it easier for those women to open up and be honest during the process of information gathering.

Three sets of factors were identified as limiting the success of the project and making it not work in places.
1. The first of these was the small budget and the resulting lack of money to have both staff people involved for the duration of the project, as well as to properly recompense both the peer researchers and their research participants for their time.
2. The second set of factors had to do with time. First, the short timeline for the project meant that some of the peer researchers were unable to get their groups together and that we ran out of time to fully develop the analysis. Second, that the initial time line for data collection ran over the Christmas holiday period, when it was difficult both for the peer researchers and their participants to find time to put into the project.
3. Finally, both of these factors converged so that there was no opportunity for follow-up with the women who came to the groups and interviews as participants. The peer researchers were often frustrated by this fact. They felt that questions were raised and issues were brought up by participants but there was no opportunity for them to look into something and get back to people or to consult with others after the group was over.

Some women did this kind of work and communicated with participants anyway. But to have this informal work validated and included as part of the "official" work of the project they felt would have made its connections to communities stronger.

The peer researchers identified three of the project's initial objectives that in their minds were either only partially met or not met at all.
1. One objective was to *increase participants awareness of ways to overcome the personal, social and systemic barriers to their health*. The factors that were identified as leaving this objective only partially fulfilled included those described above – the lack of time in the groups and the lack of follow-up after the groups.
2. The peer researchers also felt that the objective to *strengthen and coordinate AV and PWN's response to the needs of HIV positive and HIV negative women* remained only partially fulfilled. Both organizations have been extremely supportive of all women involved with this particular project. a number of women not living with HIV remained frustrated that they and other negative women are unable to access some of the services that PWN provides. Due to the need for confidentiality for all women accessing PWN's services, these are open to women living with HIV only.
3. The peer researchers also felt that both organizations had remained somewhat distant from the actual work of the project. They identified the need for they themselves to go out and actively connect with staff and volunteers at the sponsoring organizations in order to make them more aware of the project and its findings.

Our original intention was to focus on the six communities which were part of the first phase of the project; women who: are HIV+; have sex with women; are diagnosed with a severe mental illness; are Aboriginal; are current or former substance users; and are Spanish-speaking refugees and immigrants. As the project evolved, the peer researchers took more ownership of its goals and parameters. How comfortable they felt defining the communities they are part of changed, and the communities whose perspectives they felt were important to include, in some instances, shifted. In response to this shift, the communities we focused on the second phase shifted as well.

Finally, women identified the objective to document and learn from participants' experiences through the development of a local action plan for program planning and advocacy as remaining unfulfilled due to limitations of time, money, and energy. This objective has been moved to Phase 3, the follow-up and action phase of the project, and will be developed at this time.

Some of the intended results of the project included:
- holding the interviews and focus groups
- developing an analysis that explored the social determinants of women's risk for HIV infection and illness progression and identifying community-based solutions to address these determinants
- the widening of our initial framework of social determinants to include other factors and other issues that women brought forward in the groups
- working within a peer-driven and community-based research model
- production of a document that, with distribution, will increase institutional and community knowledge regarding women's unique experiences in relation to HIV/AIDS
- beginning the dissemination of results through conference presentations at the local, national, and international level and popular format magazines.

Unintended results and changes that occurred as a result of the project included
- the realization experienced by some of the peer researchers that their "community" was much wider (and more supportive) than they had originally realized
- some demonstrated levels of increased awareness among ASOs regarding the lack of follow-up services to children whose parents die of AIDS following a conference presentation;
- increased awareness about the inter-connectedness of the social determinants of health amongst peer researchers;
- increased feelings of responsibility to create action and fight for remedies to socially determined barriers to health amongst the peer researchers and project coordinator;
- personal changes regarding feelings of self-esteem, self efficacy and competency amongst the peer researchers;
- and increased self-awareness and health-seeking behaviours amongst the peer researchers.

Another important unintended result was the huge number of deep-seated personal, emotional, and psychological issues that being involved in the project brought up for the women who acted as researchers in it, and the attendant need for strong emotional support that was created by involvement in the project.

The need for emotional support for participants doing research work is an important issue for agencies and organizations contemplating taking on similar projects. An awareness of this important issue will further the possibility of women in communities taking on this kind of highly demanding, engaging, and complex work.

Effect on community/organization
Bunsy Jir writes: The community I work with in is the Downtown East Native Health Drop-in [a drop-in for HIV+ people living in the Downtown Eastside, set up to address Native health concerns but not exclusively serving this population]. [Women there were] happy finally there is something to help and cries and listening, caring for the community, to see that there is help when needed. The effect on this [community] was good and they were very interested to see the need for this to happen here [in the] Downtown Eastside. We [the peer researchers] get more training and information for our group. [The peer researchers] work[ed] together to reach more people for this project as we learn more and get information up-dated and work hard at what is needed for this. The project was very good. [T]he organization's long-term plans look good and need a lot more funding [for the peer researchers to be] taught more for this long term plan. Yes, this project advanced very well and over-all [met] the missions and goals we set out to do.

Stephanie Kellington adds: Most women felt that the project's impact to date on their communities had been overwhelmingly positive. The peer researcher working with young women in Langley noted that women in her community were given an opportunity to think about issues they might otherwise never have encountered or been forced to face. Others noted that just giving women a voice and chance to have their concerns raised and addressed by a project that will hopefully contribute in significant ways to public discourse on the social determinants of risk for HIV/AIDS illness and progression was an important tool for empowerment. However, while some of the focus groups (such as Bunsy's above) have or did continue to meet for a

period of time afterwards, this only happened as a result of the personal initiative of the peer researcher involved.

Many of the peer researchers felt that the impact of the project on their community was limited by the lack of follow-up and the lack of opportunity to arrange to meet with the exact women who had originally attended the focus groups (and in some cases the interviews – though these participants were more likely to be known to the researchers themselves and therefore are easier to contact).

The project has advanced the over-all mission and goals of both sponsoring organizations. PWN is mandated to work with HIV+ women and women at risk for HIV in BC. AIDS Vancouver has as one of its main objectives in its 2000-2003 strategic plan "to work with others to address gender inequality and gender bias experienced by people infected and affected and vulnerable to HIV/AIDS". By contributing to the knowledge base from which both organizations can pursue this work, the project has enabled both of them to better fulfill their mandates and objectives.

Target group
Bunsy Jir writes: This project did reach the people and to my amazement went well and the group [peer researchers] wanted a meeting once a week [to work on the analysis and report writing after the focus groups and interviews were done]. The focus group I [did] with one of the groups [went well and got the information we were looking for, including lots of information about problems women face everyday living with the disease]. Yes, this project was good and the group [of women I worked with] was very interested to see this happen for them and very happy this project came to them.

Inclusiveness
Wendy Wartman facilitated this discussion and asked Stephanie to write the following: The peer researchers were all in agreement and felt strongly that different points of view had been welcome in the planning and decision-making process. They felt that we worked hard to be as inclusive as possible and to encourage the full participation of people from different backgrounds and ability levels. However, due to constraints of both time and money there were certain groups of people we were not able to include as centrally or frequently as we would have liked. These included: those for whom English was not their first language (especially Spanish-speaking peoples) and those who are, in the peer researcher's words, "differently functioned", meaning people who function "differently" in the world than is the expected norm (and who may experience difficulty conforming to normative behaviours) because of a mental illness or other life/health issues.

We talked for some time about whether we had adequately included the voices of people who were disabled until some of the women pointed out that as women living with HIV they considered themselves to be disabled. One of the peer researchers is also partially deaf and one of the interviews was done with a woman who is blind. However, with the exception of one of the peer researchers who uses a cane to help her walk, none of the peer researchers themselves are visibly disabled. It was noted that one way to ensure increased participation from linguistically diverse groups was to ask for more money to do translation of various project documents.

Given that we had initially identified six target communities for the project: HIV+ women and care-givers to HIV+ people; women who have sex with women; women with a severe mental illness; Aboriginal women; current and former substances users and Spanish-speaking refugees and immigrants, the peer researchers felt that, with the exception of Spanish-speaking women, they as a group and their participants represented a good cross section of members of these diverse communities. They also felt it was important to note that they had gone beyond these boundaries by including a small number of women who were transgendered among their participants.

Finally, the peer researchers felt that the material and processes used in the project had generally been culturally appropriate and sensitive for those who were involved in it. One factor that contributed to the appropriateness of the process was the fact that there were measures taken to ensure that the focus groups and interviews would be accessible to women who may have low literacy skills. This was done by having facilitators present who could go over the consent forms and other written materials and by having large poster-board pictures used as part of the discussion of findings from the previous stage.

Nonetheless, peer researchers did identify some instances when issues arose around the appropriateness of the materials and processes including:
the fairly limited focus and amount of space given to issues around mental health concerns specifically in the questionnaires and discussion guides;
the fact that some of the younger women participants in particular didn't always have enough information to answer all of the questions and needed to have concepts and ideas explained to them; and
the fact that some of the professional women had a hard time relating to the questions about poverty.

Collaboration and partnerships
Sharyle Lyndon facilitated this discussion and asked Stephanie to write the following:
The project was inter-organizational in many ways. Firstly because it is sponsored by a partnership between AIDS Vancouver and the Positive Women's Network and, as such, does not have *one* "parent" organization. Also it, ideally, would take the form of a collaboration between these two sponsoring organizations and the peer researchers as a group. Finally, some of the peer researchers also worked with other organizations, such as the Downtown Eastside Women's Centre, DAMS, Trinity Western University, Vancouver Native Health Society and BCPWA in recruiting participants for their groups and interviews.

Some issues arose around the peer researchers claiming ownership of the project and research process. Although, generally speaking, staff at the sponsoring organizations were thrilled when this happened, it was a challenge for the peer researchers as a group to stand up and do this and this process has been bumpy for all concerned.

Also there was a lack of flow of information between the Advisory Group for the project and the peer researchers, as well as between the staff of AV/PWN and the peer researchers as a group, that sometimes resulted in suspicion and hostility. Communication between all of the different participating bodies in the project was one of our biggest challenges and the lack of communication could sometimes make people feel like either side was not listening or caring about what the other had to say.

The peer researchers would have liked to have seen the Advisory Group, as well as the two sponsoring organizations, take more of an active role in the project and noted that the current lack of involvement had made some of them feel like the organizations and individuals involved thought they were "too good or far above" the peer researchers to be involved with their work. Some of these feelings were cleared up and addressed in the joint evaluation meeting between the peer researchers and Advisory Group (which is detailed in the section on *Other Evaluative Information*) but the fact that it developed in the first place was a definite challenge to overcome.

The peer researchers suggest that there should have been a group meeting between themselves and the Advisory Group right at the beginning of their involvement with the project. Also, it should be made a criterion for involvement with the Advisory Group that its members participate in this meeting and perhaps in other sessions with the peer researchers as well. Clearer specifications around the expectations for both of these two groups would also have been helpful. Everyone involved with the project has decided that in all future phases of the project, all of the peer researchers who are interested will be invited to all of the Advisory Group meetings to try to remedy this situation.

There were also issues and problems around how budgetary decisions were made and the peer researchers suggest that in the future there be a budgetary committee set up for the project which includes at least one representative from the peer researchers to have input in these decisions. Similarly, the peer researchers would also like to see the addition of a peer researcher rep to the project's Steering Committee (currently made up solely of staff people from AV and PWN).

Finally, there were challenges to meet around policy adherence and negotiation between the sponsoring organizations and the project, both for its staff and the peer researchers. It was never specified – and should be in the future – whether the project should be adhering to policy that has been developed by the sponsoring organizations (and if so what to do when these clash) around honorarium payments, child care, pet care and any other policy decisions that arise. Currently the situation has been resolved to the extent that it has been decided that the project may look to the established policy of either sponsoring organization for direction and guidance, but is free to create its own policy to better meet project needs and demands as necessary. Some of the peer researchers remain unhappy with the differences in policy between the project (which is able to be both more flexible and more responsive to individual needs because of the smaller number of people involved) and its sponsoring organizations.

Conversely, the peer researchers saw many benefits of having worked with other community agencies in setting up their focus groups and interviews. These included:
They then had ties with agencies who were already doing work in particular communities and to which they could refer participants who they felt could benefit from contact with these agencies;
It allowed the diversity of the peer researchers as a group to be utilized to the fullest extent;
It enabled the project to raise awareness of need to a more diverse group of organizations; and
Although it could be a very rigorous process to receive permission to recruit through these organizations (particularly Trinity Western University), it allowed women more opportunities to connect with potential participants than if they had relied solely on personal contacts.

Innovation and demonstration

(Stephanie Kellington with input from the peer researchers)

The most innovative feature of our project was the use of a very disparate and diverse group of women as "peer researchers". The mere fact of having undertaken a "research" project with peers, rather than "experts", carrying out the research is a noteworthy innovation of the project in and of itself. Also noteworthy, was the way in which this team of women was able to come and work together.

If it had just been the project coordinator, or any other "outside expert" going into communities and conducting these focus groups and interviews, chances are that person would not have been able to get the same kind of responses the peer researchers did because they were (usually) known to the women they were talking with. Also because of time constraints and a lack of knowledge about where to go and how to hook up with people, it would have made the project more difficult to carry out for a single person than for many. Certainly the number of peer researchers who were able to pull in women who were friends, neighbours, and acquaintances, and who would not otherwise have talked to "researchers", enabled us to hear the voices of women who may not be represented in research with great frequency.

Had the research been conducted solely by the coordinator, the analysis and the ideas represented in it would have been on "one level" only, representing one person's point of view only, rather than incorporating such a variety of perspectives, knowledge bases and experiences.

The peer researchers felt that having co-facilitated the groups (going along to help another woman with the group in her community) allowed them the opportunity to meet people from groups they might never have met otherwise. In the case of at least one of the peer researchers, she was able to use her own knowledge and advocacy abilities to help women she met through her group access resources and services they needed.

Working with such a diverse group of women also meant that all of the peer researchers had their eyes opened to something or some aspect of other women's experience they hadn't known before. What this was is different for each person, whether it be information about what it means to live with HIV/AIDS or a greater understanding of the constraints imposed by motherhood. Everyone felt they had a greater understanding of the needs and issues for people who's life experience had been different from their own in some way. This indicated to women that we need to go out and do more of this kind of work we realize how expansive and on-going a project such as this could truly be.

Publicity and media

Gina Kjar writes: The [first phase of] the *Listen Up!* Project did receive media attention. There were two radio interviews and a print interview done. The peer researchers were not contacted about their role in the project and considering the magnitude of the project we (the researchers) felt the media coverage was woefully inadequate for this project and that our role was undermined by the supporting organizations in not making greater use of the media.

Strategies for the next phase include, but are not limited to: having a media representative to liaise with the AIDS Vancouver media person, Andrew Johnson; making use of the various community bulletin boards such as Chek 6, VTV, community notes etc.; and follow-up phone

calls on press releases to the various media, as releasing follow-up information to the participants in the project as had been requested.

Stephanie Kellington adds: The researchers have established a media contact list so when future requests for interviews come in, media will be referred to one of the researchers.

Future of the project
Natalie King writes: The peer researchers of the *Listen Up!* Project all agreed that we have every intention in seeing this project through. In doing so we are hoping that we will have financial support from such sources as: SWC (Status of Women Canada); Crime Prevention Strategy; NHRDP [National Health Research and Development Program]; the Royal Bank; DEWC (Downtown Eastside Women's Centre); and VanCity. Also foundations such as: Vancouver Foundation; Ronald McDonald Foundation (for at risk children); MAC Foundation; Body Shop Foundation; Lush Foundation. We could also approach sport teams, [such as] the Vancouver Grizzlies Bear Hug Foundation.

There is still some follow up work necessary [f]or this project which includes:
- the dissemination of the report, which entails mail-outs
- workshops to the police and other social service agencies;
- going out to the regions; and
- conferences to make the people aware of this project and its findings.
- to follow up with the participants of the first/second phase of the project in community forums
- redo the pamphlet to our liking
- translate all documents into different languages.
- an increase in media coverage.

We need the peer researchers to re-commit to the project, make sure that we, the peer researchers, go out and expand on the work we have already done. These are what are needed to maintain and build on gain.

All the women agreed that this project led to identification of new issues and clients as well as the potential for new funders and funding sources.

How the peer researchers feel about the project
Some of the peer researchers offered the following comments about how the project has affected their lives as individuals:

The only thing I look forward to, and I mean the <u>only</u> thing, has been this group.

Because the community that has developed has been amazingly supportive.

It's the first time since I've been diagnosed that I feel like there's someone
out there that a) cares and b) actually has a glimmering of understanding of what its been
like.

This [project] has played a big part in lifting my self-esteem, in getting me out there to do that [getting a job], to accept a position where I'm in the helping field, and not just with HIV but where I'm dealing with people in poverty, and dealing with sexual abuse and children that are labeled FAS or NAS and stuff. It's boosted my confidence. It's made me feel comfortable expressing how I really feel and not holding back.

I did really enjoy it. I was really reclusive there for a long time, being with a person that has AIDS, just ourselves, right? He didn't want to be involved with an AIDS community and, he didn't want anything to do with HIV or anything, so. My awareness to come into it was through [the women on the project who are positive] and say, "hey, this is what AIDS Vancouver offers and that". So I came from a different experience even though I am affected.

You came from a place of denial

Yeah, yeah.

It has shown me that such a diverse group of women, with very, very differing, intense, intense…can continue working through it. It's much easier just to let it go.

It's given me more knowledge and open-mindedness to look at people differently and know that for myself, and my own experience, having a relative that's infected and we never talked about it so it was always put on the back burner. Being with you women and you guys sharing your openness about [being HIV+] and how it's affected you guys has played such a big part in my life. I can go to my brother now and not be judgmental or look down on him or think that he's bullshitting…and being able to share that with my children. I'd have to say that that's the biggest thing I've gotten out of this is being able to sit down with my kids and talk about protection and AIDS and HIV and medication and the whole bit and not feel uncomfortable or bad about talking about that with my children.

I think that what we learned is that what these people go through with HIV and [how] people label them is very wrong…the ones that do have it are singled out and that's not right.

We got to confront a lot of realities about who we are as people by this project.

Insights and general observations
Tom-morrow Blackwind writes: We have learned that women have to be very creative with the money that they have [from income assistance]. Also, that they are taking medications that are prescribed for them and selling it to buy alternative therapies that the government will not cover. By being part of this project I've found the strength of the women, how we overcome illness, prejudice and stereotypes with determination.

Bunsy Jir writes: What I have learned about HIV and AIDS is to educate yourself around safe sex and clean needles, when shared. By gambling with your own life and the life of others too.

Gina Kjar writes: Being a peer researcher on this project has given me a new perspective on the changing face of HIV/AIDS.

Tom-morrow Blackwind continues: One of the biggest surprises we encountered was [that] the group is still together and still able to function productively. For example, none of us were too ill to continue and despite all the factors going on in all our lives, including under-funding [of] this project, we all remained committed to this project and believed in each other enough to continue.

It was a surprise that the skills [regarding interpersonal communication, conflict management etc.] we learned in the training were applied to the group [of researchers] itself rather than the participants, as we had anticipated.

The peer researchers were also surprised that the advisory group was not more involved in the project. We were shocked to learn how many of the resources that are set out for HIV+ persons were being used and abused by HIV- people. Some members of the group [peer researchers] were surprised that not everyone involved in the group was positive. Having to meet on a weekly basis [to do the analysis] was a surprise. The project ended up being more than just the interviews and the focus groups in regard to the amount of work it was going to take to complete the project.

What would you do differently if you were to do it again?

We would have better funding and honorariums [for the peer researchers].
More condensed information.
Stricter format [for the focus groups].
Fewer peer researchers [so that the available resources could be allocated to more realistically meet needs – at times we tried to do too much with too little].
Clearer picture of what was going on to be given to the peer researchers before starting the project.
More info given out about HIV/AIDS [a more prominent educational component to the project]
Some peer researchers felt they needed more training to facilitate focus groups better.
More money, food and bus tickets for the participants of the focus groups and the interviews.

Other Evaluative Information

An external evaluator conducted an evaluation of the training component of the project. Her report can be found in Appendix B. After this, we moved to an empowerment evaluation model. Empowerment evaluation theory (Boyce, 1993; Coombe, 1997) argues that traditional evaluative practices put the responsibility and *ability* to evaluate work that is concerned with social transformation (such as this project) in the hands of those who have *benefited* from or are relatively privileged within social systems as they currently exist (i.e. those who are educated and well-paid as *professional* evaluators). It further argues that, in evaluating projects concerned with social transformation and remedying systemic inequities the people who should really be evaluating success are those who stand to gain the most from success – those who are involved as clients, members, and beneficiaries of change. With this idea in mind, the peer researchers as a group took some materials developed by the external evaluator (such as questionnaires for participants) and developed their own plan of evaluation. This section reports on the results of some of this work.

Summary of research participants' evaluation responses
In order to allow the women who participated in the interviews and focus groups an opportunity to give us feedback on their experiences of the project, a brief, four question evaluation form was given out at the end of every focus group and some of the interviews. Women participating in the focus groups were asked to give us their feedback immediately. Those participating in the interviews were given the option of filling the form out at a later time and mailing it in if they were not comfortable filling it out in the presence of the peer researcher who had just interviewed them.

Forty-two of 42 participants (100%) in the focus groups filed out an evaluation form. Twenty of 44 interview participants (45%) filled out an evaluation form. The number of interview participants who were able to fill out a form was somewhat low because evaluation forms were mailed to peer researchers a few days after the completion of the training course and by the time they were received a few of the peer researchers had already completed all of their interviews. Over-all, however, we received evaluative feedback from 62 of our 86 participants, or 72% of the total number of women who participated in this phase of the project.

There were very few differences between the feedback we received on the interviews and focus groups so in the interest of brevity, the responses of these two groups of participants are combined in the summary that follows.

Satisfaction
All respondents indicated at least some satisfaction with their decision to attend the interview/focus group. In response to the question *"Are you glad you came to the interview/focus group today?"*, only two respondents (2%) replied with anything other than an unqualified yes. These two respondents replied respectively "*yes and no*" and "*yes, but I need more info*".

When asked to describe what it was they had enjoyed about the interview/focus group women's responses ranged across a diverse variety of topics.

Ten women (16%) mentioned most appreciating something they had learned that day, from information on HIV/AIDS *(we discussed many important issues involving women and HIV)* to women's health issues generally *(I never really thought about health issues until now. I'd like to learn more about it and get involved.).*

Eleven women (18%) particularly appreciated being given a chance to speak out on these topics and the feeling that their voice was being heard *(freedom to express exactly how I wanted/needed; the chance to be heard).*

Five women (8%) singled out the emphasis on solutions to social problems (rather than just problem identification) as the thing they most appreciated *(the sincere desire to instill change, to do more than just talk; suggestions to concerns were very thoughtful),* Five women focused on the possibility for personal empowerment or change at an individual level. *(For the first time I felt comfortable talking about me; [the peer researcher], she makes me feel better about myself and helps me talk more about my feelings).*

Sixteen women (25%) mentioned particularly appreciating some aspect of the format and atmosphere of the focus group or the interview or something about the peer researcher themselves *(asked for my opinion, no judgment, asked thought-provoking questions; the low key atmosphere was a good table for discussion; compassionate feedback that I received from the interviewer).*

Particular to the focus groups, eighteen women (29%) specifically mentioned something about being together in a group of other women, or the specific group of women they were with, as being what they most appreciated *(I liked how real everyone was and how open and willing everyone was to understand; I liked the open talk).*

Finally, nine women (14%) mentioned another aspect of the group or interview, ranging from the food, to *"everything"*, to the opportunity to examine unrevealed biases and misgivings as the thing they most appreciated.

Impact

Women mentioned an equally wide variety of things they felt they had got out of taking part in the focus group or interview. In response to the question *"What do you feel you got out of taking part in the group/interview?"*

Five women (8%) specifically mentioned having increased their knowledge of HIV/AIDS related topics *(I've gotten a better understanding of the health issues for HIV/AIDS)*

Twelve women (19%) mentioned gaining knowledge or learning generally as what they had gotten out of attending *(I gained information and feel slightly less ignorant for having taken part).*

Thirteen women (21%) felt that what they had got out of taking part in the research was a chance to have their opinion and ideas heard *(I'm glad that my voice can be heard. I'm glad someone asked; someone listened to me).*

Twelve women (19%) again focused on the possibility of social action arising out of the project and the opportunity to contribute to that action by taking part in this phase of the research *(being possibly part of change; it was really important to do this by women for women).* Conversely, Eleven women (18%) felt that what they had most gotten out of the process was some sense of personal empowerment or personal change *(encouragement to value myself more and to make a difference in other people's lives; I feel better about myself and not so shy to talk about my HIV).*

Two women (3%) felt that what they had got out of participating was an opportunity to be in an environment in which they felt comfortable to speak and knew they would not be criticized.

Particular to the focus groups, seven women (11%) felt that what they had got was an opportunity to be with or meet other women and the benefits this in itself had brought *(it gives*

me a chance to meet other women who are positive and feel more at ease about my HIV; an opportunity to meet other women who are concerned with finding solutions to women's health care issues).

Ten women (16%) mentioned other benefits that they felt they had received from taking part in the research from "*five dollars and two bus tickets*", to *"and awareness of the problems I've yet to solve"*, to an opportunity to work on *"…keep[ing] my heart and mind open – this type of meeting stretches and challenges set patterns of thinking".*

Critiques and challenges

When women were asked what they hadn't liked about the focus group or interview the majority (38 respondents or 61% of the total) replied with some variation of the word "nothing". A further seven women (11%) left this question blank. Of those who did respond seven (11%) mentioned something to do with the format of the group or interview (for ex. *It was too short; interruptions*). four (6%) respondents critiqued some aspect of the content (for eg, it was only one perspective. I thought a lot of the questions were vague and repetitious), and six (10%) mentioned another factor (such as I as tired; it was too warm; or not enough money).

Suggestions for other topics

In order to examine the completeness of the survey and focus group discussion guides, participants were asked what other topics they would have liked to talk about in the research process that they didn't get a chance to. The incredible diversity of the list women generated speaks well to the enormity of this topic as well as to the variety of perspectives and opinions held on it. Topics women mentioned having wanted to talk about included:

- caring for children and babies with HIV (2)
- everything; clothing; dental; actual steps towards filling a crack
- other STDs and the social issues connected to them
- other STDs and Positive Women's Groups
- more on self-esteem; more on mental illness (3)
- emotional ones and how they effect your physical health; I think there should have been more emphasis towards the theory of a healthy mind first then a healthy body; bipolar mood disorder; issues relating specifically to HIV and diseases related to HIV eg. eyes, gynecological issues (2)
- alcohol abuse
- HIV- related medication and how to take it safely (4)
- hunger; violence against women;
- prostitution;
- arthritis therapy for people who do not want to take pills to get to feeling good
- glasses, eye check-ups
- women's health in general; cancer
- doctor patient relationship in terms of 2 way communication
- pro-active medical attention
- self-care of health
- weight (over and under)
- addiction (stopping the cycle) (2)
- abusive relationships (how the hell to stay out of them)
- more support services for family members living with the virus
- homeless people

- there needs to be a clinic for multiple diagnosis
- medical marijuana

Additionally ten women (16%) left this questions blank, sixteen (26%) specifically indicated that they felt the discussion had included everything that was necessary and one (2%) replied that she had no preference, anything else would be fine.

Summary of evaluation meeting between the advisory group and the peer researchers
As part of the evaluation process for the project the peer researchers and the project coordinator jointly devised a questionnaire that was administered to the members of the Advisory Group. Four Advisory Group members attended a one hour-long meeting with the peer researchers and went over their responses verbally with the peer researchers. Three other evaluation questionnaires were mailed out, one of which was returned.

Two of the biggest challenges the Advisory Group identified pertaining to their own work with the project were around issues of communication and funding. In regard to communication they felt that there had been somewhat of a communication break down between the peer researchers as a group and themselves. They would have appreciated more feedback from the peer researchers about what they, the peer researchers, wanted from the Advisory Group as well as more formalized links between these two groups – including more direct links that were not mediated through the project coordinator.

At the joint evaluation meeting, they expressed some surprise that the peer researchers had wanted them to be more involved and indicated that it is often considered intrusive for Advisory Groups to be directly involved with attending research meetings in these kinds of projects. In order to increase communication and feedback between the two groups the Advisory Group was in support of the peer researchers joining Advisory Group meetings on a regular basis in the future.

The Advisory Group identified sourcing funding as one of the other biggest challenges they felt the project had faced. While some advisors exterior to the project have indicated that sourcing funding is not a usual role for an Advisory Group, this was an area in which our Advisory Group members were asked for advice or ideas. Actual proposals were written and developed by staff people at the sponsoring agencies and the project coordinator.

Funding has been an on-going difficulty due to the multidisciplinary approach of the project and its longitudinal nature. It is partly prevention, partly support, partly research – but community and peer-based, with few academic affiliations. It's also partly about poverty, partly about safety and partly about health care.

Other challenges the Advisory Group identified included:
- time
- making sure that all of the Advisory Group members were up-to-date and aware of what was going on with the project
- clearer articulation of the roles and responsibilities of Advisory Group members;
- the small size of the group acting as a potential barrier to complete fulfillment of its roles

- ensuring that the various members of the Advisory Group, with their very diverse backgrounds and levels of previous involvement with the "AIDS world", felt comfortable and valued at the Advisory Group meetings.

The main achievements the Advisory Group identified were that they did feel that the project had successfully achieved its research goals while acting as a model of how participatory action research could be done. They also felt that the power and strength the peer researchers had manifested and the way they had truly owned the work and process of the project were sure signs of its success as "participatory" research.

Various gains the members of the Advisory Group felt they themselves, or the organizations they represent, had achieved through their participation on the Advisory Group included:
increased knowledge about women and HIV in regards to the broad social determinants of health
increased knowledge of working with diverse communities
better knowledge of the agencies and resources available to women in the DTES
a better understanding of peer volunteer programs
increased insight into participatory community-based research projects and
more experience with sourcing and writing funding proposals.

Peer researchers/project coordinator's evaluation of ourselves as a group
The peer researchers and project coordinator also engaged in an exercise whereby we conducted brief written evaluations of each other and the way we worked together as a group. Individual women received feed-back from their peers about the things their peers saw them as having done particularly well ("I really appreciated about X that…) as well as things they found difficult or challenging about working them ("I sometimes got frustrated with X when…). Individual women's evaluations were distributed to them privately and will not be reported on here.

The peer researchers felt that the things they had done well in working together as a group included: working through conflict and disagreements; putting differences aside to work together; brainstorming; learning from each other; and being dedicated to the project in order to accomplish a great amount of work.

Things it was felt we could have done better included: managing time in meetings; completing the project more quickly; having more work-focused meetings that were less focused on helping people work through emotional issues; incorporating some of the fabulous discussion that was had at the meetings in to the writing of the actual report; sharing information from different people's focus groups and interviews; more consistent attendance at meetings; and learning to share our frustrations with each other personally rather than talking behind people's backs.

For more information on how we feel we met our objectives, factors that contributed to the success of the project, and factors that presented challenges, as well as a legion of other issues, please see the section titled "*Reporting on the project as a* project*".*

Recommendations

Poverty

1. Rates for all forms of provincial income assistance should be increased in order to provide recipients with the basic requirements to lead a health life.

   a. Community-Based Organizations (CBOs) should organize a series of meetings with provincial government officials to present their clients concerns to these officials and then *report back* on the results of these meetings to clients.
   b. Recipients of income assistance should have options about how they receive this assistance – including opt-in programs of specific accounts with different stores.
   c. A "women's advocate" position should be created to help women access DB2 and Schedule C benefits.
   d. The process for accessing DB2 and Schedule C benefits should be greatly simplified and streamlined.
   e. Preventative and maintenance dental work should be available to those living on income assistance.
   f. Year-long bus passes should be available free of charge to those living on DB2 benefits

2. All levels of government should cooperate to increase levels of funding available to develop subsidized housing stock.

   a. In recognition of women's unique social vulnerabilities to both sexual and physical violence as well as their systemic and structurally induced poverty at least some of this housing stock should be reserved for women only.
   b. In recognition of the fact that poor women currently live all over the province, not just in urban cores, at least some of this housing stock should be located in suburban and rural regions of BC.
   c. Consideration should be given to renovating existing buildings whenever possible, rather than building new ones.
   d. "Guest fees" for hotels should be eliminated and employees salaries should not be tied to the number of guest fees they extract on a shift.
   e. The number of safe houses, transition houses, second-stage housing and detox facilities *specific to women* all need to be increased.

3. Programs should be developed, at the community level, to facilitate women living in poverty receiving entrepreneurial loans.

4. Flexible, hands-on, on-the-job skills development and education programs for women, which recognize diverse earning styles as well as women's needs to be receive income while in school or training should be developed.

5. Lobby banks to alter or eliminate policies which effectively bar poor people from having bank accounts.

6. Initiate community banks, similar to the Four Corners bank, in communities outside of the Downtown Eastside (DTES).

7. The federal government should make good on its promise to develop a national child-care program of universally accessible child care.

8. CBOs should develop high-profile public awareness campaigns to increase public knowledge about the day-to-day realities of those living in poverty.

9. Food banks should:

    a. be open more days of the week
    b. give out recipes with unusual or difficult to cook with foods
    c. develop home delivery systems for those too ill or elderly to stand in line or carry food home
    d. solicit more donations from organic food producers
    e. give out more perishable items (in good condition).

10. Other CBOs should develop a barter system or trading post where members/clients could buy bulk goods more cheaply and then trade with others.

11. The public transportation system should:
    a. increase levels of service at night in all communities
    b. increase levels of service over-all in suburban and rural communities
    c. consult with communities about and then implement measures which would increase women's personal safety and security on transit.

12. CBOs should increase the number and variety of support services available specifically to poor women living all across the province.

Power in Intimate Relationships

1. Women's economic inequalities should be addressed in order to decrease the power men hold in intimate relationships.

2. Girls should be taught in school, as part of "life-skills" classes, about the nature of "healthy" relationships and how to recognize and avoid abusive relationships.

3. Education efforts addressed to boys and men should be developed to increase their awareness about what constitutes abusive behaviour and encourage them to take collective responsibility for this behaviour.

    a. Links between woman abuse and men's own health should be explored and illustrated.

4. The justice system, women's advocates, and those involved in the anti-violence movement should examine current laws regarding adult and child sexual and physical assault and see how these might be altered to better prevent abuse.

5. Service to women leaving abusive relationships should be available to all women, regardless of whether the relationships in question was with a man or a woman.

6. Levels of financial assistance available to women leaving abusive relationships should be increased.

7. Organizations in the anti-violence movement should establish "legal researcher" positions to advise women leaving abusive relationships on legal steps they may take to protect themselves from, for example, being held financially liable for a former partner's debts.

8. Children should be taught from a young age about sexism and the effects it has on women's and men's lives.

9. Increased levels of funding should be allocated to the development of "invisible" female controlled methods of birth control, such as microbicides.

10. Counseling for women and couples involved in abusive relationships should be increased and made easier to access.

11. Doctors and dentists should be receive training on how to recognize the signs of physical and sexual abuse.

12. Changes should be made to the criminal justice system to make the process of pressing charges in cases of physical or sexual assault less traumatic for the survivors of such assaults.

13. Partners of women living with HIV/AIDS should receive information and support to better prepare them for the new realities they and their partners will be living with and hence decrease abuse and manipulation due to HIV/AIDS.

Relationships with Health Care Providers and Institutions

1. Resources to enable women to better identify and connect with knowledgeable and compassionate doctors should be established.

2. Resources to enable women to better identify and connect with knowledgeable and compassionate counselors and mental health workers should be established.

3. Advocacy and educations efforts should be pursued to encourage the health care system to take up a disease model of addiction.

4. Doctors should be encouraged to see patients as more than the total of their disease-related symptoms, and then communicate this view.

5. Diefying and mythologizing of doctors should be reduced so that patients develop more realistic expectations of what doctors know and can do, as well as be less intimidated by, and hence vulnerable to abuses of power from, doctors.

6. A Community-Based Women's Health Resource Centre should be established with a mandate to:

   a. facilitate women's communication with health care providers
   b. provide women with skills, knowledge and training to empower them in their interactions with health care providers
   c. provide basic, accessible information about common women's health concerns.

7. The funding structure of the provincial Medical Services Plan (MSP) should be altered to facilitate greater access to:
   a. complementary and alternative therapies
   b. preventative and maintenance dental care.

8. Increased levels of net-working between health care providers working within different models of care should be encouraged by:

   a. the establishment of a 1-800 line that would stock and share information about treatments in different models of care
   b. increasing the number of inter-disciplinary health care clinics.

9. Measures should be put in place to attract more female doctors to practice in the DTES.

10. Doctors should be encouraged to spend more time with patients explaining how prescription medications work and detailing potential side effects and complications, or should hire assistants to do this.

11. Education for doctors, counselors, and other health care providers should be increased to include information on:

    a. HIV/AIDS and women generally
    b. HIV/AIDS and risks for young women in particular
    c. the realities of daily life for women living in poverty
    d. the realities of daily life for women living with addictions
    e. "sensitivity training" to address sexism, racism, homophobia, ableism, and ageism

12. The health care system should establish an office of "women's advocates" to assist women in negotiating services in the system.

Discrimination

1. Establish general advocacy and support programs for young women that specifically acknowledge and examine experiences of discrimination on the basis of age.

2. Establish general advocacy and support programs for older women that specifically acknowledge and examine experiences of discrimination on the basis of age.

3. Increase funding through the provincial health care system available to women to pay for non-psychiatric counseling and emotional support services.

4. Increase the number of *professionally qualified* counselors, specifically trained in feminist and anti-oppression theories, available to women, particularly those women who are living in or frequenting the DTES.

5. Increase the number of *professionally qualified* counselors available to women outside of the DTES.

6. Increase public awareness of the historical oppression experienced by First Nations people in Canada and how this continues and is reflected in present day situations.

7. More equitably distribute the social, cultural, and economic resources of contemporary BC society to more justly include First Nations people and people of colour.

8. Increase the number of services and support programs targeted specifically to First Nations communities.

9. Increase public education regarding homophobia and its effects on health, social justice, and equity.

10. Teach school children about sexism, racism, homophobia and discrimination of all kinds to enable them to better understand these concepts and hence fight against them.

11. Increase opportunities for cross-class communication and work to eliminate class stratification in order to decrease "poor-bashing" and otherizing of the poor.

12. Increase public education regarding HIV/AIDS in order to eliminate discrimination against those living with the disease.

13. Decriminalize and implement state monitoring of the sex trade.

14. Increase services and support programs available to "working girls" and others in the sex trade.

AIDS Specific Issues

1. A network of women-specific "safe spaces", open to both HIV positive and negative women, to receive information and support regarding HIV/AIDS – however it may be affecting their lives – should be established in a variety of communities across BC, *outside of* the City of Vancouver itself.

2. Among other programs, these centres could present "open houses" where the general public could learn about the daily realities of living with HIV/AIDS.

3. Measures should be developed to attract more HIV/AIDS specialists to practice in rural and suburban areas.

4. More support groups, specifically for *women* living with HIV/AIDS, should be established and widely advertised across the province.

5. Increased resources should be allocated to those living in rural and suburban regions to enable them to develop locally specific educational campaigns – including, when appropriate, bringing back HIV+ persons who have left the community in search of better services and/or safety.

6. Levels of services and support to those who are *affected by*, by not infected with, HIV – including and especially children and care-givers of HIV+ persons alive *or* dead – should be increased.

7. Educational efforts regarding HIV/AIDS and the effects it has on women's lives should be developed and presented to police, court workers, and others involved in the criminal justice system.

8. ASOs should examine developing partnerships which would allow them to distribute female condoms for free, as they currently do with male condoms.

9. Advocacy efforts should be developed to examine and eliminate discriminatory attitudes towards women living with HIV/AIDS that:
   a. make assumptions about how women became infected
   b. make assumptions that women may be more culpable for their infection than men
   c. focus on how women became infected, not on how to help them lead healthy lives once infected.

10. There should be more research done examining the realities and particularities of women's experiences living with HIV/AIDS.

11. Basic safer sex programs – including those focusing on condom use and other barrier methods – should be continued.

12. A proactive Speaker's Bureau of culturally and age- appropriate HIV+ persons should be established to seek out and then present talks in schools on the realities of living with HIV/AIDS.
    a. Contacts could be pursued through public health nurses and individual teachers and counselors.
    b. Young children, who are sexually curious, but not yet active, should be included in education efforts.

13. In some instances, particularly in suburban and rural areas, ASOs should consider being more proactive in advertising their services and making potential clients aware of their existence.

14. Women and children should be more often included in clinical trials to develop new HIV drugs.

15. An integrated plan of care/action regarding women and HIV/aids should be developed, in consultation with the community, to increase efficiency and accountability, eliminate redundancies, and identify genuine gaps in service.

Other Issues

1. The community and other interested individuals should investigate the possibility of establishing a Women's Resource Centre in Langley. Included in the mandate of this Centre should be to provide accessible information and advocacy around a range of health issues including: HIV/AIDS, women's relationships vis-à-vis their health care providers and de-mystifying the medical system for women.

2. Measures to increase the safety of women both living and working on the street should be developed and implemented.

3. Measures to increase the safety of all women in public spaces should be developed and implemented.

4. There should be increased levels of support and services specific to women's issues generally available to women in suburban and rural regions.

5. Whenever and however possible measure to facilitate community involvement, empowerment and development should be encouraged by all levels of government and CBOs.

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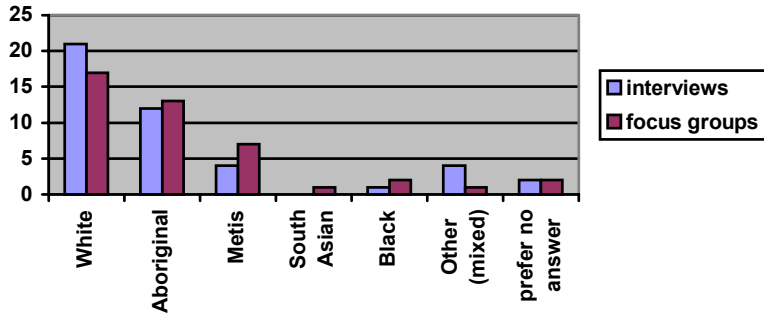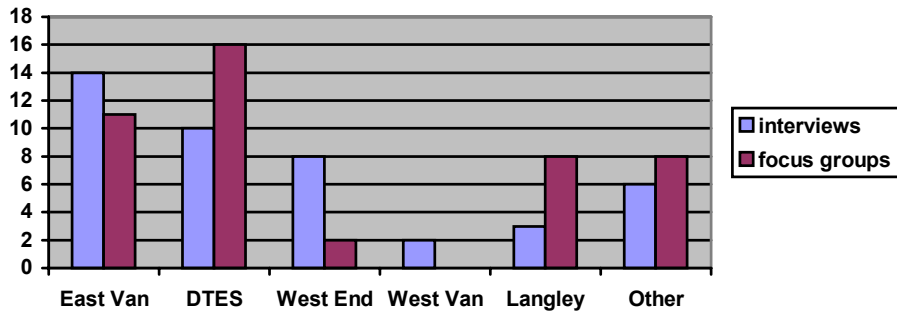# Appendix A – Participant Demographics
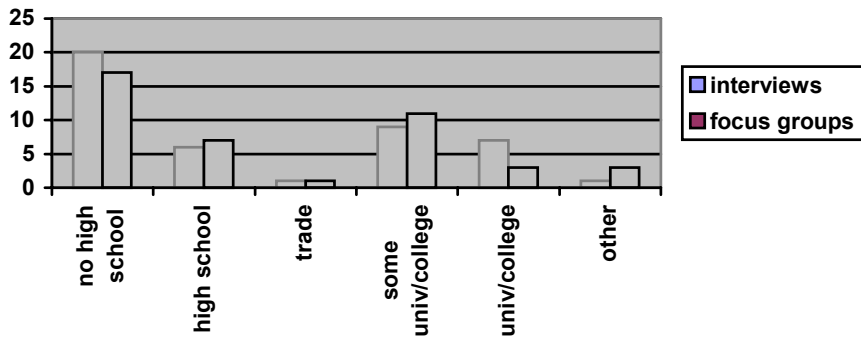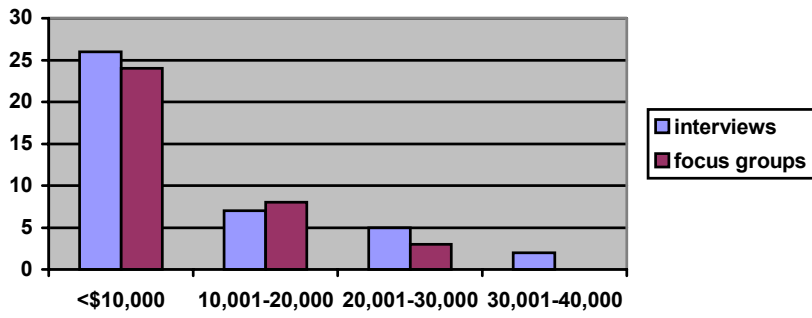
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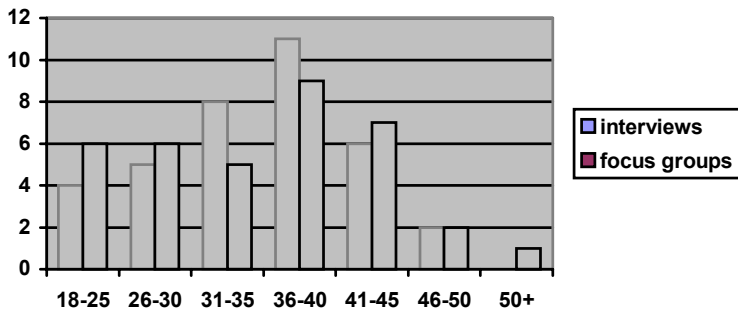
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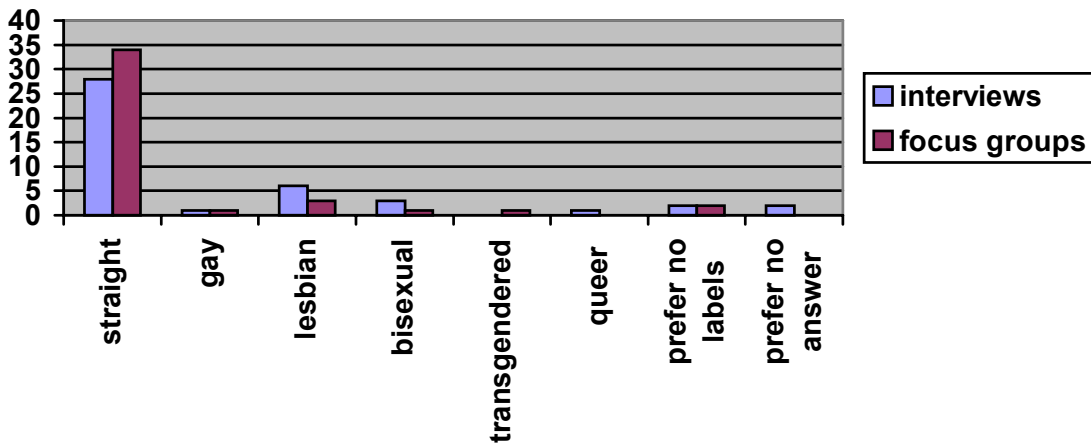
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Area of Residence
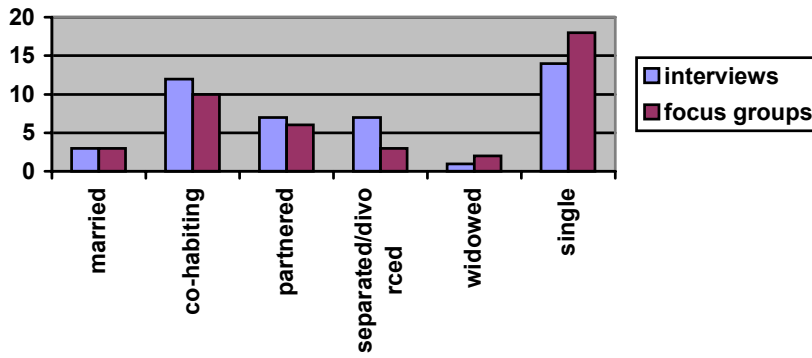

Highest Level of Schooling Completed

Income

Marital Status

Other Questions of Interest

Question	Interviews		Focus groups	
	yes	no	yes	no
Have you experienced a decline in income due to HIV infection?	0	9*	10	23
Do you have children?	27	15	23	19
Do you have pets?	23	15	10	32
Do you have other dependents?	12	30	6	33
Do you practice a religion or spirituality?	30	12	20	18
Are you HIV+?	13	24	16	22

* 28 interview participants were not asked this question

Appendix B: External Evaluator's Report of the Peer Researcher Training

I. Evaluation Process
A qualitative evaluation of the training was carried out by an external evaluator from November to January, 1999. Please see the overall evaluation plan for an outline of the purpose and guiding principles of the evaluation. This plan was developed with the input of the project's Steering Group and its community Advisory Group. Every attempt was made to ensure that the process was respectful and voluntary and that procedures for confidentiality and informed consent were maintained.

The following methodologies were used to collect feedback on the training:
Questionnaires were handed out to the participating peer researchers at the end of the training (please see section IV below for their feedback)
One-on-one interviews were conducted with the trainer and the project coordinator
A review was done of the training materials and handouts.

This process worked reasonably well. The project coordinator put the training into the context of the goals of the project and clarified the follow-up support planned for the peer researchers after the training. Although it would have been ideal for the evaluator to talk directly with the peer researchers, time and resource constraints for the training made it difficult to consider focus groups or interviews with them at this stage. However, there was a good response rate of 78% to the evaluation form. The trainer also shared the informal feedback she had collected from participants throughout the training as well as her assessment of their understanding of community research.

II. Training Achievements
The project has successfully consolidated a team of nine peer researchers to meet its objectives in involving women in each stage of the research process and to enable it to undertake participatory community research on specific health determinants affecting women's risk of HIV infection and illness progression.

Nine participants making up the research team completed an eight day workshop facilitated by an experienced trainer in November, 1999. The workshop covered aspects of doing research such as communication, group dynamics, conflict resolution, what research and action research mean, group facilitation, recruiting community members for interviews and focus groups, conducting interviews, introducing and starting a focus group, note taking, using consent forms, and confidentiality. HIV/AIDS information, a discussion of the social determinants of health and an orientation to the project, their role as peer researchers and the research questions were also provided. Some of the logistics of conducting the community research, such as selecting host agency sites for focus groups, and matching co-facilitators were resolved by the team. They were given checklists for doing the focus groups and interviews and forms for receipts and remuneration. At a subsequent meeting, evaluation of the community research process and further administrative issues were covered. Community resources such as Helmcken House contributed meeting space and a staff member of AIDS Vancouver served as a guest speaker on HIV/AIDS issues.

The training was interactive and respectful of individual learning styles and strengths. An innovative feature of the project was that it encouraged and achieved a high level of ownership by the participants. This process allowed them to have a say in defining the research questions and their role in the project. There was a strong focus on cultural perspectives in communication, roles and values. The peer researchers received information on community resources for women's health and HIV/AIDS so that they would be able to link community members to the help they needed within an action research model.

The peer researchers represented a good cross-section of women from the Aboriginal, lesbian, former drug user and HIV positive communities. They were quite satisfied with the trainer and most were satisfied with the training overall. All felt that they had gained new information and skills from the training such as stronger communication skills, a better understanding of HIV/AIDS issues, and knowledge of conducting a focus group as well as peer support from the group. Please see section IV below for a summary of their feedback.

The trainer was also satisfied with how the training went overall. She observed that a high level of trust, group cohesion, ownership of the research by the women and motivation was achieved in the team during the training. She assessed that all of the team had significantly improved their communication skills and that six out of nine seemed to have understood the research components well.

III. TRAINING CHALLENGES AND LESSONS LEARNED
A key lesson from the training is that a participatory model requires more flexibility to accommodate participants' needs and input and more time for consultation and planning with stakeholders. The women themselves decided to change the training plan for the last two days of the workshop in order to address their issues. It was important to discuss these issues so that they could feel comfortable with their role and responsibilities in the project, gain a sense of empowerment, and feel ownership of the research and research questions. Some also had to work through personal issues and attitudes about HIV/AIDS. However, this took away from the time planned to cover some of the research topics such as more practice in focus group facilitation and data transcription and analysis. As a result, a few of the researchers were less confident about doing the focus groups. The coordinator planned to debrief with each team member regularly and to review data analysis with the team as a hands-on exercise once they reached that stage of the research.

The trainer observed that in working with a group such as this, many personal and social issues were raised that needed to be addressed besides how to do research. More time would have been needed to cover these issues. For example, it would have been useful to hold an orientation for the peer researchers prior to the training in order to address some of their issues internally. It will be important for the coordinator to monitor whether each peer researcher is able to carry out the required research adequately. Since resource constraints do not allow for more group training, the coordinator will need to follow up by encouraging the team members to practice before starting the research and by providing additional support and possibly one-on-one tutoring for those who are weaker, especially the three participants identified by the trainer as less ready to do the research.
Resource constraints affected the process to some extent. The trainer would have preferred her role to be more clearly separate from tasks usually done by project staff. If resources had

permitted, it would have been useful for the coordinator to be present during the entire training. It was difficult to access free space for the training and participants noted that the lounge space worked better than the gym for this type of activity.

Twelve women started the training and nine completed it. The three who dropped out cited reasons such as grieving, mental health and addictions issues as barriers to attending regularly. While participants were screened as a part of recruitment, there will likely be higher turnover in a team made up of women at risk. However, providing remuneration, bus fare and food for the training made it more accessible for low income women as did the less formal, interactive and responsive format used.

IV. Summary of Peer Researcher Feedback
Sample of Respondents: All of the peer researchers were asked to fill in an evaluation form at the end of the training. Written feedback was provided by 7 or 78% of the 9 peer researchers who completed the training.

Satisfaction: Most (71%) of the respondents were quite satisfied with the training overall, while 29% were somewhat satisfied. All found the information presented clear and easy to follow. Most (86%) felt comfortable in the training except one respondent (14%) and most (71%) felt that they had a chance to ask questions. However, only a little over half ((57%) felt they had enough chances to practice research techniques.

They liked best the capable trainer used. Her acknowledgement of different learning styles and individual strengths, and her ability to keep the group focused and to clarify the issues raised. The chance to meet the other women, listen to each others feedback, and the bonding and support achieved among the peer researchers worked well. Some appreciated the chance to contribute to positive change, the information on HIV/AIDS and the discussion on confidentiality.

Impact: All felt that they had gained new information and skills from the training. Most felt that they had gained a good understanding of what research means (86%); how to handle group situations (71%0; how to do interviews (86%); how to do focus groups (71%) and their role in the project (86%). They cited benefits such as a greater awareness of verbal and nonverbal communication, stronger communication skills including listening skills, a better understanding of HIV/AIDS issues, skills in conducting a focus group, and peer support from the group. Six out of seven (86%) felt that they were ready to carry out the community research, while one felt apprehensive about facilitating focus groups and planned to try to practice more to get ready.

Recommendations: The majority of participants felt that there had not been enough time for the training. Respondents offered recommendations to improve the training such as:
Remuneration: More money for the peer researchers
Training content: More practice, discussion and role playing on doing focus groups
Group dynamics: Staying on topic better
Training time: More time for the training to cover all aspects of research
Space: Use of the same room for all of the training
Some indicated interest in further training on homophobia as well as more practice in facilitating focus groups.