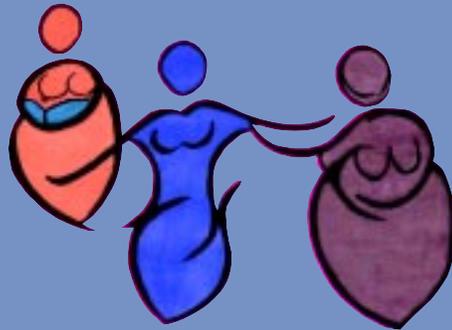


# Listen Up!

## Women are talking about...

### Women's Health Research Project Report on Phases 3 and 4



## Community Action for Social Change

### HIV/AIDS Action Plan for BC Women

October 2003

Written by: Valerie Van Clieaf

This report is dedicated to  
the memory of Wendy Wartman-Katz  
who worked with us from the beginning.

Sponsored by:



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The People of British Columbia

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with the assistance of the Government of British Columbia

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# Introduction

## Hearing Women's Voices

Listen Up! is the first peer based, community action research project of its kind to examine how the social determinants of health put women at greater risk for HIV infection than men. Women's voices - in particular, women who live with HIV - had not been actively present in HIV research when we started the project in 1998. The women who have been involved in the Listen Up! Project - as peer researchers, advisors, participants, and in the present stage as community presenters - determined both its focus and direction.

In the planning stages of this project back in 1998, we had no way of knowing just how quickly the rates of HIV infection among women would escalate.

	In Canada	In BC
1985 - 1995	9.7%	
1999 - 2000	24%	28%
2001 - 2002	44.5% (51.5%: 15 -19 yrs) (40.8%: 20 - 24 yrs)	36%

When a literature review was done for the project in 1998, approximately 1 in 10 new HIV infections in Canada were women. Shortly into the research portion of the project, the number of infections had risen to almost 1 in 4, while at this writing, the number is almost 50%. Heterosexual sex remains the primary risk factor for women, accounting for over 60% of newly diagnosed HIV infections.

Aboriginal people have been hard hit by the epidemic. A study by the Atlantic Centre for excellence in women's health shows that between 1998 - 2001, Aboriginal women made up 45.6% of newly diagnosed HIV cases. Infection occurs at a younger age for Aboriginal women than non-Aboriginal women. Young women comprise the largest percentage of new infections overall.

As Listen Up! clearly demonstrates, women know what social changes are needed to reduce their risk for HIV infection. Those involved in the research phases of the project made 73 recommendations in the areas that affect their lives: poverty; power imbalances in intimate and familial relationships; problems with health care providers; discrimination, oppression and racism; AIDS specific issues and other issues, which included for example, women's public safety.

In Phases 3 and 4 we shared the research recommendations with women in communities involved in the research and beyond, to other communities, both in the lower mainland and rural BC. In this final phase, past recommendations were given added weight but important for us also, new issues were identified.

### ***Education Needed for all Women, Men and Youth***

We found that too many women have little or no knowledge of how HIV is transmitted, let alone their greater risk for contracting it than men. In isolated regions there are still some women and men who remain unaware of its existence. The absence of accurate public knowledge has insured that myths about the disease are widespread.

- Men in many communities believe that they cannot contract HIV through heterosexual sex.
- The belief persists, even with some health care workers, that one can catch HIV from everyday contact with an infected person, including using or touching their dishes or cutlery.

### ***Role of the Media***

Print and TV media could be a powerful ally in working to slow the spread of HIV. Because of the availability of HIV medications, the media continue to portray HIV as a chronic, manageable disease. It is, in fact, debilitating and unmanageable for too many.

- Many women have had to stop, or are afraid to start, antiretroviral therapy because the side effects are so severe.
- Others continue taking medications no matter how severe the side effects because their health has deteriorated to such an extent that they have no other choice.
- Only with the release of 2001 statistics indicating a dramatic increase of new HIV infections amongst women – particularly young women – has the press begun giving this issue the attention it deserves.

### ***Fear and Stigma Must be Addressed***

HIV is now present in every community in Canada and here in BC, but fear of the disease and stigma associated with it continue to be major barriers to education, testing and accessing treatment.

- It is, then, with some urgency that women in all phases of this project have said that the fear and stigma that HIV engenders must be addressed.

### ***Social, Cultural and Economic Realities Put Women at Greater Risk for HIV***

Too many women continue to lack adequate income, food and shelter to care for themselves or their families. For economic and cultural reasons, many women are forced to remain in situations where physical or emotional abuse is a daily reality. Even with an understanding of the importance of safe sex practices, negotiating safe sex is difficult or impossible for many women.

Kunda Dixit, co-publisher of the Nepali times reminds us: “AIDS is not a medical problem but a social, cultural and economic one”.<sup>1</sup> As our research and the work of others worldwide clearly shows, it is these issues that are at the root of the HIV epidemic, both here in BC and elsewhere. Working with women to identify both why they are at greater risk, as well as the social changes necessary to reduce that risk, has been the focus of the *Listen Up!* Project. This report, and [An HIV/AIDS Action Plan for the Women of BC](#) - are the culmination of that work.

## Overview: *Listen Up!* Research

The *Listen Up!* project was initiated in 1998, when a literature review, *Women, HIV and the Determinants of Health*, done by S.C. Kong, found no published Canadian research that examined the impact of women's social, economic and political realities on HIV infection and illness progression. Past research had been limited to examining women's behaviours and how these put them at risk, for example Intravenous Drug Use (IDU) practices.

It was decided that a Vancouver-based research project would benefit AIDS Service Organizations and other women's equality and health advocacy groups. It would help them to better understand and respond to the ways in which social factors affect women's vulnerability to HIV infection. *Listen Up!*, the first research project of its kind in Canada, was designed and implemented with this in mind.

It is often the case that when women get sick, we get blamed for it as though we did something wrong (or failed to do something right) by becoming ill. *Listen Up!* research focused instead on the social, economic and political determinants of health and how these, over which women often have little or no control, put them at risk for HIV infection and the faster progression of the illness to AIDS.

Also, we wanted to shift the focus of research on women and HIV/AIDS away from an increasing emphasis on "experts" speaking for women to the voices, ideas, and experiences of women themselves. Women living with HIV and women affected by the disease have been involved since the project began, as advisors, peer researchers, and participants.

### *The Guiding Principles of the Project*

1. Health must be defined in a holistic fashion and recognize that social factors such as gender, race and class, can have a detrimental effect on a woman's health.
2. The experiences and ideas of the women participating in the project would inform and determine both its shape and the use of its results.
3. The project would be community-driven, through the use of a peer-based, action-oriented research method. The results would be given back to the communities involved as well as the larger community and beyond.

### **Research: Phase 1**

Six focus groups were held in Vancouver at:

- Positive Outlook (a drop-in space for those living with HIV at Vancouver Native Health)
- British Columbia Persons With AIDS Society (BCPWA)
- Drug and Alcohol Meeting Support for Women (DAMS)
- Downtown Eastside Women's Centre (DEWC)
- Storefront Orientation Services (SOS)
- A small community just outside the lower mainland of Vancouver, BC

These groups, of 4 - 18 women, discussed how the following social factors affect women's risk of HIV infection and illness progression:

- Income
- Power in intimate relationships

- Relationships with health care providers and institutions.

Women involved in this stage included those who are:

- HIV positive
- Women who sleep with women or are bisexual
- Have a mental illness or dual diagnosis
- Aboriginal
- Current or former substance users
- Spanish-speaking immigrants and refugee-immigrants

Results of these discussions had a number of important outcomes. We wanted to work with a very diverse group of women and this was an opportunity to test our assumptions and ensure the project responded adequately and appropriately to their concerns. Women identified a number of social barriers to their health that we hadn't included initially. These additional barriers were included in the next round of focus groups and interviews.

- Discrimination experienced with health care providers and other institutions and
- Problems with AIDS services and service organizations.

Information gathered in Phase 1 determined the direction the research would take and also helped us identify women who were interested in working as peer researchers in Phase 2.

### **Research: Phase 2**

In this phase, we worked with a community-based peer research model to learn what women wanted to see done to reduce or eliminate some of the barriers identified in the previous phase. Nine women were recruited as peer researchers for this phase and all participated in a two-week training period in community-based research methods. In November of 1999 they completed a series of 44 one-on-one interviews and focus groups with women who are:

- HIV positive
- Care-givers (paid and unpaid), family and friends of persons living with HIV or who have died of AIDS.
- Professionals
- Aboriginal
- Diagnosed with a mental illness or dual diagnoses
- Living in, or frequent, Vancouver's Downtown Eastside (DTES)
- Current or former substance users
- Christians in a university community

The peer researchers and project coordinator then embarked on a five-month project to collate and analyze the findings. From these findings emerged a comprehensive list of recommendations for action.<sup>2</sup> The recommendations women made speak clearly to the acceptance by a larger society that women and their families can live in poverty, isolation and fear. Also highlighted is women's recognition that their empowerment is a necessary first step to changing this inequality that puts them at greater risk than men for HIV infection and the faster progression of the illness to AIDS.

In the final two phases of *Listen Up!* - Community Action for Social Change - we shared these recommendations with women in diverse communities in both the lower mainland and rural BC, inviting their comments and further suggestions. Next we will look at what we accomplished as well as the challenges we faced in our community work.

## Phase 3: Community Action

Community consultation takes time, and commitment. Margreth Tolson and Stephanie Kellington were involved in different capacities in the research stages of the project. As they stated in a report on the research:

“What we are learning in our research is that truly representative community consultation and mobilization is a slow and complex process. In taking the time to develop community voice and listen for what is being said (not just what we want to hear), the sense of ownership and empowerment felt by all members of the team, and depth and diversity of information gathered has created a very rich research project.”<sup>3</sup>

The process of community consultation is time consuming, but very rewarding nonetheless. A sense of hope is engendered as more and more women from diverse cultures and backgrounds commit to working together. We have found this to be the case in all phases of the project.

Those peer researchers who had been involved in Phase 2 and several women newly recruited to the project met a number of times over a two-month period to decide on the kind and type of training they felt would assist them in community work. Skills they developed during the seven days of training arranged included:

- Liaising with communities they wanted to work with and make presentations to.
- Skills needed to host a public forum
- The hallmarks of a good presentation.

The project coordinator and peer researchers created a draft presentation of the research and recommendations, begun during the training and completed in December of 2000.

### ***Back to the Communities***

- The coordinator and researchers wrote a journal article about the project.<sup>4</sup>
- The report for Phase 2 was released in October 2000. It was distributed to community members involved in the research, and to others beyond these communities.
- A press conference was held to launch the report.
- Radio station, News 1130 interviewed one of the peer researchers.
- Vancouver’s West End Courier wrote an article on the project.
- One of the peer organizers wrote an article on the project that was submitted to the newsletters of: Downtown Eastside Women’s Centre, South Asian Women’s Centre, South Surrey/White Rock Women’s Place and Positive Women’s Network.

### ***Input on Committees of Other Organizations***

- One woman sat on an End Legislated Poverty subcommittee charged with developing an education toolkit on women and poverty that continues to be well received.
- Several women worked with the Wages and Welfare committee of End Legislated Poverty to initiate a letter-writing campaign to the Royal Bank of Canada re: one of their policies that discriminates against poor people.
- Community organizers initiated their own letter writing campaign to lobby the BC government to increase the amount of money people living on BC Benefits receive.

Draft letters were made available to participants at two public forums.

- A peer organizer worked with the 52% Coalition and their Assessment Tool sub-committee, to bring the issue of women's greater risk for HIV infection and illness progression to the forefront of the (then) up-coming 2001 provincial election.

#### ***Public forums held in Vancouver***

- A presentation on the research and recommendations was made to the Children and Women's sub-committee of the Vancouver HIV/AIDS Care Coordinating Committee;
- A second public forum was held at Vancouver Native Health and was geared to women living in Vancouver's downtown eastside.
- Evaluation forms were distributed to participants at both forums.
- As well, draft letters to the BC government, part of a letter writing initiative to have BC Benefit levels raised, were also distributed.

Comments women had about both forums bear repeating. In response to the question: The most important thing I got out of coming to the presentation today was, one woman said: "Being able to sign the letter to the BC government to increase income assistant rates." Another said: "I was encouraged to see peer researchers, women of colour, interviewing their own, women addressing their own's issues".

#### ***Conference Presentations***

- Pacific AIDS Network Conference (Vancouver, March 2001)  
Two members of the group presented on the Listen Up! project research and recommendations, at this conference held in Vancouver.
- Canadian Women's HIV/AIDS Conference (Toronto, May 2001)  
This was the first, and at this point, is the only women's HIV/AIDS conference to be held in Canada. The Listen Up presentation was very well received and in the words of one of the presenters: "showed how hungry people are for the common sense approach that the project embodied". In the past, Canada had participated in American and world conferences.

Community Action, Phase 3 ended in February 2001, five months after it began. The first three months were taken up with a good deal of planning, both for the direction of this phase and training for the women involved. This left only two months for community work to take place and given so short a time period, a good deal was accomplished.

## Phase 4: Community Action

Phase 4 lasted sixteen months, from August 2001 to December of 2002 and was the completion of a process begun in Phase 3. Our broad mandate included the following:

1. To share the Listen Up! research results and recommendations with the communities originally involved in the research, completing the process started in Phase 3
2. To focus attention on a broader range of communities in both the lower mainland and rural BC
3. To develop and HIV/AIDS Action Plan for Women in partnership with both Aboriginal and non-Aboriginal communities and organizations we were working with in the lower mainland and rural BC.

### ***A Mutual Sharing Process: Strategizing With Women For Change***

It is important to note that this stage of the project was not a one-sided process. We did not want to be a *traveling road show*. We hoped women would share their knowledge with us, to increase our mutual understanding. In all of the communities we worked with, we learned as much as we shared and the project is richer for this.

### ***The Working Group***

The Working Group brought together for this phase of the Listen Up! Project was comprised of six women. Several of the women were involved in the research phases of the project as peer researchers or advisors and have been invaluable in providing continuity. The rest of the women were new to the project.

The coordinator served as liaison with individuals and organizations in the communities we wanted to reach. Working Group members also did outreach to communities they had connections with. Applications to do presentations at a number of conferences were filed. Once an agenda of presentations and workshops had been set for several months in advance, we turned to honing the team's presentation skills.

The Working Group contributed their personal strengths and a vision of what this phase could accomplish. The project benefited greatly from the rich diversity of their experience.

### ***Training the Working Group***

The Communications Coordinator for the Positive Women's Network facilitated a workshop for the Working Group for this phase. The workshop offered the women training in a number of skills that are the hallmarks of a good presentation including:

- Choosing key messages and how to deliver them
- Holding the interest of the audience
- Key points for successful visuals and the use and importance of learning aids.

### ***Creating a Presentation***

Working with the coordinator, the Working Group created a presentation outlining the *Listen Up!* research and recommendations arising. This work went through several draft stages and over time, a number of variations on the slide presentation were developed, sometimes in response to information needs of the host community or group.

### ***Co-presenters from other communities***

Due to the lack of knowledge about HIV and AIDS in most of the communities we worked with, we added an HIV/AIDS education component to our presentations.

- In African communities and the Vietnamese we were greatly assisted by service providers who had been trained to present basic HIV information in their own language.<sup>5</sup> These women also provided simultaneous translation of presentations on *Listen Up!*
- Educators from Healing Our Spirit Aboriginal HIV/AIDS Society<sup>6</sup> journeyed with us to rural BC. They presented to both Aboriginal and non-Aboriginal groups on HIV definition and transmission.
- One member of the Working Group prepared a presentation in French for a group of Francophone women at La Boussole Community Centre in Vancouver. This centre offers services and support to French-speaking immigrants and Canadians.

In our work in both the lower mainland and rural BC, we shared the research results and recommendations of the Listen Up! project in a variety of ways which included:

- Written reports
- Community presentations and workshops in the lower mainland and rural BC
- Conference presentations
- Newspaper, newsletter and journal articles
- Participation on several public advisory committees sponsored by the Vancouver Coastal Health Authority
- Sponsoring a forum on the impact of HIV/AIDS on the women of BC
- Creation of a video of the forum, available as a teaching tool
- Participation in several radio shows and radio interviews (one interview on the CBC French language station, Radio Canada)
- Creation of *Listen Up!* project brochures
- Creation of an HIV/AIDS awareness handbill

We also benefited from interviews with key players in a number of communities and organizations. These women and men shared their thoughts both on the Listen Up! research and recommendations and on the special needs of the communities with which they work. We have learned as much as we have shared and are grateful for the commitment to women's health that all participants have shown.

### ***Research and Recommendations: Written Format***

- A précis of the Listen Up! Project, research and recommendations was included as an addendum to provincial government information packages to all Transition Houses in BC.
- Information about women's greater risk has informed the education materials developed by the Red Road HIV/AIDS Network. This BC organization offers education and skills building workshops to 56 member organizations serving Aboriginal people in BC living with HIV.
- A brochure about the project is available in English, French, Spanish and Swahili.
- A handbill, outlining testing, treatment, support and advocacy information for women living with HIV, or who wish to be tested, is available in 13 languages including: Chi-

nese, English, French, Hindi, Japanese, Korean, Persian, Punjabi, Russian, Spanish, Swahili, Tagalog and Vietnamese.

- Availability, in both hard copy and electronic format, of reports of all stages of the Listen Up! Project: Research and Recommendations Phases 1 and 2 and Community Action for Social Change Phases 3 and 4. These reports have been distributed locally, across BC and to individuals and organizations in Canada. A Spanish translation of Phase 1 is also available.
- All reports are also available from: [www.hiv-cbr.net](http://www.hiv-cbr.net) (devoted to community-based HIV research): and the Positive Women's Network website: [www.pwn.bc.ca](http://www.pwn.bc.ca).

#### Community Mobilization In Lower Mainland BC

During this phase, the Working Group made over 30 presentations to a variety of communities, organizations, conferences and on radio in the lower mainland and rural BC.

#### **Lower Mainland: Presentations**

- African communities in Vancouver - (three presentations)
- Intravenous drug users support group
- Drug and alcohol meeting support group for women (DAMS)
- Vietnamese community group in Vancouver
- Three Youth Health Fairs
- Bridge Housing Society, Downtown Eastside (street involved women)
- MOSAIC Settlement Services - to Settlement Counselors offering services and support in 20 languages to refugees and refugee immigrants.
- Vancouver Police Board
- La Boussole Francophone Centre - Outreach to Francophone women
- Association of Latin American Community Counselors
- International Women's Day, 2002. AIDS Vancouver initiative that focused on women's greater risk for HIV infection: Several Listen Up! Working Group members presented.
- St. Paul's Hospital - to students from various health disciplines enrolled in an HIV/AIDS elective, offered by the University of BC.

#### **Radio and Video**

CFRO Co-op Radio: A member of the Working Group hosted two radio shows devoted to *Listen Up!* project: (Nov, 2001, May 2002).

CBC English Language Radio: Working Group participant interview (March, 2002)

CBC French Language Radio: Working Group participant interview (Dec. 2002)

Videotape of the November 2001 forum *The Impact of HIV/AIDS on the Women of BC*.

#### **Print Media**

- **Georgia Straight** *For women, AIDS Can Be Equal-Opportunity Disease*, Gail Johnson (Dec, 2001)
- **Vancouver Sun** *AIDS isn't manageable*, Marcie Summers (2001)
- **InfoCAS** *Listen Up! Women's Health Research Project*, Valerie Van Cleef (Dec, 2001)
- **Chetwynd Echo** *Healing our Spirit, A Partnership in Healing and Women's Health*

(May 2002)

- **The Positive Side** Three articles in the newsletter of the Positive Women's Network on aspects of this stage of the project, Valerie Van Cleef (2001-02)
- **Striking to the Heart of the Matter: Selected readings on Gender and HIV** Changing the Balance of Power: *The Listen Up! Research Project and Participatory Research with Marginalized Communities*, Margreth Tolsen and Stephanie Kellington (Fall 2002)

### ***Listen Up! Sponsored Public Forum***

The Impact of HIV/AIDS on the Women of BC (Nov. 2001)

This forum was an initiative of the Listen Up! project. Guest speakers included: a woman living with HIV; Joy Ward, Aboriginal Liaison for the Health Association of BC; Gabor Maté, a doctor and writer whose patients, many with both addiction and mental health issues, live in the Vancouver's downtown eastside and; Marcie Summers, Executive Director of Positive Women's Network.

### ***Presentations at Conferences***

The Working Group made presentations on the research and recommendations at a number of forums and conferences:

- Pacific AIDS Network (PAN) Conference, Kamloops BC (March, 2002) The coordinator was one of four panelists who presented on various aspects of women's health and the risk of HIV infection.
- Facing North Conference, Prince George, BC (April 2002) This conference was geared to the unique problems AIDS Service organizations and those living with HIV face in northern BC.
- Forum on HIV/AIDS & Women: Downtown Eastside Women's Centre, Vancouver, BC. (March 2002) One of the peer presenters was a guest speaker.
- Red Road HIV/AIDS Network Quarterly Meeting (July 2002)  
Red Road, a provincial organization, offers educational materials and skills building workshops to Aboriginal educators and front line HIV/AIDS workers across BC
- BC Persons With AIDS Conference (October, 2002) Three members of the Working Group presented on the Listen Up! project, research and recommendations.

It's absolutely impossible to talk about women and HIV without placing the discussion in the context of pervasive misogyny.  
(Dr. Gabor Maté)

### ***Conference Attendance as Participants***

The Working Group also attended several conferences as participants.

- CHEOS: Health in the City, Vancouver, BC (October, 2001) This conference was devoted to the work of researchers involved in urban health issues.
- Fraser Valley Health Region, Women's Health Conference, Chilliwack, BC (Nov. 2001) Peer presenters had the opportunity to connect with a diverse group of women including several involved in Aboriginal and multicultural health issues.

### ***Outreach to Rural BC***

Our outreach to rural BC included both liaison with individuals and presentations to confer-

ences and communities.

- Chetwynd and two nearby reserves
- Chilliwack
- Kamloops
- Prince George
- Vancouver Island
- Williams Lake and area, including two reserves and a nearby treatment centre

While presentations and attendance at conferences in rural BC was an important component of our work, we also wanted to connect more directly with women in both Aboriginal and non-Aboriginal communities. To this end, we planned a series of presentations, workshops and sharing circles in Chetwynd, BC and Williams Lake, BC, spending four days in each community. We made these visits in partnership with Healing Our Spirit BC Aboriginal HIV/AIDS Society.

#### *A Partnership in Healing and Women's Health*

HOS educators provided HIV/AIDS education to all participants in both Aboriginal and non-Aboriginal workshops while Working Group members presented on the Listen Up! research and women's greater risk for HIV infection.

Our work in rural BC was greatly assisted by our partnership with Healing Our Spirit BC Aboriginal HIV/AIDS Society.

#### **Chetwynd, BC**

Two educators from Healing Our Spirit joined us for a series of workshops, presentations and meetings in Chetwynd, BC in May, 2002.

Presentations were made to:

- Saulteau Reserve Community Members on nearby Moberly Lake
- Chetwynd Secondary School students
- Northern Lights College in Chetwynd.
- Meeting with staff and board members of the Chetwynd Women's Resource Centre
- Visits to the Tansi Friendship Centre in Chetwynd and to the Moberly Reserve, also situated on Moberly Lake.

#### **Williams Lake, BC**

We traveled to Williams Lake in September, 2002. As in Chetwynd, Healing Our Spirit educators handled the HIV education component and the Listen Up! Working Group presented on women's greater risk for infection.

Presentations were made to:

- NOOPA Youth Centre: The Boys and Girls Club. Youth from both Williams Lake and 100 Mile House attended.
- Participants in a women's health project sponsored by the Canadian Mental Health Association, Williams Lake, which is examining how abuse issues increase women's risk for HIV
- White Feather Health Centre, Canim Lake Reserve

## Challenges

In order to slow the spread of HIV, we recognize that women are stronger and have a greater voice if we work together and that forming partnerships between communities, cultures and organizations would strengthen that voice. We also recognize that the women we wanted to work with reflected a wide spectrum of life experiences. Working with such a diverse group of women presented many challenges. Among them,

1. Lack of knowledge about HIV is widespread.
2. The stigma and fear of HIV and AIDS prevents many women from seeking the information and support they need.
2. Myths about the disease are widespread.
3. Divisions that already exist between and within communities here in the lower mainland and in rural BC generate mistrust and create barriers.
4. Bridging the personal isolation women in many communities face, whether or not they are living with HIV.
5. The geographic isolation rural women face.

### Education Campaigns Lacking

We found, in the communities we worked with, that most women have little or no awareness of how HIV is transmitted, let alone their greater risk for contracting it than men. Some women, and men, are unaware that HIV exists. It is a common misconception that HIV is present only in a limited number of communities.

Current HIV education efforts in BC are a patchwork of provincial and federal initiatives.

- Some are time-limited, and end before their effectiveness can be proven.
- There is very little money spent on HIV education in immigrant and refugee immigrant communities.
- Two community workers, one Aboriginal and one non-Aboriginal, in the Williams Lake area were introduced to each other when they attended one of our workshops. They were surprised to learn that they were both serving the same 10 reserves in the Williams Lake area, although in differing capacities. They have since decided to do some of their HIV education in partnership.

### A province-wide education campaign targetting all age groups would

- Reach more people
- Reduce the stigma of HIV
- Serve as the necessary vanguard for community based HIV/AIDS educators
- Encourage women, men and youth to seek HIV education
- Give youth the information to protect themselves before they need it
- Eliminate the fears associated with testing and treatment
- Reduce needless suffering
- Slow the spread of the disease
- Save tens of thousands of tax dollars which will ultimately be spent on each person who contracts HIV.

The lack of political will, both federally and provincially, to mount a province-wide education campaign as well as sufficient funding to take this information into communities where languages other than English are spoken has women angry and afraid and with good

reason.

- As a woman at one lower mainland presentation said: “You’re telling me I’m at risk. What you’ve told me frightens me. What am I supposed to do with this knowledge”?
- After a one-day workshop at the Sauteau First Nations reserve, another participant shared that it is “very emotional and frustrating that no-one really knows the facts”.

Most unsettling for us, was when we didn’t have sufficient time to deal properly with very important questions women raised.

- A young Aboriginal woman, at a presentation in the high school in Chetwynd, BC, asked us why Aboriginal women are at greater risk to contract HIV than non-Aboriginal women. This very important question deserved an in-depth answer, but our time was up and the necessity of a short response did little to allay this woman’s concerns. We were concerned that we may have contributed to her feeling stigmatized.

### ***HIV Education for Men An Identified Need***

We were reminded, time and again, that men need to be educated about their risk and the risk they pose to their partners if they practice unsafe sex.

- As already mentioned, men in many communities continue to believe that they cannot contract HIV through heterosexual sex.
- After a presentation to Vietnamese speaking women, most of the participants, with a great deal of accompanying discussion, made note of testing site information. Thoa Lam, our interpreter, told us that after this presentation, “the doctors will have many visits from their patients”. In explanation, she shared that it is common for their husbands to travel to Vietnam for holidays and “who knows what they are doing while they are back there”.
- Few men were present at any of the presentations and workshops we gave.
- Educators for both Healing Our Spirit and Chee Mamuk<sup>7</sup> who work in Aboriginal communities across BC, told us it is very uncommon for men to be present at HIV workshops they give.

Women told us there is no point in educating women about their risk if men don't receive the same information.

But as we discovered, educators in all of the communities we worked with said men are rarely present at HIV workshops.

### ***HIV Education for Youth***

Young women in BC have been identified as at great risk for HIV infection. However, efforts to educate youth about their risk face challenges as well.

- In one rural community we visited where HIV and HEPC have been identified as a serious problem among the youth, free condoms are only available from the Health Unit and the local women’s resource centre. The high school in this community refuses to allow condoms in the school washrooms.
- In the lower mainland, we were told that some schools welcome HIV educators, while others do not.
- There is no government-sponsored initiative to reach all youth in all schools in BC.
- At present, HIV educators come to schools by invitation only.

Youth in communities identified as high-risk often receive a lot of attention while others are ignored. This attention, in itself, can be stigmatizing. An African youth group we offered to make a presentation to refused it as they had already sat through a number of HIV presentations.

- One young woman thought our time would be better spent presenting to youth who didn't yet have the information.
- A young man wanted to know why African youth were receiving so much attention if HIV was everywhere and all youth are at risk.

### ***If you reach the youth, you'll reach the adults***

A number of women in different communities observed that if we educate the youth, they will educate the parents. They pointed out that many women, and men, who would not want to be seen at an HIV/AIDS presentation, might be more open to receiving the same information in conversation with their children at home.

### ***The Role of the Media***

As already stated, women recognize that HIV education for all is of vital importance. Many women we worked with in this phase stressed the important role that a partnership with the media could play in HIV education efforts.

We are an information based society and the role of the media, especially TV, exerts a powerful influence on most citizens. Many rely almost solely on TV for most of the information they get. With a life-threatening issue, such as HIV, it is imperative that this information is up-to-date and clear. If information disseminated by the media is inaccurate, or misleading, then they are in fact contributing to the problem.

Women in all phases of the project were very clear that in our efforts to reach women and slow the spread of HIV, it is of utmost importance to eliminate the stigma attached to the disease. We encountered the effects of this stigma in every community we visited.

- Stigma prevents women and men from seeking the information they need to protect themselves, as well as services and support if they are infected.
- Many living with the disease in rural BC (or other parts of Canada) leave their home communities to seek relative anonymity and the care and support available in major centers such as Vancouver.
- We know that women from a broad spectrum of communities are living with HIV; indeed, it is present in every community in BC. But this reality is not yet part of public discourse.
- Stigma dictates that to disclose or not disclose that one is HIV positive is a dilemma that all women living with HIV face.

Some women – white women, women of colour and Aboriginal women – choose silence, rather than testing and treatment. Maggie Sekeramayi of UMOJA (Unity) said [African women who know they are HIV positive] are “hoping to live as normal a life as possible for as long as they can, as the price they must pay to keep the stigma away”.<sup>8</sup> Parm Poonia of AIDS Vancouver spoke of women in South Asian communities who are “quietly dying of the disease”, rather than risking the censure of their community.

In communities where the presence of HIV has not, as yet, been acknowledged, some women chose never to disclose, even though this will end their lives sooner.

Those communities where HIV has surfaced as a health problem feel a sense of isolation, shame and despair, fallow ground for the existence of fear and the perpetuation of myths already prevalent about the disease.

### ***HIV Stigma Heightened Due to Greater Isolation***

- We were told of people who have been beaten or driven from their community once it became known they were living with HIV or AIDS.
- Workshop participants relived the grief of losing loved ones to HIV whom they had felt powerless to help.
- There are those living with HIV, who have moved to the lower mainland in search of support and treatment, who are afraid to return to their home communities, even if they are dying.

### Myths About HIV and AIDS are Widespread

Myths about the disease continue to hold sway in many communities, and in some instances by health care professionals. These myths underscore the desperate need for widespread education for everyone.

- Many continue to believe they can get HIV from everyday contact with an infected person, such as using or touching dishes or cutlery a person living with HIV has used.
- Hospital workers in one community we worked with are afraid to work with patients who are living with HIV, afraid even to touch dishes they have used.
- A woman involved in our research relived the experience of being asked to leave her doctor's office because he was afraid she would infect his staff.
- Men in many communities continue to believe that they cannot contract HIV through heterosexual sex. At one AIDS Service Organization (ASO), a male staff member was recently surprised to learn that this was not the case.
- Many women believe that if they are in a monogamous, heterosexual relationship and not intravenous drug users, they are safe from HIV. This is only true if neither of the partners had a prior sexual relationship with someone living with HIV and the sanctity of the monogamous relationship is never transgressed.
- In one community in the lower mainland, taxi drivers are blamed for introducing the disease.

If the stigma and fear at the root of these myths is not addressed, fallacies such as these will continue to be circulated.

### Barriers to HIV Testing, Treatment and Services

An important barrier for all women to overcome is the stigma the disease engenders. Assuming a woman has moved beyond this and wishes to be tested, there are obstacles that remain.

- HIV testing sites are not widely advertised in the lower mainland.

Significant changes are needed to lessen the obstacles faced by women whose first language is not English.

- What Information available about HIV testing sites is in English only.

- Most HIV testing sites offer services in English only. Only a handful of clinics who offer testing have staff who can double as interpreters.
- Women in several communities told us they would not get tested in their home community.
- Others wouldn't go for testing to a clinic that was part of a larger complex where they access other services and staff know them, such as the REACH clinic in Vancouver.
- One clinic we spoke with is part of a hospital that offers interpreter services. However, as several women told us, interpreters are often known members of the woman's home community and thus confidentiality is not assured.
- In rural BC communities and on reserve, women said that an HIV positive diagnosis can be *common knowledge* within 24 to 48 hours.

***Women with disabilities who want to be tested face similar obstacles***

- Interpreter services at one clinic in the lower mainland also include signing for a woman who is deaf or hard of hearing. But because this is a small community and interpreters often know their clients, again, confidentiality is not assured.

***Applying for a Person With Disability (PWD) Designation***

Women living with HIV who are ill enough need the extra income PWD benefits give.

- The form is very long. A doctor must complete one section, a social worker another, and the woman, another.
- They are available in English only.
- Financial Aid Workers do not automatically make them available to persons living with HIV.

A woman who doesn't speak English is faced with multiple barriers.

- The availability of this level of assistance is not advertised.
- Help with filling out the form is difficult to access.

Women on reserve living with HIV who need to make a PWD application to the provincial government face an additional barrier.

- They can only make application through a designated band official. This lack of anonymity forces some to remain silent and do without the extra financial help so necessary if one is living with HIV. This is especially harmful as poverty rates are much higher and income assistance rates are lower on reserve than elsewhere.

## What Does Community Mean?

We came to this work with a generally accepted notion of the meaning of community and discovered - from the onset of the research and throughout this phase as well - that the word community carries many and varied meanings.

Community is sometimes simply a word to describe a grouping of individuals around a perceived commonality, as in the business community, the South-Asian community or the Aboriginal community. All of these communities are, in fact, quite diverse.

Community can also indicate inclusion of certain individuals and not others; hence, by its very nature, it also implies division. These divisions are often the result of entrenched social norms held by individuals and reflected in social institutions and the wounds these divisions cause run deep. There is also often division within a community, reflective of divisions within the larger society.

Divisions Between Communities and Within Society:

There were many realities for us to consider in this phase of the project:

- Women belong to communities and each is a member of several communities.
- The inequality women face in the larger society is mirrored in most, if not all of the communities to which they feel an attachment.
- Each community is struggling in its own way to cope with the HIV epidemic with greater or lesser success, or simply ignoring it. Outsiders can be viewed as intruders with their own agenda.
- We were isolated from some of the communities we wanted to reach by language, race, culture and geographically.
- Partnership can be made difficult by the classism that divides those who live in poverty and those that have enough.
- Some communities are working with, or actively seeking partnerships with other communities around HIV/AIDS issues; others are not.
- Some communities are very isolated, and this isolation is not necessarily geographic. We know anecdotally that women are silently dying of AIDS in both urban and rural communities where the presence of the virus has not been acknowledged.
- Some feel the presence of HIV/AIDS in their community is a threat. It is easier to deny this knowledge.
- Issues of safety around disclosure of HIV status or seeking information about the virus are very real. In both urban and rural communities, attending an HIV/AIDS information session or being identified as HIV positive can jeopardize a woman's physical and emotional safety.
- Information about HIV itself, how it replicates and how it can be passed can be difficult to understand for even the well-educated. Those with little education, or those whose first language is not English are faced with an added burden.

## The Social Issues

### *Gender: All Women Are At Risk*

All women are at risk for HIV infection - no matter their education, income, the class they identify with, or the colour of their skin. The fact that growing numbers of women are being infected remains all but invisible and is, as yet, not part of common discourse.

- Middle-class women generally, including white women, long considered to be a low risk group, have proved to be just as vulnerable to HIV infection as women considered at higher risk.

Over 60% of new HIV infections in women are attributable to heterosexual sex. But women in diverse communities said their partners feel they have the right to refuse safe sex practices.

- Some women told us to try to insist on condom use is tantamount to admitting they are not faithful to their partner, not the other way around. They run the risk of being accused of being bad women.
- Some women are forced to accept that men who refuse to wear condoms are exerting an inherent right not to.
- Negotiating safe sex is impossible for women in abusive relationships.
- Some women fear that if they get tested for HIV, members of their community will judge their behaviour, not their partners.

You cannot talk about the biology of the virus without talking about the social issues."  
(Parm Poonia,  
AIDS  
Vancouver)

### *Gender and Racism*

Women of colour and Aboriginal women face daily obstacles that many are not aware of.

"The existence of higher levels of poverty among Aboriginal, racially and otherwise visible minorities, immigrants, refugee and migrant communities together with other factors such as racial discrimination, the lack of affordable housing, refugee detentions, family separations, childcare issues, rising costs of living, threats to job security and benefits, underemployment, joblessness, fear and anxiety and adaptation and integration obstacles all show that Canada does too little to equitably address its general social health status."<sup>9</sup>

It was not surprising, given the conditions they face in their everyday lives, that some women who participated in our workshops said that the threat HIV poses, while very real, was not as important as the issues they struggle with daily.

Edith Kambere of REACH Multicultural Family Services in Vancouver works with refugee and immigrant women from diverse African countries. The situation for women living with HIV who have not been tested is sobering. Husbands call Kambere to tell her their wives are sick with HIV. As Kambere said: "The wives are very shy, afraid to go for testing and fear the time when they will no longer be able to care for themselves or their families. The husbands go for testing but the wives will not."

Kambere also pointed out that there is little funding available for HIV education and

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support specifically for African women. Thoa Lam, a community worker in the Vietnamese community, echoed Kambere's concern. Education efforts in African communities and the Vietnamese community are hampered by a lack of funding but certainly not commitment.

Maggie Sekeramayi, Coordinator of UMOJA (Unity) an initiative of the Fraser Valley Health Authority, has created a number of brochures to educate African communities about HIV. When asked how successful the brochures have been, she said: "The brochures have been a success but to a very small extent. I would like to get more women to read them and then share their view of the subjects discussed." Sekeramayi explained: "Women in particular are shy about picking them up. They feel that they would have to explain to their spouse/friends their interest in the topics discussed."

"Women in particular are shy about picking up [HIV/AIDS] brochures. They feel they would have to explain...their interest in the topics discussed."  
(M. Sekeramayi, UMOJA)

Sekeramayi, echoed Kambere's concern about the limited funding available to the African communities: She said:

"I feel that women of colour do not help themselves by avoiding discussions around HIV/AIDS. If they need to know more, then money would have to be set aside to provide them with the necessary skills to tackle the infection. Right now not much money is available to organizations that serve Black people because Black people do not demand the services."

#### *Race, Language and Culture*

Federally and officially, we have declared ourselves to be a multicultural society. But divisions continue to exist, whether blatantly or systemically.

In addition to Canada's official languages of English and French, nearly 200 other languages are spoken. 50 of these are Aboriginal languages. And while languages can divide us, language commonality does not necessarily serve to unite speakers of the same language.

In speaking, for instance of the diasporas many countries have experienced, Parm Poonia of AIDS Vancouver points out correctly that: "Language does not equal religion, does not equal culture". Living in a certain geographical area does not necessarily mean inclusion in a community or communities residing there. Speaking a certain language may define the speaker (by some) as belonging to a particular ethno-cultural community or as an adherent to a particular religion. However, speakers of the same language do not necessarily share cultural or religious commonalties.

It is estimated that over 50% of those living in the city of Vancouver are emmigrants from other countries.

#### *Aboriginal Cultures*

In BC there are 198 Aboriginal Bands and 36 Tribal Councils. Nations from elsewhere in Canada are also represented in BC and include (in the Chetwynd area for instance) the Ojibwa, Cree and Beaver (Dene). 16 Aboriginal languages are spoken in BC.

A 150-year process of ethnic cleansing in the form of official government policies of forced assimilation, have worked to 'cleanse' native cultures. Many Aboriginal people are working now to re-establish both culture and identity.<sup>10</sup>

Many Aboriginal women, for a variety of reasons including exclusionary government policies both past and present, have a greater connection with Canadian culture (however one chooses to define it) and the English language, than with the culture and language of their home Nation.

- For many years, an Aboriginal woman who married a non-Aboriginal man lost her status and rights as Aboriginal with the federal government as did her children. This legislation was overturned 20 years ago but the havoc it caused in many families still remains.
- Many of these women and their children are not welcome on their home reserves.
- Other women have returned to their home reserves, as have their children causing a host of problems as they vie for scarce resources with those that never left. Their presence exacerbates levels of poverty and unemployment much higher than the national average.<sup>11</sup>

Many women, and men have never regained their status, but still feel a cultural connection to either or both Aboriginal or Canadian culture.

- If an Aboriginal woman is diagnosed as HIV positive or as having AIDS, a split in cultural allegiance and/or how she is defined by the federal government, can make choosing which services and support to access a difficult choice. If she is designated as non-status, her band does not have to support her.<sup>12</sup>
- To choose the services of a largely white AIDS Service Organization (ASO) is to risk the racism and cultural bias that one may have experienced elsewhere.

On the other hand, some women have said they fear rejection or judgment if they ask Aboriginal organizations for help, because they have not maintained close ties with their home community, or if those ties have never existed for them.

### *Poverty and Class*

Economic inequality is the daily reality of many of the women we worked with. Poverty has an impact on the choices a woman makes.

- Adequate housing is often beyond her means.
- A job that pays an adequate income may be something she has never enjoyed.
- Recent provincial cuts to income assistance have had a devastating effect on some women and their families.
- Cuts to childcare have meant loss of employment for some women we talked with. Retraining to enter the workforce with the promise of childcare is no longer an option.
- Lower rates of assistance and the lack of even the most basic services make the poverty experienced by Aboriginal women on some reserves much worse than poor women elsewhere.
- The lives of immigrant and refugee immigrant women are too often marked by poverty.

An HIV diagnosis can dramatically alter the life of a woman who has never experienced poverty. If not poor when she became infected with HIV, it can become her lot somewhere down the road.

Welfare rates on reserve are lower [than off reserve]. People on reserve [must also deal with] poor water quality, mouldy housing conditions, poor sewage systems, families cramped into one house, 'poor health' conditions, nutrition.  
(Chetwynd, BC participant)

- A woman may find herself unable to work due to the often serious and debilitating side effects of HIV medications or other health concerns linked to HIV.
- Feeding, caring for, and housing herself or her children become serious issues she cannot always cope with.

As this phase of the project began, the process of health care restructuring and cuts to social services in BC had begun.

- Current government policy has delivered cuts to those on income assistance, including those on disability and these have been devastating.

### *HIV and Addiction*

Some of the women we worked with, in all phases of the project, reported past or present problems with a number of addictions, among them, intravenous drug use, a major risk factor for HIV infection. Vancouver's downtown eastside gets press attention because of high numbers of HIV cases reported there, especially when one considers how small that community is. However, IDUs live all over BC; an estimated 40% live in rural BC.

An important recommendation of our research is that the disease model of addiction be adopted. Women are at greater risk because they are over-represented among the poor or among those who suffered abuse as children. The road to addiction is a road that few travel willingly.

- The current focus on the end result, drug addiction, and not the root, societal causes of that addiction is, at its worst, a continuation of class and, all too often, racial stereotyping.

"We'll allow that flowers don't grow well if they don't have the right conditions. We don't say that it's genetics. Somehow though we deny that conditions shape the development of human beings".  
(Dr. Gabor Maté)

### *Religious Affiliation*

The majority of the world's women who are living with HIV were infected through heterosexual sex; the number is over 60% in Canada. This is problematic for the adherents to many of the world's religions who do not recognize or condone the sexual act outside of marriage.

- One case worth noting in this regard is that Catholicism still bans birth control in any form. A Catholic woman, for instance, who faithfully adheres to the tenets of her religion, cannot insist on the use of a condom for protection from a partner's extra-marital activities, assuming she is aware of these activities.

Religion plays an important role in the lives of some of the women we worked with, but religious beliefs they hold dear are often in direct opposition to cultural mores and practices. As we attempt to untangle cultural beliefs and religious tenets from important health policy decisions that need to be made to better serve women and address the growing HIV epidemic, the number of infections continues to rise.

## Conclusion

We believe our research and the work of other community based researchers, whether peer based as ours is, or not, is a very effective tool for the empowerment and education of women and men around the important health issue of HIV and AIDS. Community based research has the potential to empower those infected and those affected (the rest of us) to demand the social changes necessary to secure assistance for those living with HIV who are not getting the support they need and equally important, to slow the spread of the disease.

HIV Education is needed for all members of our society: women, men and youth. The stigma of HIV/AIDS needs to be addressed so women can feel safe in seeking testing if they have been at risk for HIV and treatment and support if they are living with the virus. It is unacceptable that women are dying of this disease because they are afraid to seek testing and treatment, or unaware that they should seek testing.

As the United Nations stated in a report on HIV/AIDS in 2002, gender inequality is fueling the HIV epidemic, globally, Canada wide and here at home. Since Listen Up! began in 1999, rates for HIV infection have risen dramatically, both Canada wide and here in BC. Heterosexual transmission is responsible for over 60% of all new HIV infections among women. As a society, we have to decide that it is unacceptable that too many women live in poverty, isolation and fear. It is these pervasive social factors that put them at much greater risk to contract the disease and often insure a much faster progression of the illness to AIDS.

As we have said from the beginning of this project, women have the answers, they know what social changes are needed. We have also said, that giving back the information women have shared with us is a necessary step to their empowerment. It must, however, be recognized, empowerment without action at a community level, coupled with a strong provincial and federal education mandate, will result in the continued and irrevocable spread of this devastating disease. And even if we substantially increase HIV education and empowerment, this is only part of the equation.

There is a powerful societal paradox which must be addressed if we are to be successful in our efforts. As Dr. Terry Tofoya said at an HIV/AIDS conference in 2002, "The AIDS virus makes us aware of how much we're connected to others, all around the world".<sup>13</sup> This connection is made visible by the continuing spread of the HIV virus throughout dozens of countries and cultures worldwide. As recent statistics in Canada and here in BC show, HIV is a disease which doesn't recognize cultural or racial boundaries. "It is a disease which spreads through some of the most private and intimate acts of human beings"<sup>14</sup>, erasing the real and imagined boundaries that we have erected.

But it is precisely these invisible divisions and inequalities based on gender, race, class, sexual orientation, language, religion and culture that make our efforts to slow the spread of the disease so difficult. We live our lives within these unnatural boundaries that dictate the sometimes arbitrary, and often life-threatening ways we, as a society, deal with basic human needs. We can no longer minimize or compartmentalize our response to the HIV/AIDS crisis. It is a time for action and a time for change.

## Endnotes

- 1 Kunda Dixit, "HIV and the Role of Media: Lessons from South Asia: Rights, Gender and HIV". AIDS Action, Issue 50-51, January-June 2001, p. 2.
- 2 A complete list of recommendations made during research phases 1 and 2 of the project, is included in Addendum 1 of this report.
- 3 Stephanie Kellington and Margreth Tolsen, Changing the Balance of Power: The Listen Up! Research Project and Participatory Research with Marginalized Communities, Journal of the Atlantic Centre of Excellence for Women's Health
- 4 Stephanie Kellington et al, "Strategies to Reduce Social Risks for HIV/AIDS Infection and Illness Progression", WE International (Summer/Fall 2000) p. 26.
- 5 Several years ago, a number of service providers in non-English speaking communities in the lower mainland were trained as HIV educators. This project was short-term and is no longer funded.
- 6 Healing Our Spirit (HOS) is a provincial Aboriginal HIV/AIDS organization that provides education throughout BC.
- 7 Chee Mamuk provides culturally appropriate on-site community based HIV/AIDS and Sexually Transmitted Disease education and training to Aboriginal communities, organizations, and professionals within BC.
- 8 UMOJA (Unity) is a health and HIV education project for African communities in the Fraser Health Authority, which encompasses part of the lower mainland.
- 9 Ahmad Saidullah, The Two Faces of Canada: A Community Report on Racism, August 2001, p. 23.
- 10 Barby Skaling, Education Coordinator, Healing Our Spirit BC Aboriginal HIV/AIDS Society, workshop presentation at Facing North Conference, 2002
- 11 Barby Skaling, in conversation.
- 12 Phyllis Wood, North Island AIDS Coalition, in interview, November 2002.
- 13 Dr. Terry Tofoya, Healing Our Spirit BC Aboriginal HIV/AIDS Society Conference, Kamloops, BC, March 2002.
- 14 Kunda Dixit, Ibid., p. 2.

empowerment  
education

community

**HIV/AIDS  
Action Plan  
For BC Women**



Listen Up!  
Women's Health  
Research Project

## HIV/AIDS Action Plan For BC Women

The following HIV/AIDS Action Plan to reduce the risk HIV poses to the women of BC was developed by participants in more than 40 workshops, presentations and sharing circles in the lower mainland and rural British Columbia. These workshops, sponsored by Community Action, Phases 3 and 4 of the Listen Up! project, presented the research results and recommendations women identified in Phases 1 and 2 of the project.

The research recommendations, summarized in Addendum 1 of this report, are wide ranging and embrace all areas of the lives of the women who participated in the research phases. The depth and breadth of the social changes that women are calling for to reduce their risk for HIV is far-reaching, and well beyond the scope of this project. However, from the start, our mandate has been to have women identify a starting point for action - the key issues they want to see included in an HIV/AIDS Action Plan for BC Women.

### HIV/AIDS EDUCATION FOR ALL BC CITIZENS THE FIRST PRIORITY

HIV is now present in every community in British Columbia. There are no longer at-risk groups; everyone is at risk for HIV and women especially so. A comprehensive, government-sponsored and province-wide HIV/AIDS education program is needed. This program would involve, as partners, both print and TV media, and is intended to reach men and women of all ages, in languages spoken in the many and diverse communities of British Columbia.

#### An educational campaign of the scope women are calling for will:

- 1 Eliminate the stigma, discrimination and needless suffering associated with HIV
  - 2 Reach all citizens in all communities, no matter how isolated or what language spoken, with the same clear message: HIV is a disease for which there is, as yet, no cure, but which can be prevented if personal precautions are taken.
  - 3 Fulfill the stated need of a vanguard for community based HIV/AIDS educators.
  - 4 Educate women in all communities about their greater risk for infection than men
  - 5 Educate men about the risk unprotected heterosexual sex poses to themselves and their partners
  - 6 Educate health care providers
  - 7 Work to eliminate the reasons for fear associated with testing and treatment
  - 8 Slow the spread of the disease
  - 9 Save tens of thousands of tax dollars, which will ultimately be spent on each person who becomes HIV positive.
1. Eliminate the stigma and discrimination associated with HIV
    - Fear and stigma of the disease continues to present a major barrier to existing community education efforts to slow the spread of the disease.
    - Stigma is also an identified barrier to women getting tested and accessing treatment.
    - Eliminating the stigma will reduce needless suffering. In an effort to avoid dealing with the stigma, women in some communities who know they are HIV positive sometimes attempt to lead as normal a life as possible, often waiting until they are very ill to seek help, or, in some cases, not seeking help at all.
    - Reducing stigma and fear would help eliminate commonly held myths such as: one

can get HIV from touching the dishes and cutlery of a person living with HIV.

- Eliminate discrimination towards women living with HIV/AIDS that makes assumptions about how women became infected and that women may be more responsible for their infection than men.
2. Reach all citizens in all communities, no matter how isolated, with the same clear message: HIV is transmitted through the most intimate acts of human beings and, unlike a host of other communicable diseases, it can be prevented, if personal precautions are taken.
    - HIV has moved from several communities to many communities in BC in a relatively short period of time. Clearly, there needs to be an understanding that the intimate acts of human beings can take place between communities and between cultures.
    - Women are calling for a campaign that includes advertisements on multicultural language networks and print media.
  3. A province-wide campaign would fulfill a stated need for a vanguard for community based HIV/AIDS educators.
    - Current HIV education initiatives only target select communities.
    - Educators involved in grassroots community education efforts have told us their work is hampered by the lack of a government approach clearly meant to reach all citizens.
    - HIV Educators in the Aboriginal community, but one example, tell us that education efforts aimed at society in general would work toward alleviating the stigma of HIV in their communities and greatly assist them in their work. In conversation, educators from the two largest Aboriginal education initiatives in BC estimate that their education efforts to date have only reached 10% of this population.
    - UMOJA (Unity), an education initiative aimed at diverse African communities in those areas of the lower mainland served by the Fraser Valley Health Authority is hampered due to chronic under-funding.
    - There is a lack of funding for education initiatives in communities where languages other than English are spoken.
    - Young children, who are sexually curious, but not yet active, should be included in HIV education efforts.
    - Culturally and age-appropriate persons living with HIV should be invited to give talks in schools on the realities of living with HIV/AIDS. Contacts could be pursued through public health nurses and individual teachers and counselors.

#### In rural BC

- Increased resources should be allocated to those living in rural and suburban regions to enable them to develop locally specific educational campaigns. Such campaigns could include, when appropriate, bringing back persons living with HIV who have left the community in search of services and/or safety.
4. Educate women in all communities about their greater risk for infection than men  
The United Nations has recognized that women's inequality is fueling the HIV epidemic worldwide. A government sponsored education is needed to bring this message home to BC citizens.
    - It is not enough that we reach women with this message. All citizens must be

educated about the social determinants that put women at greater risk for HIV infection and the much faster progression of the illness to AIDS.

- Insure that women, no matter what language they speak, have the information necessary to determine if they have been put at risk, so that they can make the decision to get tested or seek treatment.
- Insure that all young women, now statistically demonstrated as a group at increased risk for HIV, have the information they need. The rates of HIV infection for young women, both Aboriginal and non-Aboriginal are alarmingly high.

5. Educate men about the risk unprotected heterosexual sex poses to themselves and their partners. The need for HIV education for heterosexual men is one of the more important recommendations arising from this phase of the project.

- Men in many communities believe they cannot get HIV through heterosexual sex. The entrenched presence of this myth is given credence by an HIV educator working in the lower mainland, who served as an advisor to this project.
- The widespread acceptance of this myth may explain, at least in part, why educators in all of the communities we worked with said that men are seldom present at HIV/AIDS information sessions.
- As participants in many communities said, women and men need to be educated together. There is little to be gained educating women about their risk, if their partners continue to put them at risk.

6. Education for health care providers

Health care professionals have an important role to play in ending the stigma and isolation that come with the disease. The BC Centre For Excellence in HIV has written a guide for physicians called "Treatment of HIV/AIDS and Related Conditions". Hard copies are available by request and an electronic version is available on the Centre For Excellence website at <http://cfeweb.hivnet.ubc.ca/cfe.html>. Additionally, website information as well as HIV updates are made available to all doctors in BC through the newsletter "Forecast".

There is a great deal of information on HIV/AIDS available and health care professionals can access it readily. Unfortunately, it has been demonstrated that there continues to be resistance and fear on the part of some to treating those infected. That resistance could very well be born of the fear and stigma the disease continues to generate in the population generally.

- Education for all citizens is education for health care providers. If we reduce society's fear, we reduce it for health care providers as well.
- For some health care professionals there is a lack of awareness of both: women's increased risk for HIV and; the inroads the disease has made in BC communities.
- HIV should no longer be the test of last resort when women are seriously ill. Women in communities not considered at risk are falling ill with HIV. But some doctors, who may well operate within the larger society's prevailing ignorance about the inroads the disease has made, often test for HIV as a last resort, if they test for it at all.
- Education for doctors, counselors and other health care providers should include information on how the social determinants of health put women at greater risk for HIV infection than men and the risk for young women in particular.

### Embracing a Disease Model of Addiction

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

- There are not enough detox beds anywhere in BC. Available beds for women with addiction issues, both in the lower mainland and rural BC, are all but non-existent. Vancouver detox has 10 beds for both men and women. For women with cocaine and crack addictions there are six beds at Cordova detox in Vancouver, to which a woman can gain access if she has no health issues. A detox facility in Maple Ridge only accepts people living in the South Fraser Health Authority.

### Rural BC

- For women in rural BC, detox facilities are often non-existent. For example, women seeking help who live in Chetwynd, BC, where there are no detox facilities, must travel to Prince George, which is in a different health authority, or Alberta, a different province. In either case, they must be accepted before they can be treated and acceptance is not guaranteed. Addiction doesn't have boundaries. Women are coming into the lower mainland from other areas of BC to access treatment. Women seeking entry to detox facilities who live in the lower mainland are too often turned away; a six-month wait for a bed is not unheard of.
- The number of safe houses, transition houses, second-stage housing and detox facilities specific to women all need to be increased.
- Advocacy and education efforts should be pursued to encourage the health care system to take up a disease model of addiction.
- Educational efforts regarding the effect HIV/AIDS has on women's lives should be developed and presented to policing bodies, court workers, and others involved in the criminal justice system.

### 7. Work to eliminate the reasons for the fear associated with testing and treatment

- Women in some communities in the lower mainland said they would not have an HIV test at a clinic located in a building where they access other services.
- Women in some communities are afraid of being tested because of the discrimination that will follow if the diagnosis is positive.
- Information about testing and location of clinics where HIV testing is done is not readily available in a variety of languages.
- Most clinics offer services in English only.

### 8. Slow the spread of the disease.

### 9. Save tens of thousands of tax dollars, which will ultimately be spent on each person who contracts HIV.

## MEDIA PARTNERSHIP WOULD IMPROVE EFFECTIVENESS OF AN HIV CAMPAIGN

We are a highly visual culture. It is recognized that there is extensive printed information about HIV available, but many women are not aware of it or cannot access it. A partnership with all branches of the media, including the both TV and print branches of the multicultural media, could significantly improve chances of reaching more citizens with the identical message that HIV is a disease for which there is still no cure, but that it can be prevented, if personal precautions are taken.

- It is only with the release of 2001 HIV statistics that indicated a drastic increase of new HIV infections amongst women, particularly young women, that the impact on them has been given attention by the press.
- Statistics for the gay male population, intravenous drug users and Aboriginal people continue to garner most of the media coverage.
- While statistics for these communities are of grave concern, such narrow reporting has the effect of isolating and stigmatizing them and contributing to the larger society's continued ignorance about the inroads the disease has made in every community.
- Because of the availability of HIV medications, the media continue to portray HIV as a chronic, manageable disease. While some women, and men, have had success with anti-retroviral therapy and have been able to deal with the side effects, others have not been able to tolerate the difficult drug regimes or the many debilitating side effects.
- The narrow focus on a few communities to the exclusion of others creates a false sense of security in communities on which the media does not focus, members of whom may very well feel they are safe from infection.

### SUPPORT FOR WOMEN LIVING WITH HIV

#### *HIV is not a chronic, manageable disease*

- Some women are afraid to start drug regimens, particularly if they live alone or in geographic isolation, because they fear if they become sicker than they already are, they will be unable to care for themselves. In rural BC, support services for the very ill are limited or non-existent.
- We know, from our work, that many women have had to stop antiretroviral therapy because the side effects are too severe.
- Others continue taking medications no matter how severe the side effects because they have no other choice.
- A "women's advocate" position should be created to help women living with HIV to access Person With Disability (PWD) benefits or Person with Multiple Barriers to Employment (PMBE) benefits. The process for accessing PWD benefits especially should be greatly simplified and streamlined.

#### *On reserve*

- Women applying for PWD or PMBE benefits should be able to do so directly to the government. Some who are in need of these benefits are not making application, because they must go through a band health representative, compromising their need for confidentiality.

#### *Complementary and Alternative Therapies*

Many women living with HIV have said that complementary and alternative therapies are all they can tolerate. The funding structure of the provincial Medical Services Plan (MSP) must be altered to provide them greater access to complementary and alternative therapies and preventative and maintenance dental care.

### *Support groups*

- Too many women, particularly in rural BC and without support of any kind as they struggle with this disease. More support groups, specifically for women living with HIV/AIDS, should be established and widely advertised across the province.

### *Treatment*

Many women in rural BC have to travel to the lower mainland for treatment and support.

- An integrated plan of care/action regarding women and HIV/AIDS should be developed, in consultation with all communities, to increase efficiency and accountability, eliminate redundancies, and identify genuine gaps in service.

### SERVICES AND SUPPORT FOR THOSE AFFECTED BY HIV

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

### MICROBICIDE RESEARCH AND WOMEN CONTROLLED PROTECTION

The important point was made throughout this project that having the educational information needed to protect oneself from HIV infection was of little use if accepted cultural mores or an individual's situation made the negotiation of safe sex impossible.

- Increased levels of funding should be allocated to the development of "invisible" female controlled methods of birth control, such as microbicides.
- ASOs should examine developing partnerships that would allow them to distribute female condoms for free, as they currently do with male condoms.

### HIV/AIDS RESEARCH

- There should be more research done examining women's experiences living with HIV/AIDS.
- Women and children should be more often included in clinical trials to develop new HIV drugs.

### HIV TESTING SITES

There is an absence of information available in many communities about the location of HIV testing sites. Women in the two immigrant communities we worked with were adamant that for reasons of confidentiality, they would not get tested if the clinic where HIV testing is done is located in the same building that they access other services.

- Widespread advertising of HIV testing sites
- Advertised and available bilingual staff at more sites
- Greater accessibility and measures to increase confidentiality for women with disabilities including sight and speech impairment
- HIV testing sites should not be tied with other services community members access.
- The experience of those for whom confidentiality has been broken due to a positive diagnosis has made others fearful of getting tested.

- Training on the importance of confidentiality has been identified as very much needed.

#### TREATMENT CONCERNS OF WOMEN LIVING IN RURAL BC

- It is often impossible to find a doctor familiar with HIV.
- Many women have been forced to move to the lower mainland to access treatment.
- Some women who decide not to move must travel to the lower mainland, often at their own expense, to access treatment.
- We were told there is no housing available for people coming to Courtney, BC from the surrounding areas and further north, for treatment.
- Women we spoke with in Chetwynd, BC must travel south, or to Alberta to access treatment.
- Measures need to be taken to attract more HIV/AIDS specialists to practice in rural and suburban areas.
- 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.
- There should be increased levels of support and services specific to women's issues generally available to women in suburban and rural regions.
- 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 persons living with HIV who have left the community in search of better services and/or safety.

## Addendum 1: Recommendations, Phases 1 and 2

Listen Up! is the first community-based HIV research project of its kind in Canada to look at how social factors put women at greater risk for HIV infection than men and as well, a much faster progression of the illness to AIDS. Women who participated in a series of six focus groups held during Phase 1 and an additional eight focus groups and 44 one-on-one interviews conducted during Phase 2, made the following 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 healthier life.
  - 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.
  - Recipients of income assistance should have options about how they receive this assistance - including opt-in programs of specific accounts with different stores.
  - A "women's advocate" position should be created to help women access DB2 and Schedule C benefits.
  - The process for accessing DB2 and Schedule C benefits should be greatly simplified and streamlined.
  - Preventative and maintenance dental work should be available to those living on income assistance.
  - 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.
  - 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.
  - 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.
  - Consideration should be given to renovating existing buildings whenever possible, rather than building new ones.
  - "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.
  - 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 should be developed. As well, women need to be receiving income while in school or training.
5. Lobby banks to alter or eliminate policies that 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 program of universally accessible childcare.
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:
  - be open more days of the week
  - give out recipes with unusual or difficult to cook with foods
  - develop home delivery systems for those too ill or elderly to stand in line or carry food home
  - solicit more donations from organic food producers
  - 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:
  - increase levels of service at night in all communities
  - increase levels of service over-all in suburban and rural communities
  - 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. 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 relationship 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 negative effect 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 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 counsellors and mental health workers should be established.
3. Advocacy and education 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. There needs to be recognition that doctors are only human so that patients develop more realistic expectations of what doctors know and can do, as well as be less intimidated by, and hence less vulnerable to abuses of power from, doctors.
6. A Community-Based Women’s Health Resource Centre should be established to:
  - provide women with skills, knowledge and training to empower them in their interactions with health care providers
  - 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 provide greater access to:
  - complementary and alternative therapies
  - preventative and maintenance dental care.
8. Increased levels of networking between health care providers working within different models of care should be encouraged by:
  - the establishment of a 1-800 line that would stock and share information about treatments in different models of care
  - 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 possible side effects and complications, or should hire assistants to do this.

11. Education for doctors, counselors and other health care providers should include information on:
  - HIV / AIDS and women generally
  - HIV / AIDS and risks for young women in particular
  - the realities of daily life for women living in poverty
  - the realities of daily life for women living with addictions
  - “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 available to First Nations communities.
9. Increase public education regarding homophobia and its effects on health, social justice and equality.
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 caregivers 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 that 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 discrimination towards women living with HIV/AIDS that:
  - make assumptions about how women became infected and that women may be more responsible for their infection than men
  - 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 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 Speaker’s Bureau of culturally and age- appropriate HIV+ persons should be established to seek out and then give talks in schools on the realities of living with HIV/AIDS.
  - Contacts could be pursued through public health nurses and individual teachers and counselors.
  - 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 look into the possibility of establishing a Women's Resource Centre in Langley, BC. 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 measures to encourage community involvement, empowerment and development should be encouraged by all levels of government and by CBOs.

## Addendum 2: Project Evaluation by the Working Group

It was felt that it would be helpful to those interested in peer-driven, community action research to get an inside look at how those most intimately involved in this stage of the project felt about what had been accomplished.

Susan Dann was asked to conduct this evaluation. Her report follows.

Summary:

Listen Up” is the first community-based research project in Canada to look specifically at how social factors increase women’s risk for HIV infection, and the faster progression of the illness to AIDS. The Project, sponsored by the Positive Women’s Network (PWN) and AIDS Vancouver (Phases 1 and 2), involved research and action planning, peer education and community development. Among other results, the project provided clear indications of the overwhelming need for basic HIV education for women. In light of that need, there was disappointment and frustration when funding for the project ended.

The HIV/AIDS Action Plan for Women, and the approach used by the project, created a legacy that will benefit others.

### ***Evaluation methodology:***

The evaluation report was based on the Evaluation guidelines of Status of Women Canada, B.C./Yukon region. Using those guidelines, two interviews were held: one with the Project Coordinator and one with a group of four peer Educators, all were women living with HIV who had been involved in the project. The rationale for this approach was threefold:

- a. to maximize existing resources
- b. the evaluation was initiated after the project was completed
- c. to capture the knowledge that those most intimately involved would be best able to supply.

### ***Evaluation Questions and Responses***

1. What impact did your project have?
  - From the perspective of the Peer Educators, this project had significant impacts at two levels: in the community, and in terms of its effect on the life of individuals.
  - The presentations offered basic HIV information, and in all communities, time was allotted for feedback on what participants wanted to see included in an HIV/AIDS Action plan For Women. This allowed women’s voices to be heard - often for the first time. One peer educator described the approach as “education where education needs to be.”
  - At the personal level, the project helped “individual women...to open up and feel comfortable about opening up, about their own issues - being HIV related or not.”
  - The Peer Educators also thought that the project created a sense of empowerment for some of the women it touched. This idea was expressed as:
    - “Women needed their own input to be added to it.”
    - “This is probably in many cases, the only time in their lives where they have been included in anything.”

- Women were shown appreciation that “their lives are important”.

At the community level, the Peer Educators saw important impacts in connecting with other women in various communities. For one thing, this allowed for identification of the huge need for women (especially in rural BC) to be knowledgeable about and to act in addressing HIV. According to one peer educator, the Project “shows how this is the tip of the iceberg - how much more is needed to be done.”

Furthermore, the Peer Educators recorded significant impacts on their own lives as a result of the project. All felt they had developed improved presentation skills and developed a greater awareness of the situations of other women. “To feel part of a bigger picture, because all my HIV experience was in Vancouver, it was overwhelming for me to listen to the situation of women - not just [about] HIV but also the horrors they go through.” One peer educator stated that being involved in the project “...helped me in my own addiction recovery, as well as trying to keep well with my own HIV recovery.”

Another Peer Educator, an immigrant from a country where HIV is endemic, found the project “...a learning experience about HIV/AIDS here in BC and Canada. An interesting comment from this woman was her expression of shock when she heard stories about fear and lack of resources. She asked, “Are we in Canada, or in an underdeveloped country where the system represses people, where people go by the group? Or are we in a developed country where people talk about freedom of expression, freedom for choices? For me this is...not the Canada I came to. Right now I’m still confused about it. There is so much information outside, there are the groups, BC is organized, [there are] so many ASOs - and [still] people don’t know and people die. I don’t know.”

## 2. What specific changes did you bring about?

In responding to this question, both the Coordinator and the Peer Educators talked about the social and political environment, which clearly affect this project. Phases Three and Four of “Listen Up” were carried out as government cuts to social programs in BC were begun. Within that context, the Peer Educators felt considerable frustration. One said: “We were knocked back down with government changes (the reaction of people), as we were at the point in “Listen Up” to go back into the communities and make action plans. The communities’ planning around the crisis created by cuts bombarded us.”

In spite of the political context, there was a sense that the Project had achieved some desired changes. The Peer Educators said that one specific change they had created was an increased awareness of HIV. In the course of the Project, the Peer Educators encountered fear, misinformation and sabotage. One perception, echoed by others working in the HIV/AIDS community, was that “Things are getting worse. Because of the media talking about therapies, the public thinks that HIV/AIDS is over, while in fact HIV is spreading in new groups of heterosexual women. I’m worried.” The educators felt they spent time “debunking ignorance and misinformation, instead of giving basic information.” Peer Educators also felt that they had achieved change by “sparking interest in social action.” The HIV/AIDS Action Plan for BC Women was seen not only as a policy and action document, but also as a teaching tool.

For PWN as an organization, this project will have long-term organizational benefits. “We saw partnerships develop - for example, between PWN and both African communities and the Vietnamese community, through REACH Multicultural Family Centre and; between PWN and Healing Our Spirit, for the workshops presented in rural BC. UMOJA Health Education and Family Resource Centre, an organization that offers HIV/AIDS information and support services sponsored an additional presentation” the Coordinator pointed out. A partnership, between Healing Our Spirit, UMOJA and PWN, which has been suggested by UMOJA, “has great promise for future actions to support communities in addressing HIV/AIDS.” A link has also been made to Red Road (an umbrella organization of Aboriginal ASOs). There is, however, a dark side to all this: “The existence of the partnerships indicates the progression of HIV’s inroads into the communities.” “There is recognition that if we work together, we’ll be more effective.”

3. Did these changes in any way contribute towards an improvement in the situation of marginalized women?
  - Many marginalized communities were reached by this project. As a result:
  - The dialogue was moved forward for all marginalized groups - specifically women of colour, in particular within the Vietnamese and African communities.
  - Women who sleep with women were also reached. For example, one of the Peer Educators did a presentation on COOP Radio’s Fruit Salad, which addressed woman-to- woman transmission of HIV.
  - A Peer Educator fluent in French was interviewed on CBC’s French language station, Radio Canada. She also gave a presentation to a group of women at La Boussole, an organization offering outreach and support to the Francophone community.
  - The disabled community was contacted through the BC Centre for Persons with Disabilities (BCCPD) which raised the issues of physical accessibility to testing and treatment sites (for example, the need to have a translator for hearing impaired women to communicate with health service providers) and the issue of confidentiality in small communities.
4. What, in your estimation were other major achievements of your project?
 

Three other major achievements were cited:

  - The success of the community based peer educator approach. As one Peer Educator said, “It was a community issue, as opposed to a specialist issue. It made a huge difference to people that this was a peer.” Another commented, “People - HIV + women, not specialists - took the issue in their own hands. It made an impact by offering real experience.”
  - The creation of the HIV/AIDS Action Plan For Women was in itself seen as an achievement. The Action plan, which arises both from the research and recommendations, as well as additional concerns gathered from women in this phase, is available in hard copy and on the web, and can be adapted by anyone wishing to use it. From the Coordinator’s perspective:
    - \* the tenets of the project have been circulated
    - \* different ASOs are picking up the results
    - \* project recommendations have been circulated widely

\* results have been included in other organizations' planning

\* people are adapting our work

- For Positive Women's Network (PWN), as an organization, and for the Peer Educators, the successful completion of this project, through the trials created by changes of personnel, funding delays and government cutbacks just as the final phase began, was an achievement in itself. The project was well managed: communication was good, problems were worked out, and the peer Educators remained at their posts. The Peer Educators saw that they had "fought hard to maintain this project as a peer project - that makes this project so much more accessible and resourceful." The demands from many communities far outstripped the project resources. The project was always invited back; particularly in "...marginalized communities (immigrant and aboriginal women) everyone wanted them back and to bring their friend." Furthermore, "People are asking for the project and expecting it to be there" and "[the] project has a good reputation and credibility."
- The interviewees thought that through this project, the profile of PWN was raised, and it became better known as a resource.

5. What can be learned from your experience?

"There's lots still to do."

The scope of the project was enormous. The Peer Educators experienced the overwhelming needs of women and communities. Exasperation at the ending of the Project, with so much still needed to be done, left them wanting "...somebody to acknowledge that the work is not yet done, that rather than re-invent the wheel [Listen Up should] continue."

Even though PWN focuses on the needs and strengths of women living with HIV, all those involved in the project appreciated that "HIV/AIDS is a societal problem for both men and women." The social status of some women produced comments such as "Married women with a full-time partner and kids at home, they are not in control. Men need to be educated." The need for educating men came up often. Peer Educators were asked, "When are you going to speak to the men in our community?" Women asked for the project to talk to the men in their community. The status of women in immigrant communities was raised as well.

"We can reach people more effectively through a peer approach."

"We can get through to an entire group of people that professionals or staff is not touching."

"There is a huge difference if an HIV+ (person) makes the presentation."

"You are making yourself vulnerable in putting the issues out there, but with Listen Up, there is support."

Peer education requires a supportive organization and staff. The emotional cost to the educators is great. "Something inside breaks, giving a part of ourselves...a debrief [is] necessary, support for telling your story."

"Listen Up" provided team support, and the professional staff involved had counseling experience. "When you speak, you need support - but that is not what you usually get." A poignant reminder: "Speaking to strangers who have issues [when] presenters also have [them] - race, addictions and abuse issues are triggered, [and you] make

yourself vulnerable.”

The Peer Educators are highly motivated people. Their personal commitment has been a key factor in the success of the project. When asked why they make such personal sacrifices, they responded:

- “Because it makes a huge difference.”
- “If it only affects one person in the crowd, that person is going to take the information and is going to go out there. Kids say they will ‘...tell all my friends,’ or ‘I’m going to tell my Mom, going to tell the school...’Such a huge impact, even if it is one person they are going to connect with. If I can reach a kid, if I can reach a social worker student and medical student...”

One peer educator stated the situation and her motivation clearly:

“In presentations - I say I’m not doing this for my benefit...basically, standing there naked and having a group of people judging your life. Opening up the darkest and most vulnerable time in your life, and hoping they will accept you and accept the knowledge you are bringing with you. Right up there and vulnerable. I still panic every time I do it, and I still cry a lot of the time. I still keep going back, because I see that it makes a difference to those people I’m talking to - and as long as I feel that, I’ll keep doing it.”

“Human needs don’t change, but the way we deal with human needs changes.”

The project Coordinator summed up her learning from this project by citing the above quotation by Dr. Terry Tofoya (an Aboriginal American HIV/AIDS educator). She came to this project as an experienced community worker. “I approached the project coordination by balancing leadership and participation. As Coordinator I set out plans, designated certain activities appropriate for the strength of each woman, informed the Working Group. Women from diverse communities and backgrounds came together as a coordinated team -supported each other.”

6. “How might your strategy, model or approach be transferable to other issues, other communities?”

“Empowerment is the key - it’s not just a word.”

“As long as women as a group don’t feel empowered (separated by race and class) the attempts to educate and address HIV won’t be as effective.”

The following is a list of simple but profound ideas about community development raised as part of “Listen Up”:

- Be willing to listen to the concerns of the communities
- Seek out people who want to talk and want to learn from others
- Raising the consciousness of workers in a respectful, caring manner
- Learn as much as you share
- Strategize around trying to promote the understanding of other communities - try to lessen the barriers within the communities
- Working together is the goal
- Our partnership with Healing Our Spirit Aboriginal HIV/AIDS Society, for our work in rural BC was so very important. They have been doing this work for eight years and have incredible strength and understanding about all the issues. We learned so much from them.

7. What would you identify as the particular strength of your strategy, model or approach?

“Understanding that when working with communities, groundwork is very important - establishing mutual respect and understanding is essential to going anywhere.”

8. What were the noteworthy obstacles/sources of resistance you encountered in carrying out your project?

The following are direct quotes from the interviews:

- Educating HIV+ heterosexual men who are homophobic - they would rather die than have someone see them at AV (AIDS Vancouver).
- Gay women will deny they are at risk (myth that lesbian women don't get HIV)
- Basic ignorance about HIV
- Culture used as an excuse - 'We don't talk about drugs and sex' - how can you do education? At least in the mainstream Caucasian group, there is talk of sex, pregnancy prevention. African communities don't talk about it. Accused of turning her back on her culture (and that) "...she is trying to behave like a white person."
- Lists of do's and don'ts" don't use the word penis, or vagina; don't leave condoms
- Women's groups talking about abuse issues can't proceed because the conversation shuts down if there is a man in the group
- Gay men admitting they are IDUs (Intravenous Drug Users)
- Resources-Money
- Unrealistic mandate, frustration, time
- Fear of HIV
- Stigma attached to the disease
- Unwillingness on the part of some members in some communities to dialogue
- Politics of communities
- Phase 4 of "Listen Up" started just as the BC cuts began; no Ministry office any longer in some rural areas, coming closure of Women's Centres, etc.

9. How have you evaluated your initiative?

An ongoing evaluative process was used in this project. This included:

- Regular debriefing meetings - what worked and didn't work? What are we doing next? Each debriefing led to "personal support and action".
- Evaluation sheets, which were used at some presentations, and (where possible) the workshop evaluation were used to modify subsequent presentations
- Evaluations with the community, held after each community presentation
- PWN staff supervision, including monthly progress sessions, constant checking in "we certainly accomplished what we set out to do, and even beyond."

10. What follow-up is now required to your project?

Given the perception that "We really just touched the tip of the iceberg," the Peer Educators said, "it feels criminal to leave it at this point." They asked, "Why are we stopping now?" they feel frustrated by government priorities that don't support the project and are "...disappointed at the lack of funding for such an important project that has proved itself." There was a consensus on the need for support and action from the provincial and federal governments.

This is a project that “shouldn’t have an end unless the virus has an end; it should be ongoing. We have developed the resources, and...[if we] fold up our camp...then tomorrow someone else will have to start from scratch and do it all over again.” Although vocally thankful to Status of Women Canada and the Vancouver Foundation, the Peer Educators suggested that efforts be made by themselves as project representatives and by PWN to seek other funds to continue the work.

As part of the project follow-up, every community visited and many individuals will receive the final report that includes the HIV/AIDS Action Plan for Women. This report will also go to representatives at the six provincial health authorities. All reports on the project are available on [www.hiv.cbr.net](http://www.hiv.cbr.net) and [www.pwn.bc.ca](http://www.pwn.bc.ca). Peer Educators hope that the project will get the recognition it merits. They suggested that PWN and AV promote “Listen Up” and take it to a national level.

As a final comment, the hope was expressed that as a society, we will “...continue to recognize that HIV/AIDS has touched us all. Diverse communities need to work together. People-oriented solutions are the only thing that will work.”