



**Positive Women's
Network**

**LEAD
Leadership, Engagement, Action and Dialogue Project
Final Report**

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Positive Women's Network offers education, support and resources for women living with HIV and for service providers working with women and their families. As the only AIDS service organization west of Toronto exclusively serving women, we also provide community development and educational resources across the country.

For women with HIV, we provide support and advocacy, HIV education, and community connections online, over the phone and in-person.

For people working in health care, social service or education, we provide training and resources as well as information on HIV health and social justice issues.

The purpose of the Leadership, Engagement, Action and Dialogue (LEAD) Project is for the Positive Women's Network (PWN) to work with local AIDS Service Organizations (ASOs) and the women living with HIV/AIDS in British Columbia to examine both what is working well in communities and to identify any gaps in service delivery. Thirty-four HIV-positive women from Kamloops, the West Kootenays, Victoria, Abbotsford, Kelowna, Nanaimo, Prince George and YouthCo in Vancouver have been interviewed individually and in groups in order to gauge the experiences of women seeking services across the continuum of care in this province. In addition, staff at PWN and local ASOs were asked to provide feedback about their attempts to provide services for women. All respondents were given the opportunity to present ideas about improving services for women.

EXECUTIVE SUMMARY

Women living with HIV/AIDS in British Columbia were invited to discuss their experiences when accessing services across the entire continuum of care: prevention/awareness services prior to testing positive, their testing experience, accessing HIV-related services and medical services. They were given the opportunity to provide suggestions about how services can be improved, what they would like to have in terms of services that do not already exist and how they would like to be involved.

The majority of women did not recall seeing much in the way of public awareness campaigns before they tested positive for HIV. Women who were street-involved stated they received any information they had about HIV from street nurses, front-line workers or other people in their situations. Many of the women who were not street-involved were under the misconception that only street-involved people were at risk.

Very few of the women reported receiving any pre-test counselling and only about half of the women received post-test counselling. A few of the women reported that they were not aware they had been tested for HIV until they got their positive result.

The majority of women were pleased with the services that were provided by their local ASOs, but desired more women-specific services. In addition, women were satisfied with the services they received from PWN. In particular, the retreats were popular and well-liked.

All of the women had a desire to have more contact with other HIV-positive women. Most preferred to have face-to-face contact, but they were willing to look at other options recognizing that this is not always possible. There was a positive response to utilizing telephone and internet options (i.e. Skype or social networking sites).

Many of the women outside of Vancouver and Kelowna must travel to another community in order to seek HIV-specific medical services. This is taxing on their energy reserves, but, for the most part, they do not encounter many barriers. The barriers exist in their own communities when attempting to access medical care between specialist appointments. Many medical professionals (i.e. physicians and dentists) in small communities lack an understanding of HIV.

Nearly all of the women were either interested in becoming or were already involved with their local ASOs and/or PWN. Many women stated that they were interested in attending more peer-support training, workshops and conferences.

FINDINGS

CONTINUUM OF CARE

Prevention and Awareness

Women were encouraged to describe their awareness of prevention programs and campaigns prior to testing positive for HIV. Many women stated that they had had no real awareness or knowledge of HIV. They reported that they did not remember seeing any awareness programs or campaigns that made any impact on their knowledge and their decisions. Of the women that did have an awareness of HIV, many stated that they received their knowledge from street outreach nurses, front-line workers and other individuals in their situation. Many of the HIV-positive women that have never been street-involved stated that they did not believe that they were at-risk for HIV because they thought that only women that use injection drugs or are involved in sex work are at risk.

The majority of the women stated that they were not in a position to protect themselves due to their life circumstances, often citing being in relationships in which they were not aware of their partner's status or they did not have the power to request regular condom use or clean needles and equipment. Approximately half of the women stated that they did not care enough about themselves to care about protection in the time before testing positive.

The disturbing fact that there is no needle exchange program in the Fraser Valley was discovered upon speaking to women and service providers in the area. The local government has passed a law making it illegal to operate any needle exchanges. Respondents in the area stated that there are people running underground programs, but they are always at risk of being shut down. Victoria is another location that is having trouble with its needle exchange program. Victoria had a fixed site for needle exchange until 2008 when neighbours successfully shut it down. Agencies in Victoria provide needle exchange through street outreach services, but the city has been without a fixed site for approximately a year and a half.

Most of the women who had been street involved acknowledged that contact with street nurses and front-line workers did provide one protective factor in their lives. These workers were described as being an important point of contact with the system in which the women were able to obtain clean drug using equipment, condoms and information about HIV and other sexually transmitted infections and blood-borne pathogens.

HIV Testing Experiences

Very few of the women, whether they had a good or a bad testing experience, stated that they had received relevant pre-test counselling.

Over half of the women described their testing experiences as being positive given the circumstances. They stated that they were treated with respect throughout the process, given compassionate support when told of their HIV positive status and provided with information about community programs and supports available. Each location visited by the LEAD project was represented by at least one woman that had this experience; although, they had not necessarily had the experience in that location but another part of the province or country.

The rest of the respondents did not have good experiences. Some of these women did not have any real awareness that they had been tested for HIV (i.e. blood work was taken for a pregnancy or for immigration purposes), so they did not have the opportunity to prepare themselves for the possibility of a positive result. In addition, women who did not have good experiences cited reasons such as being treated with no respect and not receiving appropriate post-test counselling that included information about HIV and the supports available. One woman stated that she found out later that the doctor who gave her the result, and subsequently sent her back onto the street with no support or information, had never delivered a positive HIV diagnosis before and was uncomfortable doing so. This demonstrates that there is a need for more information and training for family physicians about HIV and the appropriate steps to take when administering an HIV test.

Some women stated that their shock and fear made it difficult to utilize or take in any of the information presented to them during the appointment in which they found out they were positive. Those that had had follow-up appointments stated that they had been useful. Some women stated that they would have liked to have been provided an easy to use guidebook for the newly diagnosed or the number of a hotline they could call. A few women said they wished they could have had an option for someone to call them for follow-up, as their fear initially kept them from seeking services.

LIVING WITH HIV

Local Services

Most women stated that they had positive experiences accessing outreach services through their local ASOs and relevant agencies. They described staff as hard-working and compassionate and willing to do whatever they could within their means to make their lives easier. The only complaint that women seemed to have about outreach services was that they felt that staff were stretched too thin. This was acknowledged by staff who stated that they felt there was not enough time or resources available to reach everyone who needed help. Staff in Kamloops stated that they have to triage outreach services for those most in need and staff in the West Kootenays reported that the geographic area is too large to provide frequent and timely services to everyone in

need given the resources. Often, the weather and road conditions interfere with service delivery.

Many women reported that they were disappointed with the lack of women-specific services available locally. They stated that they would relish the chance to make or strengthen connections with other HIV-positive women in their service areas, but that these opportunities are few and far between. Service providers acknowledged this need and expressed frustration over the lack of funding available to start women-specific programming. They stated that when they do receive funding for such services it is often one-time, limited funding that provides for programming over only a short period of time and sometimes it is just enough for a one-off event. Most of the other organizations stated that they were in the process of trying to put something together for women but once again cited funding as a challenge.

YouthCo does provide a monthly Women's Night which is well attended and AIDS Vancouver Island (AVI) recently started a POZ Women's Writing Group Series. In addition, AVI has helped HIV-positive women coordinate "The Viral Monologues," which is a production similar to the "The Vagina Monologues" in which women present their experiences with HIV in a dramatic format. This has been produced for a number of years in conjunction with World AIDS Day and offers the women involved an opportunity to meet throughout the year in order to work on the production.

Organizations stated that when they do put together events or programming for women, there is often a problem with attendance. Women gave various reasons for not attending the women-specific programming or other general programming available at their local organizations. They stated that the programming was not always family-friendly and that child-care can be an issue. In addition, they felt that programming was not scheduled during times that they could attend (i.e. while kids are in school or in the evenings). There were some women who expressed a desire to have opportunities to meet with other women without staff present.

Many women cited that they were not comfortable going to their local organization because they were aware of the stigma associated with entering the building; this was particularly true in Kelowna where stigma around HIV is high. Some women stated they do not feel that they are supported within their personal relationships to seek services. Other women reported that they did not feel that their local organization has a female-friendly environment where they can feel comfortable. The organizations in Abbotsford, the West Kootenays, Prince George, Nanaimo and YouthCo were acknowledged as being comfortable. AIDS Vancouver Island moved to new offices in October of 2009 and women stated that they are in the process of adjusting to the move.

Another area that women said needed improvement was more help accessing fresh food and vitamins. They stated that the local food banks did not always offer the kinds of foods that are necessary for maintaining a healthy immune system.

Positive Women's Network

Over half of the women were members of PWN or had heard of the organization. The experiences of women who have accessed services through PWN have been positive. Women often cited the retreats as being their main contact with PWN. Most of the women stated that they thoroughly enjoy the retreats and reported that they really enjoyed the opportunity to relax and meet other HIV-positive women from throughout the province. They stated that they love Bowen Island but would be willing to go other places should the opportunity be presented. There was some desire to see retreats done locally but most of the women enjoyed the opportunity to leave their communities. One area that some women and service providers stated required improvement was the application process. They stated that they found it confusing.

Other services that women acknowledged enjoying were the newsletters and grocery voucher program. Women who have accessed the drop-in said that they find it comfortable and enjoyable. Women who have attended the leadership training have found it a valuable experience and expressed a desire to do more leadership training. Most of the women had not accessed the outreach services, but stated that they would feel comfortable contacting PWN for more information about them.

Women throughout the province expressed a desire for PWN to have a larger presence in their communities. Women in Victoria and the Fraser Valley were particularly disappointed about the lack of services available to them from PWN. Service providers expressed a desire to do more partnering with PWN and staff stated that due to the isolation they feel in their roles as support workers, they would appreciate any leadership that PWN can provide to help them make connections with other service providers throughout the province.

Both women and service providers have requested that PWN produce more materials that offer relevant and practical information about the specific challenges that women face. Some of the themes mentioned: best practices for working with women, coping/talking with children and families, HIV and aging in women, developing women-specific programming, starting peer-support groups and developing support for children. Another request made of PWN is to provide more workshops about women's perspectives and needs throughout the province.

Peer Support

All of the respondents expressed a desire for more access to peer support, but the means by which women would feel comfortable accessing these services varied depending on individual preference. Most women stated that their preference for peer support would be face-to-face either one-on-one or in groups. When presented with the idea of telephone support groups, most of the women responded favourably that they would be willing to try this, especially if they had physically met the women with whom they would be communicating. A few of the women stated that they would prefer one-on-one contact with another woman, as they do not like groups and would consider participating if they were matched with another woman.

Many respondents expressed an interest in using Skype, an online telephone program that allows users to see each other when talking if they have video webcams. In addition, utilizing instant messaging programs and social-networking sites such as Facebook were discussed as options for creating and strengthening connections. Some women stated that they would be interested in trying online methods of communication, but do not have access to computers or do not have the knowledge and confidence to use a computer. Should these methods be implemented in any way, there would be a need to provide access to computers and training.

HIV Information

The majority of women were happy with the quality of information available. Some service providers expressed a need for more information geared towards older women with HIV. Many women stated that they would like more access to information and advice about talking to their families about their HIV positive status.

Many women stated that they preferred face-to-face discussions for receiving HIV-related information. There was almost a 50-50 split as to whether they preferred traditional print materials or internet materials. Many of the women who stated that they prefer traditional print reported that they do not have access to computers and/or do not have strong computer skills; therefore, it is important that service providers and agencies keep relevant up-to-date print materials available.

Other information media that were discussed were books and videos. Many women reported that they would appreciate more access to such materials. One woman presented the idea of providing a mail-order library service in which PWN could provide videos and books specific to women's issues via mail-order to service providers and/or women.

Medical Access

Most women stated that they did not have difficulty accessing medical services and medications. The chief complaint remains that many women do have to travel outside of their communities in order to access a doctor who specializes in HIV. Many women stated that this can be an ordeal in terms of draining energy reserves, but they recognize that these visits are necessary. Women in British Columbia who live near the Alberta border used to have access to doctors in Calgary but, according to service providers in the West Kootaneys, Alberta put a stop to this in 2009. These women now have to travel to Kelowna or Vancouver.

Another complaint that women have is that their local doctors are not always educated about HIV, which impedes their ability to get regular care between specialist visits. One woman stated that she would no longer go to the hospital in her community due to the poor treatment she had received in regards to her HIV status. In addition, some women have encountered stigma when seeking dental services, as the dental providers did not have information about working with HIV-positive patients. This created situations in which the women were treated poorly and offered fear-based treatment.

Involvement of Women Living with HIV

Most women stated that they would enjoy the opportunity to be more involved with their local ASOs and PWN in a leadership capacity. This meant different things to different women. Some stated that volunteering would be preferable. Others reported that they would like to have the opportunity to provide education in their communities or local schools. Many women stated that they would like to be involved in peer support and advocacy on a systemic level. Many of the women interviewed are already involved in some way in their community: for example, many of the women in Prince George travel throughout the region with the “Positive Prevention Frontline Warriors” telling their stories and providing HIV awareness and education in Northern B.C.

There is a growing group of women who would like to see more HIV-positive women in staff roles at PWN and their local ASOs. They stated that they have vital first-hand knowledge and experiences that could make them great support workers and advocates. They would like more opportunities to be remunerated for their involvement in the HIV movement.

Most of the women who had prior opportunities to attend conferences or leadership training through PWN had enjoyed the experience and nearly all of the women interviewed expressed a desire to attend more conferences and leadership training.

The main reason for women expressing reluctance for greater involvement had to do with fear around stigma. Many women do not feel comfortable with too many people knowing their HIV positive status and fear that greater involvement in their community may expose their status to the wrong people. Other women described lack of energy as a reason to not get too involved. They stated that it would tax their already limited energy reserves.

The Challenges of Living on Reserve or in Small Communities

The majority of women spoken to for the LEAD project who live on-reserve or in small communities stated they face many challenges that differ from those facing women living in urban areas. Small communities and reserves tend to have fewer services that cannot cater to all of their needs, and points of contact with the services can be few and far between depending on the size of the geographic service area. The people providing those services usually need to take on multiple roles, which can lead to higher rates of burn-out and turnover which affects clients’ trust and comfort with an organization. In addition, there is a greater possibility of a service provider being a prior friend or even a family member, which can create the very real fear that confidentiality will be compromised.

Many of these communities do not have much knowledge and understanding about HIV, which can create high levels of fear and stigma associated with HIV among community members. In addition, there is very little choice in medical practitioners; therefore, if a woman is seeing a medical practitioner who has little understanding of HIV, she does

not necessarily have the option to seek out another practitioner. One woman stated that she actually left her community because the medical practitioner in her original community treated her with very little dignity and respect due to her HIV status.

Service providers in these communities have different challenges from urban providers as well. These can include having limited resources, working with transient populations, providing services to large geographic areas and needing to take on multiple roles. Creating boundaries in small communities can be challenging, as there is a greater likelihood of having contact with clients outside of work. The fact that funders and policy makers often live in urban areas can be a challenge for small communities. Often they have a limited understanding of the dynamics of small communities and the challenges associated with this work, and require service providers to work within frameworks not designed for small communities. What works in a large urban centre is not necessarily going to work on-reserve or in a small rural community.

RECOMMENDATIONS FOR IMPROVING SERVICES

The main recommendations provided by the women and service providers include:

- Provide more opportunities for women to gain and strengthen connections with other HIV-positive women;
- Invest in alternative methods of providing peer-to-peer support that utilize different technologies such as telephone and internet;
- Provide more women-specific programming and information;
- Lobby funders to provide more money for women-specific programming;
- Continue PWN retreats;
- Develop and provide more materials that focus on women-specific issues;
- Provide more workshops throughout the province;
- Encourage medical practitioners throughout the province to become more aware about HIV and HIV testing practices;
- Look for more opportunities to partner with other organizations in order to maximize funding opportunities;
- Develop a greater understanding of the challenges associated with living on-reserve and in small communities;
- Provide leadership to service providers throughout the province to help them gain and strengthen connections with each other;
- Provide more opportunities for women to be more involved in a leadership capacity;
- Provide more opportunities for women to attend conferences and leadership training.

SUMMARY

The LEAD Project only provides a small sampling of the experiences, challenges and opinions of HIV-positive women living in British Columbia. It is apparent that the system that these women must negotiate is far from perfect, but there is much passion and many positives and successes throughout the Province which demonstrate that there is hope for continued improvement. One of the most important findings in this report is that there is a need and a desire for PWN, the women and service providers to work together in order to find solutions to the challenges that HIV-positive women face everyday. This will be especially important given the recent funding cuts made to community HIV programs. The need for creativity and cooperation within the HIV movement has never been greater or more relevant.

APPENDIX

LEAD PROJECT CONSENT FOR RELEASE OF INFORMATION

The goal of the Leadership, Engagement, Action and Dialogue (LEAD) Project is to allow the Positive Women's Network (PWN), local AIDS Service Organizations and the women living with HIV/AIDS in B.C. to work together in order to determine the most practical means by which we can continually meet the needs of women in this province.

The processes by which PWN hopes to achieve this goal is via speaking with women and local ASOs to determine what programs are available, what is working, what is not working and the challenges and barriers that women are facing when seeking services. PWN wants to brainstorm around practical solutions to issues and encourage HIV-positive women to take leadership roles. The hope is to spark a culture of collaboration whereby we all work together in order to help HIV-positive women in B.C. lead full and normal lives.

All information gathered is confidential. At no point will names be used in any material being offered to the public. Every possible effort will be made to make this process as anonymous as possible.

The LEAD Project Coordinator, Emily, is open to answering any questions should a woman choose to gain more information about local programs, PWN or taking a more active role. Or she can contact:

Positive Women's Network: 1 866 692 3001 (Toll free in B.C. only)

pwn@pwn.bc.ca (email)

<http://pwn.bc.ca> (website)

OR

Your Local AIDS Service Organization

I, _____, give the Positive Women's Network permission to use the information collected today for all efforts related to the LEAD Project. It has been explained to me that all information collected during this focus group/interview will be confidential. I acknowledge that I have received \$20 for my participation.

Participate Signature: _____

Date: _____

Witness: _____

LEAD PROJECT - QUESTIONS

CONTINUUM OF CARE (50 minutes)

1. Prevention and Awareness (10 minutes)

- Prior to testing positive for HIV did you know how to protect yourself?
 - Did you know you were at risk; was it something that you thought about?
 - Were you aware of any prevention programs or campaigns?
 - Did you know where to go to ask questions about HIV?
 - Were you comfortable asking questions?
 - Were you in a position to protect yourself?

2. Testing (10 minutes)

- How comfortable were you when you got tested for HIV?
 - Did you feel that you had a choice to get tested?
 - How safe did the testing environment feel? (Did you get tested in your community?)
- What level of counselling/intervention did you receive when you tested positive? (both immediately and in the following weeks)
 - Were you made aware of the services that would be available to you as an HIV-positive woman?
- How could your testing experience have been improved?

3. Living with HIV (20 minutes)

- Do you know about the services in your community that are available to you as an HIV-positive woman?
 - What are they? (Both general and women-specific)
 - Do you feel comfortable accessing these services? (Why/why not?)
 - What barriers do you face when trying to access services?
 - What did you think of the services that you did access (positive/negative)?
 - How can they be improved?
- Are you aware of the Positive Women's Network and its services (i.e. outreach services, retreats, information services, telephone services)?
 - Are you a member?
 - Have you accessed PWN services? (Which ones?)
 - What did you think of the services that you did access (positive/negative)?
 - How can they be improved?
 - In terms of retreats, would you prefer to do something local or go somewhere else (i.e. Vancouver or another community)?
- Is peer-to-peer support a need/want?
 - Do you enjoy the level of peer support that you are currently accessing (if accessing any at all)? (Why/why not?)
 - Would a telephone support group be helpful and what would that look like to you?
 - Any other ideas for peer-to-peer support?
- Is information about living with HIV readily available to you?
 - What is the quality of information available?

- What information would you like to have that you do not have access to currently?
- How do you like to access information? (i.e. pamphlets, internet, one-on-one)
- What services would you like to have access to that do not exist right now?

4. Medical (10 minutes)

- Do you have an HIV-specific doctor? (Where?)
- What barriers have you faced when seeking medical services/drugs?
 - What exists or what could exist to ease these barriers?

WORKING TOGETHER (15 minutes)

1. How do you think that your local organizations and PWN can realistically work together in order to make a difference in your life?

- Easing barriers?
- Providing information?
- Providing services?

2. How do you think that you could be involved in this process?

- Would it interest you to take a leadership role in your community?
 - If so, what would that look like to you?