

**WOMEN AND HIV PREVENTION IN CANADA:  
THE PAST, THE PRESENT AND THE FUTURE  
IMPLICATIONS FOR RESEARCH, POLICY AND PRACTICE**

**18<sup>TH</sup> ANNUAL CANADIAN CONFERENCE ON HIV/AIDS RESEARCH**

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# Appreciations

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CAHR and Mark Tyndall

Sea to Sky (Ian Holliday and Sandy Haertling)



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## Session Overview

In collaboration with a variety of Canadian HIV/AIDS researchers, policy analysts and community stakeholders involved in the areas of women and HIV prevention, care, treatment and support, Dr. Jacqueline Gahagan from Dalhousie University and her research partners hosted a day-long satellite session as part of the 18th Annual Canadian Association for HIV Research (CAHR) Conference. The session, held in Vancouver on April 23, 2009, reflected the theme of the CAHR conference, "Facing the Evolving Epidemic," which captures the challenges in HIV prevention, care, treatment and support.

The day-long session, entitled *Women and HIV Prevention in Canada: The Past, the Present, and the Future—Implications for Research, Policy and Practice* provided an opportunity for disseminating findings from key national projects related to women and HIV in Canada and identifying gaps to help inform future directions in research, policy and practice. More than 90 people from research, policy and community sectors attended the session.

## Welcome and Objectives of the Session

Dr. Jacqueline Gahagan, Professor of Health Promotion in the School of Health and Human Performance at Dalhousie University, welcomed participants to the session and outlined the objectives of the day's session, which were to:

- ❖ Discuss the current state of women and HIV in Canada in terms of research, policy and practice;
- ❖ Discuss the challenges of measuring and capturing the complexity of women and HIV prevention in Canada in research, policy and practice; and,
- ❖ Identify gaps and potential implications for future research, policy and practice on women and HIV in Canada.

Dr. Gahagan reviewed the agenda and welcomed Zena Sharman, Assistant Director, Canadian Institutes of Health Research—Institute of Gender and Health, who co-facilitated the session. She also thanked the meeting sponsors for their generous contributions and members of the organizing committee and research team for their hard work.

# 1 Current State of Women and HIV in Canada in Research, Policy and Practice

## 1.1 Overview of HIV/AIDS Epidemiology in Canada—Chris Archibald, Public Health Agency of Canada.

**Dr. Chris Archibald**, Director, Surveillance and Risk Assessment Division, Public Health Agency of Canada, provided an overview of HIV statistics among women in Canada and compared these to the general population and vulnerable populations. He highlighted the distinction between *surveillance*, which is based on the actual number of people who test positive for HIV and are formally reported to governments, and *estimates*, which are generated using mathematical models that draw on surveillance and other data to arrive at the number of people living with HIV (prevalence) and the number of newly infected individuals in a given year (incidence).

At the end of 2005, the number of Canadians living with HIV/AIDS was estimated to be 58,000, representing a 16% increase from 2002. The next set of estimates are currently being developed for the period ending December 31, 2008, and are expected to be released in the Fall of 2009.

Of the roughly 2,500 individuals who test HIV-positive each year, about 25% are women, a proportion that has grown substantially since the start of the epidemic. However, this proportion is significantly higher in certain populations. For example:

- ❖ Women represent more than half of all new HIV-positive tests among Aboriginal Canadians;
- ❖ Women in the 15 to 19 year old age group represented 60% of all positive test reports for that age group in 2007, and 35% in the 20 to 29 year age group. Among Aboriginal Canadians, these proportions rise to 80% for the 15 -19 age group and 60% for the 20-29 age group.
- ❖ Aboriginal women, who represent about 4% of the total Canadian female population, accounted for about 45% of all positive tests among women in 2007.
- ❖ Black women, who represent a little more than 2% of women in Canada, accounted for about 20% of all positive tests among women in 2007.
- ❖ For known exposure categories, roughly 35% of HIV positive test results were associated with injection drug use (IDU), a proportion that rises among Aboriginal women where 63% report the IDU risk category.

The number of babies born to HIV-positive women has risen steadily over the last 10 years. However, a large proportion of these women received anti-retroviral treatment,

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which has helped decrease mother-to-child transmission substantially.

Dr. Archibald highlighted the following gaps in surveillance data:

- ❖ Completeness of ethnicity data (currently the two largest provinces of Ontario and Quebec do not provide ethnicity data);
- ❖ Better exposure information on heterosexual cases, including better definitions. Currently there are three heterosexual sub categories.

**Questions and Answers**

In the question period following Dr. Archibald's presentation, the following points were made:

- ❖ 20 years ago women represented less than 3% of new infections. At the time, community advocates called for investments in HIV prevention programs targeting women in order to prevent this number from increasing but were told that the low numbers did not justify the resources. Today the number has risen to 25%. This might have been avoided if governments had responded before the numbers reached epidemic proportions.
- ❖ The surveillance system needs to clearly distinguish between morbidity and mortality. A significant number of HIV-positive individuals are dying from the toxicity of the treatment cocktails they take. Surveillance data need to distinguish between these individuals and those who die from AIDS-related complications.
- ❖ Surveillance data are vital to informing the response to the epidemic in Canada. Government surveillance programs must work closely with frontline workers and other stakeholders to ensure that the data collected are useful for directing the response to HIV/AIDS.
- ❖ Women in prison have higher HIV prevalence rates than men (about 4% compared to 1-2% for men) and even higher HCV prevalence rates. This is due in part to the greater proportion of women in prison who have a history of injection drug use. The prison venue provides an opportunity to offer HIV prevention counselling for women before release or as part of a pre-release program.
- ❖ There are two sources of AIDS mortality data: 1) deaths among AIDS cases reported to PHAC; and 2) deaths attributed to HIV reported to Statistics Canada. PHAC acknowledges that discrepancies exist due to differences in the definitions for cause of death used in the two databases. PHAC is working with the provinces and territories to link care databases with diagnosis databases to arrive at a better picture of HIV-related mortality and morbidity.

## **1.2 Overview of Key Findings in the HIV/AIDS Status Report for Women—Clare Jackson, Public Health Agency of Canada**

**Clare Jackson**, Policy Analyst (Populations), HIV/AIDS Policy, Coordination and Programs Division (HIV/AIDS Division), Public Health Agency of Canada (PHAC), described work to develop Population-Specific HIV/AIDS Status Reports for key populations identified in the Federal Initiative to Address HIV/AIDS in Canada. She provided a brief summary of some of the findings from two of the draft Status Reports: 1) for Women; and 2) for Aboriginal People. Immediately following her presentation, her colleague **Marc-André Gaudreau**, Manager, Program Development and Evidence-Based Interventions, HIV/AIDS Division, PHAC, provided a summary of work underway to develop a comprehensive framework to guide HIV testing and counselling in Canada.

### **Status Reports**

There will be eight Status Reports, one for each of the key populations identified in the Federal Initiative. They are at various stages of development, with the final two reports expected in 2010. The reports provide a detailed overview and analysis of the available information and evidence on HIV/AIDS published in Canada since 2002. Each report will include current Canadian information on the population's demographic profile, state of HIV infections and AIDS cases, research on factors that increase vulnerability to HIV/AIDS, currently funded research activities, and an analysis of the state of the response to HIV/AIDS in those populations. The reports will be used by PHAC to inform future directions in HIV/AIDS policy, programs, research, and by other stakeholders. It is important to note that all of the Status Reports, with the exception of the report for gay men and other men who have sex with men (MSM), will include a discussion of women.

Biologically, women are more susceptible to HIV infection through heterosexual exposure than men. In addition to the biological vulnerability of women to HIV infection, gender inequities are a key driver of the HIV/AIDS epidemic among women. Gendered norms and power relationships are reflected in HIV exposure categories, and risk behaviours among women often relate to power imbalances in social relationships. For example, women in heterosexual relationships may be unable to negotiate the use of condoms, or women who inject drugs may receive injections from others, making them unable to control drug quantities or ensure the use of clean equipment.

Gender inequities are also evident in terms of levels of income and social status, which in turn affect women's vulnerability to HIV infection. The average earnings of employed women are lower than those of men – and certain groups of women, such as Aboriginal women, earn less than their white female counterparts. Low socioeconomic status often forces women to engage in behaviours, which increase their risk of HIV infection. For example, poverty can manifest itself in dependent relationships, inability to acquire stable housing, or the need to engage in survival sex as a means to access food or shelter.

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A history of sexual abuse is associated with risk-taking behaviours in adulthood, meaning that children who experience sexual abuse are more likely to engage in behaviours that put them at risk of contracting HIV. Women are more likely to be survivors of childhood sexual abuse than men, and Canadian research suggests that people who have survived sexual violence are more likely to be HIV-positive.

For Aboriginal women, the multi-generational legacy of residential schools, cultural disruption, violence, racism and poverty are all factors that increase vulnerability to HIV infection. Injection drug use is associated with the majority of positive HIV test reports among Aboriginal women, accounting for 64% of positive tests between 1998 and 2006. Aboriginal women who use injection drugs are also often survivors of sexual abuse during childhood.

Studies suggest that Aboriginal women are over-represented in visible, street-based sex work. Participation in sex work or survival sex can increase the risk of HIV infection for a number of reasons, including unprotected intercourse with clients or non-client sexual partners, injection drug use and unstable housing or homelessness. Dependence on sex work for survival may result in a reduced ability for women to utilize HIV prevention strategies.

The literature review for the Status Report for Aboriginal People also identified some key sources of resilience for Aboriginal women. These sources of resilience include connectedness with culture and spirituality, family and children, and access to culturally appropriate social supports.

HIV testing is a key component for reducing the spread of HIV and improving access to medical care for those who are HIV positive. Women face a variety of barriers to accessing testing, including discrimination, fear of violence, stigmatized views of HIV/AIDS, and cultural barriers around sexuality. Aboriginal women may face complex issues in deciding whether or not to access HIV testing, including fear of judgement, and fear of losing children as a result of revealing risk behaviours or discovering a positive diagnosis.

***HIV Counselling and Testing Guidelines and Policy Framework***

PHAC is leading the development of a comprehensive HIV testing and counselling policy framework for Canada, which will include renewed counselling guidelines. PHAC is actively consulting with provincial and territorial governments and other stakeholders, and has established an expert working group to advise on the development of the guidelines and framework. The working group's membership is drawn from professional associations, health care providers, frontline workers (public health and outreach), populations at risk of HIV, community-based organizations, provincial governments, researchers and legal/ethics experts. Among other things, the working group has provided the following direction to PHAC as it develops the framework and guidelines.

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- ❖ The framework should favour maintaining the '3 Cs' of testing (confidentiality, counselling and consent).
- ❖ Pre-test counselling may differ depending on circumstance and setting.
- ❖ Post-test counselling is critical in terms of the opportunity for prevention messaging and referral to treatment.
- ❖ Approaches must be adapted to target specific populations and settings (i.e., the guidelines must be adaptable and evergreen).
- ❖ A more integrated approach to screening for infectious diseases is needed, recognizing the specific nature of HIV.
- ❖ Appropriate dissemination and training are important, once the guidelines have been published.
- ❖ A plan for evaluating the uptake, implementation and impact of the framework and guidelines must be developed from the outset.

It has been noted that the guidelines must ensure that testing programs provide a safe and confidential environment and adapt pre- and post-test counselling to the particular needs and cultural backgrounds of women. Counselling must also consider the implication of test results for pregnancy and pre-natal care and refer women to the appropriate services. The importance of informed consent is paramount.

Mr. Gaudreau advised that online public consultations will be conducted in May and June, and invited all participants in the room to participate. For those without Internet access, a toll-free number will be set up for ordering printed copies of the survey. Renewed guidelines will be published in December of 2009.

### ***Questions and Answers***

In the question period following Ms. Jackson's and Mr. Gaudreau's presentations, the following points were made:

- ❖ An online consultation may exclude some of society's most vulnerable, including women who do not have access to the Internet.
- ❖ There is no one-size-fits-all strategy for getting women in for HIV testing. Testing programs therefore need to be creative in terms of how they reach women who may not be allowed to leave their homes except for specific purposes. In Toronto, for example, HIV testing and counselling are being offered in community kitchens which are among the few places that women from some communities can visit unaccompanied by family members.
- ❖ Programs are needed to educate doctors about the potential negative consequences of nominal testing which may expose some women to violence

because their husbands or partners will be informed of their HIV status through the public health system. The counselling guidelines must ensure that women understand the consequences of a positive test and are given the information needed for pursuing alternatives (e.g., where to go for anonymous testing).

- ❖ Training and resources are key to implementing HIV testing programs and to avoid infringing on people's rights in the pursuit of diagnosing the undiagnosed cases.
- ❖ Because the guidelines are being developed by the federal government but implemented by the provinces and territories, there is potential for a disconnect between their intended use and how they are implemented across the country. Resources and training will need to be provided to ensure consistent implementation across the country.

## 2 Challenges of Measuring and Capturing Women and HIV in Canada in Research, Policy and Practice

### 2.1 *Positive Places, Healthy Spaces: Key Findings—Ruthann Tucker, Ontario HIV Treatment Network*

**Ruthann Tucker**, Senior Director of Community-Based Initiatives and Organizational Development, Ontario HIV Treatment Network (OHTN), and **Saara Greene**, Assistant Professor, School of Social Work, McMaster University, reported on key findings related to HIV-positive women from the Positive Spaces, Healthy Places Study, a community-based research project that is exploring issues around HIV, housing and health. The study enrolled 605 people living with HIV in communities across Ontario and followed them over a one-year period using both quantitative health surveys and qualitative interviews conducted by peer research assistants. Of the 605 participants, 142 were female, 456 were male and 7 were transgendered. The majority of women participating in the study were heterosexual (90%) and living with children (78%). About half of participants were from African/Caribbean or Aboriginal communities. While the study focused on housing and health, it necessarily collected data on a broad range of social determinants that impact housing and health such as income, substance use, experience with the criminal justice system, etc.

Key findings of the study were:

- ❖ A majority of the women in the study reported difficulty buying food (2/3) and clothing (72%).
- ❖ Compared to men, women reported higher living costs and were three times as likely to be unstably housed. However, 40% reported that they were less likely to

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move because of limited options. 1/3 reported being homeless at least once in their lives.

- ❖ Rates of homelessness were twice as high among women in the study than men (12.7% vs. 5.6%).
- ❖ Women were more likely than men to worry about being forced to move, and this was especially evident among women with children.
- ❖ More women (40%) reported experiencing housing discrimination than the overall group (33%). The top three reasons given were discrimination based on: 1) the number of people in their households; 2) race; and, 3) gender. These reasons differed from those of the overall group, which reported race, source of income and HIV status as the top three sources of discrimination.
- ❖ Women were more likely to experience significant depression and have lower overall mental health than other participants in the study. Women were less likely to use alcohol and substances in a harmful manner.
- ❖ Women were significantly less likely to be satisfied with all aspects of their dwellings and neighbourhoods, and 50% more likely to say that they could not stand being at home than men.
- ❖ The top four services that women identified as being needed were: 1) respite care (3 times more likely); 2) child care (2.8 times more likely); 3) massage therapy (2.8 times more likely); and, 4) life skills training, cooking and budgeting.

In terms of lessons learned, the study found that:

- ❖ Housing solutions for women must address the context of their lives;
- ❖ Staying in one place does not necessarily mean that women are living in appropriate housing;
- ❖ HIV positive women need access to treatment options that fit with their daily lives;
- ❖ One type of housing and housing support does not work for all HIV-positive women.

Follow-up phases of the study are underway or in development, and will incorporate questions on prevention, criminalization and sexual practices. Phase 4 will recruit at-risk HIV-negative populations to study the links between housing, the social determinants of health and risks of HIV infection. Participants were invited to email or otherwise contact the presenters with any questions.

### **Questions and Answers**

In the question period, the following points were raised:

- ❖ Women have many responsibilities to juggle such as caring for others in their household, food, rent, utilities and their own health. This is something that is heard repeatedly in working with women living with HIV. It points to an urgent need for social programs and policies that help women with these responsibilities.
- ❖ Women need support before they become ill, not just once they are ill.
- ❖ A big source of insecurity and fear for some women is Community and Social Services (“CASS”). Women who become ill may need to take their kids out of school to help around the house, which can trigger child welfare services. This is an example of the need to work with other ministries and departments outside the traditional health portfolio to address the critical needs of women living with HIV.

### **2.2 HIV Prevention in Canada: A Meta-Ethnographic Synthesis of Current Knowledge—Jacqueline Gahagan and Tracey Prentice**

**Tracey Prentice**, University of Ottawa, and **Jacqueline Gahagan**, Dalhousie University, presented an overview of the preliminary findings from a CIHR-funded study to systematically review qualitative literature on HIV prevention related to Aboriginal and non-Aboriginal women in Canada published between 1996 and 2008. The objectives of the study were: to identify where specific knowledge of HIV prevention needs is lacking or where there is a lack of consensus; to generate a synthesized understanding of the conceptual frameworks expressed in the literature; to connect findings to the policy response at the federal, provincial and territorial levels; and, to produce new knowledge and identify wise practices and gaps in existing knowledge that can be used to inform future research directions. The study included 38 articles for review and analysis based on a set of inclusion criteria established at the outset. The papers had a broad ethno-cultural focus with a significant proportion (40%) addressing issues related to Aboriginal women and HIV. A key finding of the review is that most articles treated women as a homogenous group and lacked details on the diversity of women’s experiences in relation to HIV prevention. A limited number of articles addressed issues of sexual orientation or gendered sexual dynamics.

Preliminary analysis of the data suggests the following:

- ❖ Despite increases in HIV infections among women in Canada, there continues to be a limited focus on the diversity of women-specific HIV prevention issues;
- ❖ There is a lack of attention to women outside of “normative” contexts (i.e., pre-natal) or contexts of risk (i.e., injection drug use);

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- ❖ There is a limited focus on other populations of women such as those with children, older women, those from other countries, LGBTI;
- ❖ Most studies do not address heterosexual/opposite sex sexual partners in HIV prevention or gender dynamics as key factors in understanding HIV prevention;
- ❖ The focus remains on empowerment of women and increased prevention training in isolation from political and economic structural factors;
- ❖ There is a lack of systematic monitoring and evaluation of HIV prevention efforts.

These preliminary findings suggest a number of future directions for research, policy and practice as they relate to HIV prevention among women:

- ❖ For **research**, the findings suggest the need for:
  - An augmented focus on the diversity of women's experiences in HIV prevention research;
  - Active inclusion of both HIV-positive and HIV-negative women in shaping research questions, methods, etc;
  - More connections to existing mechanisms within the NGO sector to shape research priorities.
- ❖ For **policy**, the findings suggest the need for:
  - Reframing HIV prevention policies so that they are more inclusive of women's unique experiences, particularly in relation to issues of housing, childcare, etc;
  - Greater recognition of the complexities of women's lives and identities and the cumulative impact of race, class, age and colonialism on the unequal distribution of disease;
  - Funding for systematic gender-based analysis and evaluation of HIV/AIDS at the local, provincial and national levels.
- ❖ For **practice and programming**, the findings suggest the need for:
  - Alternative models of empowerment and education away from the "deficits model" of prevention failures;
  - Greater focus on the ways in which women resist oppression in HIV prevention programming;
  - Systematic evaluations of what is working and what is not;

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- Greater emphasis on the uniqueness and diversity of women's HIV prevention experiences and needs;
- Addressing the ongoing use of generic prevention messages directed at "women".

The presenters emphasized that the presentation today focused on preliminary results and that further analysis was planned. They advised that an edited volume on key topics related to women and HIV in Canada would eventually be developed and invited participants to contact them regarding next steps.

### **Questions and Answers**

In the question period that followed the presentation, the following points were noted:

- ❖ Grassroots organizations and NGOs are not equal in terms of their resource levels and influence. One way to empower women is to give HIV-positive women a paid role in the research.
- ❖ There is evidence that women acquire HCV before they acquire HIV. This suggests that the testing and counselling guidelines being developed by PHAC should include a component on HCV, not just HIV.
- ❖ Prevention strategies need to take into consideration age. They have tended to focus on younger women and women of child-bearing age.

### **2.3 IDU, Sex Work and Women—Mark Tyndall, University of British Columbia.**

**Mark Tyndall**, Associate Professor of Medicine, University of British Columbia and Head of Infectious Diseases at St. Paul's Hospital, provided an overview of the challenges in providing HIV care and treatment to marginalized women in Vancouver's downtown eastside where rates of infection among women are the highest in Canada. He reviewed the results from a number of studies that looked at the risk factors associated with HIV sero-conversion among female sex workers and at a model for providing treatment and support for women who might otherwise be excluded from treatment altogether.

The MAKA Project is a community-based partnership between the BC Centre for Excellence in HIV/AIDS and the WISH Drop-In Centre that is examining the HIV-related vulnerabilities and barriers to accessing care among women engaged in survival sex, and the impact of current prevention and harm reduction strategies on this population. It also aims to involve these women in the development of sustainable and culturally-relevant HIV programs. Among participating women, the study found that HIV infection was associated with: 1) unprotected sex with intimate partners; 2) daily crack cocaine

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use; 3) daily cocaine injection; 4) Aboriginal ethnicity; and 5) initiation into sex work at a young age (less than 18 years of age).

Dr. Tyndall reviewed a number of studies that show anti-retroviral treatments are more successful if started before an individual's CD4 cell count drops below 250 cells/ $\mu$ l. Other studies suggest that by lowering an individual's blood viral load this may in turn decrease the chances of their infecting others. This has led to calls for expanding the number of individuals on treatment as a form of prevention that can halt the epidemic. However, adherence to treatment regimens is critical to keeping viral loads low and preventing the development of new strains that are resistant to treatment. New simplified treatment taken as a single pill once a day are now available and show promise for increasing adherence. However, these new treatments are not appropriate to all women. The paradox remains that those that are most likely to transmit HIV have the most obstacles to consistent care and treatment.

A peer-driven intervention (PDI) among 20 women in the downtown eastside of Vancouver has shown promise for women who might otherwise be excluded from treatment altogether. Beginning January 2007, 20 HIV-positive women (both ART-naïve and those previously unsuccessful in adhering to ART) were enrolled in the PDI. The program consists of four parts: 1) weekly peer support group meetings where women are introduced to HIV care and stabilization modules dealing with a wide variety of issues such as HIV and nutrition, drug use-ARV interactions, side effects, budget planning, etc.; 2) health advocacy ("buddy") system; 3) peer outreach; and, 4) onsite nursing care. Adherence was measured onsite through weekly self-reporting and verified with pharmacy records. Overall, the intervention resulted in high rates of treatment adherence.

In summary, women engaged in sex work and/or dependent on illicit drugs are disproportionately impacted by HIV. Due to a range of social and structural factors, access to HIV care and treatment is poor. Innovative and comprehensive programs can make an impact but are underutilized. In the next five to ten years the downtown eastside will be gentrified as a result of processes accelerated by the 2010 Winter Olympics. This will cause a migration of marginalized women to other areas around Vancouver. There will likely continue to be opposition from government on harm reduction and legal reforms. There will need to be a move toward expanding antiretroviral treatment (and HCV treatment) among drug users.

### ***Question and Answers***

In the question period following the presentation, the following points were raised:

- ❖ There are ethical problems with any initiative that aims to get HIV-positive individuals on treatment in order to prevent other people from getting infected. There are significant individual costs of treatment related to side effects and

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morbidity. There is too little data to support the notion that such a prevention strategy will be effective. The Swiss study looked at HIV levels in blood but not in semen, for example.

- ❖ We need to determine how to expand the peer-driven intervention to other groups of women and beyond a focus on anti-retroviral treatment. We need more peer-led support programs to address the social determinants of health among women. Women can help other women budget for housing, learn how to negotiate safer sex, live healthier lives, etc.

**2.4 *The Politics of Poverty: Meeting the Needs of Aboriginal Women Living with and Affected by HIV—Kevin Barlow, Canadian Aboriginal AIDS Network.***

**Kevin Barlow**, Chief Policy and Research Officer, Canadian Aboriginal AIDS Network (CAAN), described the root causes of the HIV/AIDS epidemic among Aboriginal women in Canada and the response required. In 2005, PHAC estimated that between 3,600 and 5,100 Aboriginal persons were living with HIV/AIDS in Canada, of which about half were women (48.1%). According to the 2007 *Epi Update*, other unique aspects of the HIV/AIDS epidemic among Aboriginal women include:

- ❖ More HIV-positive Aboriginal women inject drugs compared to non-Aboriginal women;
- ❖ Aboriginal women tend to be diagnosed at the AIDS stage, missing the opportunities and benefits of HIV therapies which could prolong life.

Without a doubt, poverty is driving the HIV/AIDS epidemic among Aboriginal people. Study after study done by CAAN reveal how the simple necessities of life such as food and shelter are not being met. Combine this with childhood abuse issues and the influence of historical trauma, it is little wonder that some Aboriginal people turn to drugs and alcohol to cope. This is compounded by the negative experiences and poor treatment at the hands of some in health services. In the end, there is little to entice an Aboriginal woman to become engaged with services that ought to be there for her.

Aboriginal women who have trusted CAAN with their stories, have identified a number of needs. One of these needs is for a safe space where HIV-positive Aboriginal women, with or without children in their care, can meet to support each other and build confidence to raise their issues and needs in larger fora. They have also identified the need for access to elders and ceremonies.

In response to these needs, CAAN has created a position for an Aboriginal Women and Leadership Coordinator and is developing an Aboriginal Women's Action Plan. An

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Aboriginal Women's Gathering is planned for this year. Alliances between men and women must be created to begin undoing the damages created by colonialism and to meaningfully change the way Aboriginal people live.

**Questions and Answers**

There was no time for questions following the presentation.

**2.5 Taking Action on HIV/AIDS in Black Communities in Canada—Dionne A. Falconer.**

**Dionne A. Falconer**, DA Falconer & Associates Inc., and author of *Taking Action on HIV and AIDS in Black Communities in Canada: A Resource for Moving Ahead*, provided an overview of strategies to enable better planning and delivery of HIV/AIDS programs and services to Black women in Canada.

Black women in Canada are disproportionately affected by HIV/AIDS. According to PHAC estimates, 16% of new HIV infections and 12% of all HIV infections were attributed to the "HIV-endemic" exposure category in 2005. However, Ms. Falconer pointed out that the use of the category "endemic", which historically referred to people from high-prevalence countries in the Caribbean and Sub-Saharan Africa, where the populations are predominantly Black, is problematic, as it does not provide a clear picture of who is infected. This is particularly so as the list of "HIV-endemic" countries now includes countries such as Cambodia, Myanmar and certain countries in Latin America.

A major obstacle to understanding the epidemic among Black women is the incompleteness of ethnicity data. Between 1998 and 2006, women accounted for 54.2% of all positive HIV cases and 41.8% of all AIDS cases reported to PHAC for the HIV-endemic category. These figures do not include Ontario and Quebec which together represent 85% of the Black population in Canada.

In the past, issues related to Black women and HIV/AIDS received little attention but this situation has been slowly changing over the last few years with the publication of a number of studies and needs assessments. The most recent of these is *Taking Action on HIV and AIDS in Black Communities in Canada: A Resource for Moving Ahead*, representing the second phase of the Springboarding a National HIV/AIDS Strategy for Black Canadian, African and Caribbean Communities project. *Taking Action* was developed based on a review of documentation supplemented with interviews and focus group discussions in 6 cities across the country. The research revealed a lack of visibility and prioritizing of HIV and AIDS in Black communities in Canada which are very diverse and geographically dispersed. Likewise, funding for initiatives targeting Black communities is fragmented, limited and difficult to access. Fear, HIV stigma and

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discrimination are negatively affecting Black people coming forward for HIV prevention information, care, treatment and support. Issues around immigration and settlement are an additional layer that affects the population. In terms of implications for Black women specifically, the following are noted:

- ❖ There is the differential impact of gender and this is reflected in the disproportionate rates of HIV and AIDS.
- ❖ The intersection of factors such as gender, race, socioeconomic status, religion and sexual orientation affects sexual behaviour, increases risk and impacts the ability to cope with living with HIV/AIDS.
- ❖ Although existing reports and the forthcoming PHAC-sponsored Black Community HIV/AIDS Status Report are a good start, more evidence and targeted initiatives are needed.
- ❖ Black women need to participate and be engaged in dialogue, decisions and actions around research, policy and practice.

Key recommendations of *Taking Action* include:

- ❖ Governments need to increase their investment and provide targeted funding to address the disproportionate rates of HIV and AIDS in Black communities.
- ❖ Policy makers need to engage with the Black community to revise and make policies that will have a positive impact on preventing further HIV transmissions in the Black community and meeting the care, treatment and support needs of Black people living with HIV.
- ❖ Community members, including Black people living with HIV, need to come together, strategize, plan and take action.
- ❖ Service providers need to enhance their capacity to respond more effectively to community needs.
- ❖ Researchers need to undertake all types of HIV and AIDS research that will be beneficial to the Black community.

### ***Questions and Answers***

In the question period that followed the presentation, the following points were raised:

- ❖ Interviews and focus groups for the *Taking Action* study were conducted in either English or French. However, there is recognition that the Black community has multiple language needs in addition to English or French.

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- ❖ Confidentiality is a significant issue among immigrant groups. The *HIV Prevention Guidelines and Manual for Service Providers Serving African and African Caribbean Communities* (2006) and the research study *HIV/AIDS Stigma, Denial, Fear and Discrimination* (2006) are good resources on this issue.
- ❖ The need to work with churches to raise awareness of HIV/AIDS in Black communities has been recognized. The AIDS Bureau of Ontario is working with a coalition of Black churches in Toronto to launch an HIV testing and awareness program. A speech to the Anglican Diocese on the occasion of World AIDS Day has led to some follow-up work.

**2.6 Trans PULSE Project—Greta Bauer, University of Western Ontario.**

**Greta Bauer**, Assistant Professor in Epidemiology and Biostatistics at the University of Western Ontario, provided a summary of preliminary findings from the Trans PULSE Project, a community-based study of how social exclusion affects the health of trans communities in Ontario and creates vulnerability to HIV. Due to limited data and research on trans populations, the true prevalence of HIV among trans people is not known. However, two recent meta-analyses in the US and overseas suggest that these rates are high (about 27% for trans women in the US). The Trans PULSE Project will be completed in three phases consisting of “community soundings,” surveys (of up to 1,000 individuals) and interviews to add depth to the survey responses. The following nine factors that contribute to HIV vulnerability in trans women were identified in published research and the community soundings, and will be explored further through the surveys and interviews:

- ❖ Barriers to finding or maintaining employment;
- ❖ High financial and social costs of transition;
- ❖ Established demand for sex work;
- ❖ Periods of low self-esteem, depression, anxiety and poor body image;
- ❖ Difficulties—or anticipation of difficulties—in finding healthy sexual or intimate relationships;
- ❖ Sexual exploration or validation following surgery;
- ❖ Lack of appropriate prevention messages, programs and information (e.g., wrong gauge of needles for hormones obtained illegally);
- ❖ Lack of trans-appropriate health care;

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- ❖ Lack of research and information on HIV, factors affecting vulnerability, effects of multiple stigmas and treatment for both HIV and sex reassignment.

A major phenomenon that affects the health of trans people is the “erasure” of trans identities and experiences, which help sustain popular misconceptions about trans people and reinforce the stigma and discrimination they face. Institutional erasure of trans people occurs through a lack of health care, education or hiring policies that accommodate trans identities or trans bodies, including the lack of knowledge that such policies are even necessary. Information erasure includes both a lack of knowledge regarding trans people and trans issues, as well as the assumption that such knowledge does not exist, even when it may. Underlying all of these processes of erasure is cisnormativity (the belief that trans identities or bodies are less authentic or “normal”). These processes mutually reinforce each other such that the emergence of a trans person as a job applicant, patient or client is seen as an anomaly, and one that is not backed by a visible community of any number or strength. Thus, it too often falls on individual trans people to attempt to remedy systematic deficiencies and policies, and to acquire the knowledge necessary to address their needs.

**Research** to identify and reduce vulnerability to HIV among trans women must address the following:

- ❖ Addressing historically rooted distrust of researchers;
- ❖ Reversing erasure of trans people from research;
- ❖ Tracking of trans status in HIV epidemiology;
- ❖ Developing appropriate measures to assess sexual risk behaviours;
- ❖ Addressing multiple stigmas related to being trans and living with HIV.

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**Policies** for reducing HIV vulnerability among trans women must be built on the following:

- ❖ Employment policies that support hiring, promotion and retention of trans employees;
- ❖ Explicit human rights protection for gender identity and gender expression;
- ❖ Removing surgical requirements for changing sex on legal identification.

Changes in **health care infrastructure** to reduce HIV vulnerability among trans people are needed in the following areas:

- ❖ “Men’s” and “Women’s” services in reproductive and sexual health;
- ❖ Sex-segregated wards, not just in health care, but also in other systems such as shelters and prisons;
- ❖ Sex-based procedural billing;
- ❖ Sex identification on health cards;
- ❖ Consistent public funding of sex reassignment care.

HIV prevention **practices** must take into consideration the following to reduce the HIV-related vulnerabilities of trans people:

- ❖ Make all HIV prevention programming trans-appropriate, including programs in First Nations, Métis and Inuit communities; with newcomers to Canada; for youth; for older adults; for gay, bisexual and other MSM; prevention for positives;
- ❖ Develop or implement trans-specific HIV prevention programming.

### ***Questions and Answers***

In the question period that followed the presentation, the following points were raised:

- ❖ How a trans person is categorized can have severe consequences for her / his health and safety. For example, in prisons where gender is assigned by genitalia, a trans woman may end up in the men’s prisons and be subjected to violence and abuse.
- ❖ It is difficult to provide a demographic breakdown of trans people because the data have not been collected.

- ❖ Countries all differ in how they treat trans people. Even among those that have progressive policies and support services for trans people, individual countries differ in their relative strengths and weaknesses. Thailand is more accepting of male-to-female trans people and provides good health care to those who can afford it. The Netherlands provides health care across the board. The United Kingdom is ahead in terms of legal issues relating to changing ID. However, there are problems with its Gender Identity Act, which requires a person undergoing sexual reassignment surgery to get legally divorced.

### **3 Gaps and Potential Implications for Future Research, Policy and Practice on Women and HIV in Canada**

#### ***3.1 Implications of the Blueprint for Action on Women and HIV/AIDS—Louise Binder***

**Louise Binder**, Chair of the Canadian Treatment Action Council (CTAC) and Vice-Chair of Voices of Positive Women, led an exercise to identify the top 3 priority areas of action from the Blueprint for Action on Women and Girls and HIV/AIDS. The Blueprint is a comprehensive strategy to stop the HIV/AIDS epidemic among women and girls (including transgendered women). It identifies 6 broad areas requiring an adequately funded, sustained and ongoing response from all stakeholders. The full text of the Blueprint can be downloaded from: [womensblueprint.org](http://womensblueprint.org).

Participants were provided with copies of the Blueprint and a checklist of the Blueprint's 6 areas of action from which they were asked to identify 3 priority areas and rank them from 1 (most important) to 3. They were then asked to identify the top priority issue within each of the 3 areas they chose. Participants' rankings were tallied in plenary. Twelve participants also handed in their checklists, which mirrored the ranking in plenary and provided additional information on priority issues in each area. The information is provided below:

#### **1. Diagnosis and Treatment, which includes testing:**

- Confidentiality of testing which requires training for doctors so that they understand the vulnerabilities and risks that women may face in relation to testing and are better able to counsel their patients on options and consequences;
- Drug coverage for all;
- "Safe" testing (socially safe re: privacy and violence);
- Culturally appropriate and explicit testing guidelines (X2);

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- Education on testing options and pregnancy testing;
- More studies involving women;
- Access to treatment, address barriers in health centres and affordability;
- Expanded access to treatment and testing in rural areas and among at-risk populations (e.g., through rapid testing).

**2. Stigma and Discrimination:**

- Racism and discrimination→Accessing services;
- Culturally and socially appropriate services for health care and community integration;
- Leadership from the private sector;
- Address colonization and its effect on Aboriginal people;
- Criminalization of HIV;
- Need for education and campaigns to promote greater understanding.

**3. Prevention and Education:**

- Microbicides advocacy (X2);
- Workshops / training of peer supporters / mentorship programs;
- Support for culturally and linguistically appropriate prevention and education strategies for First Nations, Inuit and Métis;
- Testing sites;
- Access to prevention messaging that is appropriate to women's particular situations (beyond male condoms) in places where women congregate;
- New messages for youth (via schools), expanded use of condoms, added education on "risky" sexual behaviours;
- Tailoring the prevention messages and approach to reach specific populations.

**4. Care and Support:**

- Outreach programs;
- Accelerated funding for peer support, advocacy and access for rural and vulnerable areas of Canada;
- Leadership from all levels of government and the private sector to develop comprehensive, culturally and linguistically appropriate plans to redress the inequalities that women and girls face in relation to the social determinants of health.

**5. Research:**

- None identified.

**6. Legal, Ethical and Human Rights:**

- Decriminalization of sex work (X2);
- Criminalization of HIV;
- Violence against women.

**3.2 National HIV Pregnancy Planning and Fertility Guidelines—Shari Margoless, Voices of Positive Women and Dr. Mona Loufty, University of Toronto.**

**Mona Loufty**, Infectious Disease Specialist and Clinical Researcher, University of Toronto, and **Shari Margoless**, Voices of Positive Women, provided an overview of work to develop national HIV pregnancy planning guidelines in response to a growing prevalence of HIV among women of child-bearing age in Canada. Women represented 27.7% of newly diagnosed HIV cases in 2004, the majority of whom (82.8%) were aged between 20 and 40 years. This, coupled with improvements in life expectancy and quality of life for HIV-positive individuals and new treatments that have reduced the mother-to-child transmission of HIV to less than 1%, has led to an increase in the number of individuals seeking to become pregnant and have a family. The guidelines are part of the Canadian HIV Fertility Program, which aims to provide guidance and assistance to people living with HIV in Canada with their fertility and pregnancy planning desires in a holistic, ethical, supportive and medically sound manner. The project will be completed in four phases starting with a needs assessment and gap analysis, development of linkages with key national stakeholders, development and publishing of the guidelines followed by the development of knowledge translation and capacity-building tools to increase awareness and, eventually, evaluation of the guidelines.

As of April 2009, a draft of the guidelines has been developed and is currently under review by a guidelines development team of more than 30 experts with membership from HIV clinical HIV specialists, fertility experts, obstetricians, midwives, paediatricians, researchers, community members and policy members. The team has met several times by teleconference and once face to face. A final draft of the guidelines will be issued in May/June and submitted for publication in July/August 2009. The presenters invited participants to contact them should they wish to be part of the development team.

### **Questions and Answers**

In the question period that followed the presentation, the following points were raised:

- ❖ In recognition of the important link between post-test counselling and pregnancy planning, the project has members who also sit on the Ad Hoc Working Group for the HIV Testing and Counselling Framework being developed by PHAC.

### **3.3 Women, HIV/HCV and Harm Reduction in Federal Prisons—Anne Marie DiCenso, Prisoners HIV/AIDS Support Action Network.**

**Anne Marie DiCenso**, Executive Director, Prisoners' HIV/AIDS Support Action Network (PASAN), provided an overview of the federal female prison population, infection rates for HIV and HCV, and the challenges related to the delivery of harm reduction and health promotion in this population.

There are 449 women incarcerated in federal prisoners, representing a small but growing proportion of the total population of 12,500. The majority of women in federal prisons are serving time for non-violent crimes or crimes by association, in self-defence or out of poverty. An incarcerated woman is most likely to be:

- ❖ A survivor of emotional and sexual abuse (82% of the total female population, a rate that rises to 90% among Aboriginal prisoners);
- ❖ Suffering from mental illness (1/4 of women in federal prisons were identified at admission as presenting mental health issues such as depression, bipolar and personality disorders, etc.);
- ❖ A survivor of childhood disruption (57% experienced a high level of disruption in their early lives);
- ❖ Undereducated (20% have below grade 8 education, 50% below grade 10 and 22% have high school diplomas);
- ❖ Unemployed or underemployed with little or no work experience;
- ❖ User of drugs and alcohol (7 out of 10 prisoners admit to having a substance dependency problem that would warrant treatment while in prison);
- ❖ Poor, homeless or under-housed.

Prevalence rates for infectious diseases are higher among women prisoners. Approximately 4% are living with HIV and 41.2% are living with HCV, compared to 2%

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and 23.2% for men, respectively (2001 figures). Despite these high rates, there is a lack of harm reduction tools and education in prisons, and health promotion is compromised by security concerns. High-risk behaviours among women prisoners include:

- ❖ Tattooing and piercing (about 25%);
- ❖ Injection drug use (19%);
- ❖ Slashing and self-injury (59% of women report self-injurious behaviour and 92% report having slashed themselves).

The most significant issue facing women in prisons is access; access to treatment, access to care, access to nutritional supplements for those on anti-retroviral therapy, access to counselling, access to harm reduction tools, etc.

The particular challenges faced by transgendered / transsexual women include the discrimination, harassment and violence that arise from the practice of housing prisoners according to their genitals instead of according to their gender identity.

A study conducted in 2001 by PASAN involving interviews with 156 female prisoners recommended to Correctional Service Canada that resources be provided for increasing access to women-specific HIV and HCV prevention programs throughout the system and that these programs be developed and implemented by both CSC and community-based groups. Prevention information should be made widely available in a variety of form in plain language and discreetly packaged. However, there continue to be a variety of barriers that make it difficult for community groups to access prisoners or carry out programs.

### ***Questions and Answers***

In the question period that followed the presentation, the following points were noted:

- ❖ CSC piloted a safer tattooing project in prisons several years ago. The pilot was cancelled by the Conservative government in late 2006. An evaluation of the pilot will be released shortly.

## 4 Panel Discussion and Wrap-Up

In the wrap-up session, members of the panel provided different perspectives on the day's proceedings.

### 4.1 Theme: *Invisibility of Women*—*Marcie Summers*

**Marcie Summers**, Executive Director, Positive Women's Network, noted the following recurrent themes:

- ❖ *Invisibility of women* across all populations: HIV-positive women who are transgendered, sex workers, immigrants and refugees, older women, incarcerated women, women of colour, women of Aboriginal origin and women living in rural and remote communities. It has been difficult to get women's issues on the agenda front and centre and all the more so for populations at risk of HIV infection. To increase the visibility of women and foster real action, leaders in the different communities need to be identified so that genuine partnerships can be built between affected communities and women living with HIV. There is a need to cultivate and amplify the diverse voices of women and avoid tokenism.
- ❖ *Women need their own spaces and women-only agencies and programs*—There is an urgent need for spaces where women living with or at risk of HIV can come together to learn about HIV prevention, care, treatment and support, network, share strategies and resources for improving their quality of life, and build the confidence and leadership skills needed to raise their issues in other fora. HIV-negative women need to find ways to support HIV-positive women in partnership.
- ❖ *Peer model of prevention*—This is an essential tool in preventing HIV among populations at risk of HIV infection. Programs exist but more are needed.

### **Questions and Answers**

In the discussion that followed, additional points were noted:

- ❖ Retreats for women have been a powerful tool for identifying leaders among women living with HIV or at risk for HIV. Generally, women with natural leadership abilities will come to the fore if provided the right environment.
- ❖ More resources and paid positions are needed to support the creation of spaces for women. We cannot continue to over-rely on volunteerism. Women should always be compensated for their work.

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- ❖ Approaches to working with women need to be age-specific and culturally competent.
- ❖ Sometimes populations are invisible for their own protection. Fostering leadership is a long process. A mentorship model for leadership development is an approach that works, but it is time-intensive.

**4.2 Theme: The Need to Address the Social Determinants of Health—Louise Binder**

Louise Binder noted that an underlying theme of the session was the interconnectedness of the social determinants of health, which operate at a number of different levels to fuel the HIV epidemic. This can be seen in the poor social determinants of health experienced by those populations that are over-represented in the HIV epidemic. Any policy or program that hopes to turn the tide on the HIV epidemic must address these multiple factors that put individuals at increased risk of infection. Ignoring the social determinants of health will meet with failure. In terms of immediate needs, Louise identified the following:

- ❖ More peer mentorship programs, community kitchens and safe places for women to meet are needed;
- ❖ More networks where HIV-positive women can share treatment information are needed. This will help give women the confidence and knowledge they need to interact with their doctors and hospitals and to make informed treatment decisions;
- ❖ Micro-financing schemes need to be made available to women so that they can begin addressing the poverty and lack of control that are behind the epidemic and poor health outcomes;
- ❖ More women's programs that are inclusive of HIV-positive women are needed;
- ❖ More low income housing policies and programs are needed;
- ❖ More jobs for women in the HIV community are needed;
- ❖ More options for anonymous HIV testing must be provided so that women can be tested without risk of reprisal from their partners or families.
- ❖ HIV prevention and testing programs must look at alternative models of delivery to increase their accessibility to women from different populations. They need to recognize that what works in one community does not necessarily work in another and that not all communities allow their women equal access to HIV programming.

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- ❖ The criminalization of HIV must be stopped otherwise the epidemic will be driven underground.
- ❖ Trans women need an HIV/AIDS strategy of their own.

#### **4.3 Theme: The Challenges Faced by Aboriginal Women—Doris Peltier**

**Doris Peltier**, Aboriginal Women and Leadership Coordinator and APHA Advocate, Canadian Aboriginal AIDS Network, noted the commonalities between the situation for Aboriginal women and other populations of women, although for Aboriginal women there are many more layers to the gaps in services and poor social determinants of health that put them at increased risk:

- ❖ A root cause of the epidemic among Aboriginal peoples is the destruction of the traditional social fabric and roles of men and women. Traditionally men represented the protective outer circle of the community, but this role has been lost, which has led to increased violence and, in turn, greater vulnerability to HIV for women.
- ❖ Many Aboriginal women do not get tested for HIV out of fear of stigma and discrimination from their communities and fear that their children may be apprehended.
- ❖ Many Aboriginal women living with or at risk of HIV live in isolation and do not have access to prevention, care, treatment and support. Stigma and discrimination are big barriers that drive this isolation. In some Aboriginal dialects, HIV/AIDS translates as “dirty disease.”
- ❖ Homelessness rates are high among Aboriginal people living in urban areas. This puts them at risk of HIV infection.
- ❖ Childhood sexual abuse is a significant issue that has repercussions that extend into the social determinants of health and lead to riskier behaviours which place individuals at increased risk for infection.
- ❖ An economic strategy for HIV-positive Aboriginal women is needed; one that goes beyond the GIPA principles and recognizes the episodic nature of HIV.
- ❖ We also need to focus on the resilience of Aboriginal women that speaks to their strengths and ability to survive and not just on the negative. In recent consultations, it has been suggested that a book along the lines of a “Chicken Soup for the Soul of Aboriginal Women” be compiled, one that is filled with stories of resilience among Aboriginal women.

#### **4.4 Theme: Role of Migration—Wangari Tharao**

**Wangari Tharao**, Program and Research Manager, Women's Health in Women's Hands Community Health Centre, identified some of the gaps in research and knowledge about HIV and women and specific populations:

- ❖ There is a lack of data and research on the role of migration in HIV. The assumption usually is that people immigrate when they are already infected, however UK and Ontario data indicate that a substantial number of people from Black communities are infected post migration due to travel to their home countries.
- ❖ It is important to ensure that research captures the impacts of “transnationalism” and migration between multiple locations as global citizens; how does movement between multiple locations that people call home impact on HIV diagnoses, abilities to cope and/or limit transmission of HIV to sexual partners? How can these experiences be captured in research?
- ❖ More work is needed to ensure that research is translated into action and influences practice. For example, research has been conducted over the years that shows that testing and counselling guidelines are applied differently in different settings and has resulted in a number of documented bad experiences. However, little seems to have been done to use this research and knowledge to ensure that the guidelines are implemented correctly and consistently.
- ❖ We need to broaden the discussion on research beyond the social sciences, which is where the discourse on women and HIV tends to take place. For example, people from African countries are infected with different strains / subtypes of the virus than those that are common in North America. We need to understand if there are differences in transmissibility, clinical outcomes, disease progression, etc.
- ❖ We need to figure out how to use our research to mitigate the impact of stigma and discrimination on HIV. We hear a lot of talk about anti-oppression frameworks but we hear little about the specifics.
- ❖ We need to develop population-specific programs and strategies in order to respond to the epidemic effectively.
- ❖ Culturally competent programs require researchers and frontline workers to understand the risks of acquiring HIV that are inherent in some cultural practices that are not openly talked about such as polygamy, female genital mutilation, vaginal cleansing, etc.

#### **4.5 Theme: The Need to Work Together—J. Evin Jones**

**J. Evin Jones**, Executive Director, Pacific AIDS Network, identified the need for more opportunities for frontline workers, service providers and researchers from across the country to share what is working on the ground, their best practices and innovative programming in order to avoid the “silo-ing of services”. There have been many successes in terms of women taking leadership at all levels in the response to HIV: in research, primary health care and communities. We need to work on fostering and mentoring the next generation of women leaders in the field, including youth and others who are under-represented at the table including Aboriginal and trans women.

#### **Questions and Answers**

In the discussion that followed, additional points were noted:

- ❖ Anonymous testing is a double-edged sword. On the one hand, it addresses many of the issues of confidentiality that prevent more people from being tested. On the other hand, it renders individuals invisible to the surveillance system and makes understanding which populations are being hardest hit by the epidemic more difficult. In a way, the demand for anonymous testing is an indicator for HIV stigma and discrimination.
- ❖ Internal migration is a growing issue, especially with the economic downturn that has seen an influx of people returning from the oil fields to the Atlantic provinces.
- ❖ There is a need for prevention programming directed at heterosexual men, many of whom remain very isolated. If they do not tell anyone, chances are they will not start using condoms at home, and this puts women at risk.
- ❖ We need to provide support to help immigrant women find work and more fully use their skill sets.
- ❖ Inspot ([www.inspot.org](http://www.inspot.org)) is an Internet site that is being used by gay men to notify sexual partners via email. It can be used by people anywhere in the country, but has only been promoted in Toronto and Ottawa

## **5 Wrap-Up and Appreciations**

Dr. Gahagan thanked the presenters and participants for their contributions to the day’s proceedings, noting that the day had provided a very broad overview of the social research on women and HIV. She informed the group that an edited volume of papers would eventually be produced and asked participants to be in contact with ideas including contributing papers. Finally she thanked the funders and the organizers of the session.

## Appendix 1: Biographies of Presenters

**Chris Archibald**, MDCM, MHSc, FRCPC, Director, Surveillance and Risk Assessment Division, Centre for Communicable Diseases and Infection Control, Public Health Agency of Canada. Chris obtained his doctor of medicine degree from McGill University in Montreal, Canada, and then studied family medicine in Vancouver at the University of British Columbia. After practising family medicine for a year, he returned to the University of British Columbia to specialise in community medicine and public health. During this training, Dr. Archibald published several papers on the risk factors for HIV-associated Kaposi's sarcoma among gay men in Vancouver. After completing his specialist certification, he worked in Malaysia on sentinel surveillance of HIV and in Singapore on the evaluation of behavioural interventions for commercial sex workers. Since 1995, he has been Director of the Division responsible for HIV/AIDS epidemiology and surveillance at the Public Health Agency of Canada, Ottawa. In addition to his national responsibilities, Dr. Archibald has worked on HIV/AIDS projects in Colombia, the Caribbean, eastern Europe, and south Asia in support of the Agency's role as a UNAIDS Collaborating Centre.

**Greta Bauer**, Ph.D., MPH, Assistant Professor, University of Western Ontario. Greta is an Assistant Professor in Epidemiology & Biostatistics at the University of Western Ontario. Her interests are in research methodology for marginalized communities, with an emphasis on HIV, sexually transmitted infections, and the health of sexual and gender minority communities. Her work in HIV has spanned the biological, behavioural and social, with a strong emphasis on quantitative research methods.

**Kevin Barlow**, Chief Policy & Research Officer, Canadian Aboriginal AIDS Network. Kevin is Mi'kmaq from Indian Island First Nation in New Brunswick. He has been doing HIV work for over 17 years, starting as an Addictions worker on his reserve. As a consultant, Mr. Barlow developed the Aboriginal Strategy on HIV/AIDS in Canada. He has also developed numerous other HIV resources for inmates and youth, as well as leading research examining residential schooling and cultural competency, among others.

**Louise Binder**, Chair of the Canadian Treatment Action Council (CTAC) and vice-chair of Voices of Positive Women. Louise is also a member of the Community Advisory Committee of the Canadian HIV Trials Network; one of the founding members of the Blueprint for Action on Women and Girls and HIV/AIDS; Chair of the Canadian Advisory Committee for the Ukrainian HIV+ Children's Hospital Project led by the Canadian Society for International Health; and member of the Global Coalition on Women and AIDS Leadership Council. Louise has been involved in many of the important advocacy struggles of this community over the last thirteen years including the battle to save, and then to increase, federal funding for HIV/AIDS; the battle to get timely access to safe and effective drugs at the federal and provincial government levels; and the battle to ensure earlier access to drugs in development by the pharmaceutical industry.

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**Anne Marie DiCenso**, Executive Director, Prisoners' HIV/AIDS Support Action Network. Over the last 17 years Anne Marie has worked on issues related to people in prison in Canada. Her work has been driven from a harm reduction and anti oppression framework and has had a strong focus on women, street involved people and people living with HIV/AIDS. Anne Marie has been working for PASAN (Prisoners' HIV/AIDS Support Action Network) for 13 years and has been their Executive Director for over 5 years. Anne Marie has presented to the Canadian Human Rights Commission on Women in Prison, on Criminalization and HIV Disclosure for Women and on CBC Radio on Harm Reduction and HIV/AIDS. Anne Marie has also written many articles and opinion pieces on HIV/AIDS and prisons. She sits on the Board of Directors for HALCO (HIV/AIDS Legal Clinic of Ontario) and of APAA (Africans in Partnership Against AIDS).

**Dionne A. Falconer**, DA Falconer & Associates Inc., is a consultant who works in Canada and internationally on HIV/AIDS, health and social issues. She has authored numerous reports, including the recently released Taking Action on HIV and AIDS in Black Communities in Canada: A Resource for Moving Ahead (Taking Action). She will be presenting information gathered from the nation-wide interviews and focus groups for Taking Action.

**Jacqueline Gahagan**, PhD, Professor of Health Promotion, Dalhousie University. Professor Gahagan teaches at both the graduate and undergraduate levels in Community Health Promotion, Measurement and Evaluation, and Women's Health and the Environment. Jacqueline's research focuses on the social and behavioural aspects of HIV/Hep C and sexual health with a particular emphasis on gender as a key determinant of health. Her current research includes HIV prevention among women in Canada, HIV counselling and testing, health service utilization among young adults, the development of sexual health indicators, and ethics review processes, among others. Prior to joining Dalhousie University, Jacqueline worked in public health in the areas of substance use and tobacco control, HIV/HCV prevention education and women's sexual health. Jacqueline has worked and volunteered in the areas of HIV/AIDS advocacy, HIV/HCV research, sexual health program planning and evaluation for two decades.

**Marc-André Gaudreau**, Manager, Program Development and Evidence-Based Interventions, HIV/AIDS Policy, Coordination and Programs Division, Public Health Agency of Canada. Marc-André graduated with a MA (Economics) from the University of Ottawa in 1999. His main areas of research were on health economics and the efficiency of public health care systems. He started a career in the federal public service at the Department of Finance in 1998. Since 2000, he has worked with Health Canada/Public Health Agency of Canada (PHAC), in program and policy development and implementation, in various health promotion and disease prevention areas. He is currently the Manager, Program Development and Evidence-based interventions, PHAC's HIV/AIDS Policy, Coordination and Programs Division, where he is responsible for leading the development of guidelines for health professionals (e.g., counselling guidelines for HIV testing), as well as the management of national HIV/AIDS funding

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programs.

**Saara Greene**, PhD, Assistant Professor, McMaster University. Saara is an Assistant Professor in the School of Social Work at McMaster University. She has long history of practice and research in women's health and has a particular interest in the experiences of families who are affected by HIV. Saara is a Co-Principal Investigator on Positive Spaces, Healthy Places: A Community Based Research Study aimed at exploring HIV, health and housing. Saara is currently researching the housing needs and experiences of mothers who are HIV positive in partnership with Fife House, a community based HIV AIDS housing organization in Toronto.

**Clare Jackson**, Policy Analyst (Populations), HIV/AIDS Policy, Coordination and Programs Division, Centre for Communicable Diseases and Infection Control, Public Health Agency of Canada. Clare holds a Bachelor of Public Affairs and Policy Management from Carleton University with a specialization in human rights. She has worked for the federal government since 2005, first as a strategic policy analyst in Health Canada's First Nations and Inuit Health Branch and presently as a policy analyst with the HIV/AIDS Policy, Coordination and Programs Division in the Public Health Agency of Canada. Currently her main project is the development of a Population-Specific HIV/AIDS Status Report for Aboriginal People.

**J. Evin Jones**, BA, LLB, Executive Director, Pacific AIDS Network. Evin has held Executive Director positions with YouthCO AIDS Society, the only youth-driven HIV/AIDS service organization in Canada working exclusively to meet the needs of HIV+, Hepatitis C+, "at risk" and affected youth, and the Vancouver Friends for Life Society, a community-based organization operating an innovative health and wellness centre for people living with life threatening illnesses. Effective September 2008, Evin became the Executive Director of the Pacific AIDS Network, a provincial network of 37 organizations that are HIV/AIDS mission-stated or that run programs devoted to addressing the care, treatment, support or prevention-education needs of persons living with HIV/AIDS or those "at risk" (see [www.pacificaidnetwork.org](http://www.pacificaidnetwork.org)). Evin looks forward to building on the successes of PAN and also exploring how the network might be further involved in facilitating community-based research in British Columbia, in relation to PHAs and the social determinants of health, notably housing.

**Mona Loufty**, MD, FRCPC, MPH, Infectious Disease Specialist and Clinical Researcher, University of Toronto. Dr. Loufty is currently an Assistant Professor at the University of Toronto and an Infectious Diseases Specialist and Clinician Scientist at Women's College Hospital. She has a private HIV practice at the Maple Leaf Medical Clinic, a Toronto group practice inner city clinic, providing care for over 2,500 HIV-positive patients and where she also serves as the Research Director. Her research interests are in women and HIV with a particular focus on pregnancy planning and adverse events related to the anti-HIV therapy such as lipodystrophy. She launched a Women and HIV Research Program in 2006 at the Women's College Research Institute

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to address these areas of need. Dr. Loufty works from a community-based framework involving a multitude of members and groups representing the communities directly impacted by her research and collaborates heavily with them at all stages of her research.

**Shari Margolese**, Voices of Positive Women. Shari is a Co-Principal investigator on several research projects including the development of an Ontario HIV Pregnancy Planning Initiative and National HIV Pregnancy Planning Guidelines to assist HIV-positive people with their fertility and pregnancy planning needs. Shari's volunteer commitments include working with Voices of Positive Women (VOPW) in Toronto, Blueprint for Action on Women and Girls and HIV in Canada, and ATHENA. Shari's roles include governance, policy, program and resource development as well as advocacy and education locally, regionally, nationally and internationally.

**Doris Peltier**, Aboriginal Women and Leadership Coordinator & APHA Advocate, Canadian Aboriginal AIDS Network. Doris is an HIV-positive, 52 year old Odawa consultant living in her home community of Wikwemikong First Nations and is currently working for the Canadian Aboriginal AIDS Network in the role of Aboriginal Women and Leadership Coordinator, as well as advocate for Aboriginal people living with HIV/AIDS. Doris has six years experience working and volunteering in Aboriginal HIV/AIDS at the local, regional and national levels. Aboriginal Women's issues and Leadership Engagement and being a spokesperson (local, regional and national) for Aboriginal HIV positive peoples top the list of her activities.

**Tracey Prentice**, PhD candidate, University of Ottawa. Tracey Prentice is a qualitative community-based researcher with a commitment to equity and social justice. For six years she has worked with Aboriginal and non-Aboriginal communities to better understand the impact of HIV/AIDS on communities, and in particular on women and youth. Research topics have included the experience of depression for Aboriginal people living with HIV/AIDS, HIV testing and care, the inclusion of people living with HIV in ASOs, the development of HIV-related anti-discrimination policies, and the use of arts-informed methods in HIV prevention. Tracey has also worked with Indigenous women in India to develop a culture and gender sensitive research instrument. She has an M.A. in Cultural Anthropology and is currently completing her PhD in Population Health at the University of Ottawa where she holds a CIHR Doctoral Training Award in Aboriginal Community-Based HIV/AIDS Research. Her current research interests include the social determinants of health with a particular interest in culture and gender, mental health, and the use of arts-informed participatory research methods to affect policy and program change.

**Zena Sharman**, Assistant Director, Canadian Institutes of Health Research - Institute of Gender and Health. Zena holds degrees from the University of Western Ontario and Simon Fraser University. Zena is currently a PhD Candidate in the Interdisciplinary Studies Program at the University of British Columbia. Her doctoral research, which

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focuses on the working conditions of home support workers in rural and remote communities, reflects her longstanding interest in gender and health.

**Marcie Summers**, Executive Director, Positive Women's Network. Marcie has a long-standing history in human services, most particularly in the fields of women's health, violence against women and HIV/AIDS. Marcie is a committed advocate for the community of women living with HIV/AIDS. She believes women are the experts when it comes to creating and sustaining their own best health practices. As Executive Director of the Positive Women's Network for over fifteen years, Ms. Summers has taken a national leadership role around issues of women and HIV/AIDS.

**Ruthann Tucker**, Senior Director of Community-Based Initiatives and Organizational Development, Ontario HIV Treatment Network (OHTN). Ruthann is a Co-Principal Investigator on the Community Based Research study, "Positive Spaces, Healthy Places."

**Wangari Tharao**, Program and Research Manager, Women's Health in Women's Hands Community Health Centre. Wangari is also a PhD candidate at the University of Toronto, Dalla Lana School of Public Health, Health and Behavioural Sciences Program. She has sat on various boards, working groups and advisory and review committees including the OHTN Scientific Review Committee, Ontario Advisory Committee on HIV/AIDS, Ontario HIV Endemic Task Force, and Ministerial Council of the Canadian Strategy on HIV/AIDS. She is currently the Co-Chair of the African and Caribbean Council on HIV/AIDS in Ontario (ACCHO), Chair of the Governing Council of the African and Black Diaspora Global Network on HIV and AIDS, and a member of the OHTN Community Network Advisory Committee.

**Mark Tyndall**, MD, ScD, FRCPC, Associate Professor of Medicine, University of British Columbia and head of the Infectious Diseases division at St. Paul's Hospital. He joined the BC Centre for Excellence in HIV/AIDS in 1999 where he is the Program Director for Epidemiology. He is currently conducting a number of research projects in Vancouver, including epidemiologic studies of HIV and Hepatitis C transmission, antiretroviral uptake and adherence among injection drug users, and the impact of harm reduction strategies on HIV prevention.

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## Further Inquiries

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