



# **“Vectors, Vessels and Victims”**

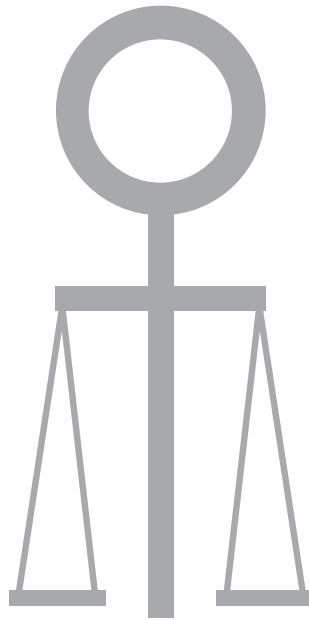
HIV/AIDS and  
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## HIV/AIDS and Women’s Human Rights in Canada

Canadian HIV/AIDS Legal Network



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Canadian HIV/AIDS Legal Network

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This report was written by Joanne Csete.

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## Executive summary

HIV/AIDS was first understood by Western scientists as a health concern of men, especially gay men. It took time and overdue research to understand that women are physiologically more vulnerable to HIV transmission than men, at least where heterosexual transmission is concerned. It took even more time to bring the world around to the idea that physiological factors were only one aspect of women's vulnerability to HIV/AIDS.

Today, researchers, the United Nations and many bilateral donors have developed sophisticated analyses of the inequalities and human rights violations that contribute to women's vulnerability to HIV – their disproportionate exposure to violence and sexual coercion, including forms of violence such as marital rape that are often not recognized as crimes; their disproportionate bearing of the burden of poverty; their inequality under property and inheritance laws, their unequal access to health services and information and to education; their burden of care for others; and other factors. It is easy to get the sense from United Nations and other documents on the subject that this analysis of women's vulnerability to HIV linked to their multifaceted subordination pertains especially to women in the poorest countries in the world or those where women's equality under the law remains a distant dream.

This paper makes the case that while women in Canada may not suffer the extremes of subordination faced by many of their counterparts in other parts of the world, inequality and violations of women's human rights still contribute to their vulnerability and to the challenges they face in seeking treatment for HIV/AIDS. As in other parts of the world, women living in poverty, women who inject drugs, Aboriginal women, women in the sex trade, and many women who come from countries where HIV is endemic are particularly vulnerable to HIV/AIDS, but vulnerability extends to all women who may not be aware of their own risk and who day to day may not be able to control all of the elements that add up to safer sex or safer drug use.

Since the beginning of the epidemic, women and girls have accounted for a steadily larger proportion of new HIV transmission in Canada, representing over 26% in 2004, primarily the result of sex with an HIV-infected male partner. In spite of this, programs designed especially to address the root causes of women's vulnerability



to HIV/AIDS are sparse in Canada. Programs for the most vulnerable women barely exist and hardly address poverty, subordination and other core elements of their vulnerability. Evidence summarized in this paper indicates that women's issues figure to some degree in public health policy – but women themselves are seen primarily as **vessels** (spread of HIV to the fetus *in utero*), as **vectors** of the spread of HIV to their infants and their sexual partners, and as **victims** of coercive sex or sex with HIV-positive partners who do not disclose their status. But women's universal subordination and the systematic abuse of their rights are not adequately informing program development and resource allocation in Canada's response to HIV/AIDS at home.

Women in Canada face many challenges in the clinical setting. They are more likely to be tested for HIV because pregnant women are all offered an HIV test as a matter of policy in Canada, though the application of this policy still appears to depend somewhat on provincial standards and judgments of clinicians. The policies of some provinces to test pregnant women for HIV unless they explicitly “opt out” of testing risks violating women's right to fully informed consent and to pre- and post-test counseling, at least as some women have experienced the application of this policy. The trend toward opt-out HIV testing in Canada raises many human rights concerns, particularly as this testing is geared only to women. Women living with HIV/AIDS also deal with physicians and other health professionals who are not informed about the distinct clinical needs of women including the possibility of different side effects and reactions to antiretroviral and other treatment. Treatment programs often do not adequately take into account women's child care needs and other demands on their time. Family caregiving burdens fall to women in most communities, regardless of their HIV status.

Virtually all women have to deal with social and economic subordination in some aspects of their lives, but some women in Canada face additional challenges that augment their HIV risk:

- HIV prevalence is much higher among Aboriginal women than among their non-Aboriginal counterparts in Canada. For many Aboriginal women, poverty, violence, social exclusion and subordination are heightened due to the historical and continuing marginalization of Aboriginal communities.
- Women in the sex trade, while a very diverse population, often experience violence and sexual coercion. Criminalization by Canadian law of some aspects of the sex trade contributes to women's HIV risk. Prohibitions on “bawdy houses” limit some sex workers to street-based work whereas without the law they would be likely to work in safer venues. The targeting of sex workers for the offence of “communicating in a public place for the purpose of prostitution” can mean that street-based sex work is carried on in ways that put women at greater risk of violence and of HIV/AIDS.
- Women who inject drugs also face particular human rights and health concerns. They are more likely than men to rely on assisted injecting, which takes more time and is thus more difficult when a police presence may pressure them to inject quickly, and they are disadvantaged when safe injection sites prohibit assisted injecting.

- Women in prison in Canada have often had poor access to prevention, treatment and care for HIV/AIDS and hepatitis C. Prisons are a uniquely opportune environment for ensuring that women at high risk of HIV or those living with the disease are counselled and informed about safer practices both in and outside prison; this opportunity is being largely missed in Canada.
- Women living in Canada from countries where HIV/AIDS is endemic were only recently recognized by the government as a group at high risk. In addition to racism and xenophobia, the subordination they face may be compounded by traditional practices, including female genital mutilation. Fears of deportation or lack of information on their immigration status may keep these women from seeking the care or prevention services they need. HIV/AIDS-related stigma and discrimination within their own communities create further barriers.

This report recommends a number of steps that could lead to a more coherent and effective response to HIV/AIDS and HIV risk among women in Canada. Among these are:

- program-oriented research on the real-life risks faced by women, especially those living in poverty;
- more and better programs for women that are informed by an understanding of the human rights challenges they face and that empower women as peer service providers, including programs for and by women sex workers, women who use drugs, Aboriginal women, women from countries where HIV/AIDS is endemic, and women in prison;
- explicit earmarking of government funding for women's programs;
- systematic representation of women at all levels of policy-making related to HIV/AIDS;
- establishing links among HIV/AIDS programs and policies and anti-poverty and anti-violence programs;
- measures to ensure that pregnant women are fully informed about HIV testing and that their informed consent is a precondition for testing;
- training of care providers to give women living with HIV/AIDS the best support possible in antiretroviral therapy; and
- a major effort to ensure high-quality prevention, treatment and care services for women in Canadian prisons.





# Introduction

Although statistics are useful in monitoring the rates of HIV transmission and prevalence among women in Canada, they do not tell us the whole story. All women who engage in unprotected vaginal or anal sex or use unclean needles for drug use, piercing or tattooing are at risk for HIV transmission. However, some women in our community are at increased risk because of social, economic and political factors such as immigration status, poverty, homelessness and gender imbalance [power differences between men and women].

– AIDS Committee of Toronto<sup>1</sup>

In the early years of the HIV/AIDS epidemic in North America, this new disease was understood as a health concern of men. Paul Farmer recounts that a popular U.S. scientific journal in 1985 informed its readers that a woman’s “rugged vagina,” designed for the rigors of childbearing would resist this virus, especially compared to the “vulnerable anus.”<sup>2</sup> In the early 1980s, it was the rare physician or public health expert who believed that women in North America and Europe were a risk group for HIV. Sadly, it was also the rare public health expert anywhere in the world who paid any attention to the rapid HIV transmission in sub-Saharan Africa, where the disease was being spread by sex between men and women.

From 1983, the year of the first HIV diagnosis in Canada, through much of the 1980s, women barely figured in public policy or public perceptions of HIV/AIDS. As late as 1989 at the Hassle Free Clinic in Toronto, founded in 1973, staff were battling the generalized view that women were not at risk, which was conveyed to some women by doctors who did not see reasons to refer them for testing.<sup>3</sup> According to Jane Greer, this perception began to change in a widespread way only in 1991 when U.S. basketball star Earvin “Magic” Johnson, a heterosexual man, spoke openly about

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<sup>1</sup> AIDS Committee of Toronto, Women and AIDS in Canada: How are women becoming infected? (information sheet periodically updated), available at [www.actontario.org/website/home.nsf/pages/womenhivaidsCanada](http://www.actontario.org/website/home.nsf/pages/womenhivaidsCanada).

<sup>2</sup> P Farmer, *Infections and Inequalities: The Modern Plagues*, Berkeley: University of California Press, 1999, p.61.

<sup>3</sup> J Greer, director, Hassle Free Clinic, personal communication, June 6, 2005.

being HIV-positive. “That made a big difference,” she said. “Testing [of women] tripled practically overnight.”<sup>4</sup>

In 1988, the Hassle Free Clinic and the AIDS Committee of Toronto helped start a support group for HIV-positive women in Toronto. Analyzing the experiences of women in that pioneering group in 1990, Darien Taylor said most of the women were infected by a bisexual partner and were not aware of their partner’s bisexuality; a few of the women had had sex with men from countries where HIV was endemic, and a few had shared syringes.<sup>5</sup> As Taylor noted: “Most women who receive a positive HIV antibody test do not know any other women in the same situation. As a result, they can experience an isolation much more profound than that experienced by a gay man who tests HIV positive.” Similar groups were formed around 1990 with the support of the Vancouver Women’s Health Collective and Comité Sida Aide Montréal.<sup>6</sup> Support groups for women were especially crucial, in Taylor’s view, because the media at the time characterized women living with HIV/AIDS as either prostitutes or “innocent victims,” and because the many gay men’s groups working on HIV/AIDS did not have the capacity to deal with women’s varied concerns.

By the late 1980s in the U.S., where the epidemic was running a year or two ahead of HIV/AIDS in Canada, it was estimated that women, while a small minority of those living with HIV/AIDS by official figures, were dying six times faster after diagnosis than men.<sup>7</sup> It was thought by activists that many women were dying of HIV/AIDS without being diagnosed as such because so many doctors did not understand women’s HIV/AIDS risks. In her account of the neglect of women as the HIV/AIDS epidemic in the U.S. unfolded, Corea posits that entrenched sexism in the U.S. medical establishment was a barrier to scientific understanding of women’s HIV risk. At the time the human immunodeficiency virus was identified, she notes, 84 percent of physicians in the U.S. were men, and women were frequently seen to be “neurotic complainers” whose health problems tended to be “all in their heads”.<sup>8</sup>

In Canada as in the U.S., HIV/AIDS among women drug users and women sex workers as well as among young children provided early signals that the “men’s disease” characterization was inadequate. From the first, then, policy-level concerns about women and HIV/AIDS were a function of concern for children or concern about women who were not in the social mainstream.

In 1986, the World Health Organization established the Global Programme on AIDS, the first worldwide UN effort focused on the disease. It was becoming clear not only from the pattern of HIV spread in Africa but from the growing North American and European epidemics that women’s “rugged vaginas” were not protective after all. By the time of the release of the landmark publication *AIDS in the World, vol. 1* in 1992,

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<sup>4</sup> Ibid.

<sup>5</sup> D Taylor, Testing positive, *Healthsharing*, Spring 1990, p. 9.

<sup>6</sup> Ibid.

<sup>7</sup> J Walker. Mothers and Children. In: ACT UP/New York Women and AIDS Book Group. *Women, AIDS and Activism*. New York: Between the Lines, 1990: 165.

<sup>8</sup> G Corea. *The Invisible Epidemic: The Story of Women and AIDS*. New York: HarperCollins, 1992: 3, 4.

women were noted as a risk group for HIV transmission.<sup>9</sup> The first AIDS epidemic update of the new United Nations Joint Programme on HIV/AIDS (UNAIDS) in 1998 estimated that about 43% of people living with HIV/AIDS in the world were women or girls and that “women appear to be heading for an unwelcome equality with men” where HIV/AIDS was concerned.<sup>10</sup>

It took time, then, both to get the physiology right and to get consensus around the fact that women’s and girls’ vulnerabilities to HIV/AIDS were about much more than physiology. The physical susceptibility factors are now frequently described in the clinical literature and in public health information on HIV/AIDS: the vagina has a large exposed surface area; small tears and lesions can occur during sex and become portals for HIV; sperm from an HIV-positive man is more virus-dense than are vaginal secretions from an HIV-positive woman; coercive sex can lead to lesions that increase risk; and these vulnerabilities are dramatically more pronounced for girls and young women.<sup>11</sup> There is not complete consensus on quantification of the physical risk faced by women compared to men in consensual heterosexual sex, but many estimates are in the range of two to four times higher risk for women.<sup>12</sup>

By the late 1990s, a fairly sophisticated gender analysis – including of social and economic and not just physiological factors – was becoming generally accepted in assessments of the global HIV/AIDS crisis. These analyses in many ways paralleled WHO’s focus on “social determinants of health” models, which recognize that health is an outcome not just of exposure to pathogens but of such environmental factors as poverty, working conditions, unemployment, social support and exclusion, and exposure to violence and abuse.<sup>13</sup> Many UN reports have highlighted the situation of women in Africa and Asia and the way in which their subordinate status increases their risk of HIV transmission and impedes their access to care if they are living with HIV/AIDS.

The excerpt below, a quotation from the “Human rights, women and HIV/AIDS” fact sheet of the World Health Organization,<sup>14</sup> exemplifies points that appear often in United Nations and scholarly analyses of root causes of HIV/AIDS among women and of poor health outcomes among women living with HIV/AIDS:

Women’s right to safe sexuality and to autonomy in all decisions relating to sexuality is respected almost nowhere. As it is intimately related to economic independence, this right is most violated in those places where women exchange sex for survival as a way of life. And we

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<sup>9</sup> J Mann, DJM Tarantola, TW Netter, *AIDS in the World*, vol. 1, Cambridge, MA: Harvard University Press, 1992.

<sup>10</sup> Joint United Nations Programme on HIV/AIDS (UNAIDS) and World Health Organization, *AIDS epidemic update: December 1998*. Geneva: United Nations, 1998: 2.

<sup>11</sup> See, e.g., the frequently consulted educational web site The Body: Women and HIV/AIDS: Key Facts and Issues, *Bulletin of Experimental Treatments for AIDS* 2000 (The Body: Complete HIV/AIDS Resource), available at [www.thebody.com/sfaf/summer00/women\\_facts.html#vulnerable](http://www.thebody.com/sfaf/summer00/women_facts.html#vulnerable).

<sup>12</sup> United Nations publications tend to use the figure of two; The Body, *ibid.*, for example, uses four.

<sup>13</sup> These ideas as developed by WHO are captured in numerous documents. See, e.g., World Health Organization Europe Regional Office. *Social determinants of health: the solid facts*. 2003. Available at [www.who.dk/document/E81384.pdf](http://www.who.dk/document/E81384.pdf).

<sup>14</sup> World Health Organization. Human rights, women and HIV/AIDS (fact Sheet no. 247). 2000. Available at [www.who.int/mediacentre/factsheets/fs247/en](http://www.who.int/mediacentre/factsheets/fs247/en).

are not talking about prostitution but rather a basic social and economic arrangement between the sexes which results on the one hand from poverty affecting men and women, and on the other hand, from male control over women's lives in a context of poverty. By and large, most men, however poor, can choose when, with whom and with what protection, if any, to have sex. Most women cannot. As such, our basic premise has to be that unless and until the scope of human rights is fully extended to economic security (i.e. the right not to live in abject poverty...), women's right to safe sexuality is not going to be achieved.

### The major issues:

- **Lack of control** over own sexuality and sexual relationships.
- **Poor reproductive and sexual health**, leading to serious morbidity and mortality. Rates of infection in young (15-19) women are between 5 and 6 times higher than in young men (recent studies in various African populations).
- **Neglect of health needs**, nutrition, medical care.... Women's access to care and support for HIV/AIDS is much delayed (if it arrives at all) and limited. Family resources nearly always devoted to caring for the man. **Women, even when infected themselves, are providing all the care.**
- **Clinical management** based on research on men.
- **All forms of coerced sex** – from violent rape to cultural/economic obligations to have sex when it is not really wanted, increases risk of microlesions and therefore of STI/HIV infection.
- **Harmful cultural practices:** from genital mutilation to practices such as “dry sex.” [Surgical cutting of the clitoris or labia, or female genital mutilation, is widely practiced in some communities and may be associated with lingering injury that can increase HIV risk. Dry sex describes the practice common in some settings whereby women use herbs or other preparations to make the vaginal walls dry to afford greater pleasure to male sex partners. This practice can increase the risk of laceration and other vaginal injury, which in turn increases HIV risk.]
- **Stigma and discrimination** in relation to AIDS (and all STIs): much stronger against women who risk violence, abandonment, neglect (of health and material needs), destitution, ostracism from family and community. Furthermore, women, are often blamed for spread of disease, always seen as the “vector” even though the majority have been infected by only partner/husband.
- **Sexual abuse:** there is now evidence that this is an underestimated mode of transmission of HIV infection in children (even very small children). Adult men seek ever younger female partners (younger than 15 years of age) in order to avoid HIV infection, or if already infected, in order to be “cured”.
- **Disclosure of status, partner notification, confidentiality.** These are all more difficult issues for women than for men for the reasons discussed above....
- Because disclosure is more difficult, women's **access to care and support** is further decreased. Voluntary counseling and testing (VCT) as an entry point for care and prevention is vital. Protection for women when they disclose status must be assured....

### Human rights issues relating to mother to child transmission (MTCT)

- Informed consent to testing during pregnancy, to the intervention itself and to termination/continuing with the pregnancy;
- Provision of adequate pre-test [and post-test] counseling, pre-intervention counseling/information; infant feeding counseling; contraceptive advice [after the birth of the child];
- Protection of confidentiality, including shared confidentiality in the interests of care and support; and the problem of not breastfeeding when this amounts to “public disclosure” of positive serostatus. Legal provisions, health service practices and community/NGO support...;
- Women's [right to] access to care and treatment apart from the MTCT intervention.



Some other analyses add an additional focus on women's economic dependence on men and the exacerbation of that dependence by inequitable laws in the domains of property, inheritance and divorce.<sup>15</sup>

Women's risks and challenges with respect to HIV transmission and access to care, treatment and support for HIV/AIDS, like violations of women's rights more generally, are integrally linked to poverty. That the burden of poverty in most parts of the world falls so heavily on women parallels the increasing burden of HIV/AIDS on women. Poverty and gender inequality go hand in hand. If women were not discriminated against in property and inheritance laws, for example, they would be less likely to be in poverty, and if they were not living in poverty, they would be more likely to be able to organize and assert their rights.

Reading United Nations documents, one might easily conclude that abuses of women's human rights are helping to drive the HIV/AIDS epidemic in developing countries but not particularly in North America. The dire poverty and extreme gender inequality in developing countries are always pillars of the analysis. There is no question that the status of women and the laws and policies that protect their rights are radically different in Canada than, for example, in countries where rape within marriage is not considered a crime or where "honour" killings are sanctioned by law. But is it right to assume that some of the same violations of the human rights of women that impede the struggle against HIV/AIDS in developing countries do not also undermine HIV/AIDS prevention, diagnosis, treatment, care and support for women in Canada and other developed countries?

In this paper, we examine this question with reference to the experience of Canadian women living with HIV/AIDS or vulnerable to the disease. The focus is on the specific issues of human rights challenges faced in prevention, testing and treatment, and challenges faced by Aboriginal women, women drug users, women sex trade workers, incarcerated women, and women from HIV-endemic countries. The partitioning of this analysis into these subject areas risks giving the impression that these issues are discrete. On the contrary, one of the central conclusions of this paper is that women in Canada face numerous overlapping and inter-related sources of stigma, discrimination and abuse that impede their struggle against HIV/AIDS. Poverty exacerbates all of these. Youth also exacerbates most of the risks discussed here. But even in the absence of poverty and even for older women, the subordination that Canadian women face is most often a complex interaction of sexism and discrimination linked to other status (for example, recent immigrant, detainee, ethnic or racial minority, sex worker, drug user, lesser income-earner, or worker in a caring profession not valued by the community) with direct consequences for their ability to protect themselves from HIV infection or to gain access to care, treatment and support services.

Gender analysis, obviously, is not only about women. It is increasingly well recognized that it is futile to talk about women's risks with respect to HIV/AIDS

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<sup>15</sup> See, e.g., Human Rights Watch. *Policy paralysis: A call for action on HIV/AIDS-related human rights abuses against women and girls*. 2003:40-50.



without understanding the situation of men and boys, including the social pressures on them to assert their masculinity in ways that represent risks for them as well as for women and girls.<sup>16</sup> We focus this paper on women, however, especially on the few pieces of research in Canada that have attempted to base their findings on first-hand testimony from women living with or affected by HIV/AIDS. Many of the vulnerabilities discussed in this paper, particularly those linked to poverty, are also faced by men and boys, if in different ways and to somewhat different degrees. It is clear, moreover, that there is an urgent need for a better understanding of the role that men and boys play in mitigating the impact of HIV/AIDS on themselves, their female sexual partners and their children, a subject beyond the scope of this paper.

As global analysis of women's rights and HIV/AIDS has become more sophisticated, bilateral and multilateral donors as well as civil society organizations around the world have embraced the idea of improving women's rights as part of the fight against HIV/AIDS. Somehow, however, well-funded efforts to advance women's rights as part of HIV/AIDS programs remain rare; there is little to show for all the rhetorical espousal of these ideas. In the case of Canada, as for the developing world, we suggest that the need for better informed and better funded HIV/AIDS programs and policies for women is urgent.

Mobilization of resources commensurate to the challenge will probably only happen when programs to address women's vulnerability transcend the image of women as vessels (women's vulnerability to HIV/AIDS is of interest only because they give birth and may transmit HIV during pregnancy), vectors (women as sex workers and sex partners are conceived as transmitters of HIV to men) or victims (discrete acts of violence, coercive sex, or sex with men who do not reveal that they are HIV-positive draw attention to women's vulnerability). Rather, protecting, respecting and fulfilling the human rights of all women in all circumstances need to be seen as central elements of national HIV/AIDS responses. There is no excuse for the inequities and injustices that continue to impede the struggle against HIV/AIDS among Aboriginal women, women who use drugs, women who do sex work, women of colour, women living in poverty, incarcerated women and all women whose subordination limits choices and carries the risk of abuse and violence.

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<sup>16</sup> G Rao Gupta. Gender, sexuality and HIV/AIDS: The what, the why and the how. *Canadian HIV/AIDS Policy and Law Review* 2000; 5(4): 86-93, available at [www.aidslaw.ca/Maincontent/otherdocs/Newsletter/vol5no42000/guptadurban.htm](http://www.aidslaw.ca/Maincontent/otherdocs/Newsletter/vol5no42000/guptadurban.htm).



## Origins of this report

The first National Conference on Women and HIV/AIDS in Canada in May 2000 identified a large number of research and program recommendations, including many related to legal, ethical and human rights concerns.<sup>17</sup> A second national conference was planned but not held as the NGO coalition planning the conference was unable to secure adequate funds. A steering group was formed in 2000-2001, however, that raised a number of human rights and legal concerns. (A new incarnation of this group, the Blueprint for Action on Women and HIV/AIDS in Canada, has recently been convened with a goal, among others, of influencing the content of the International AIDS Conference in Toronto in 2006.) The Legal Network undertook to review and analyze existing research on legal and human rights issues of women linked to HIV/AIDS and to consult directly HIV-positive women in Canada and those providing services to them for their assessment of how the legal and policy framework affected their lives.

The Legal Network was able to conduct extensive interviews with 20 women in Canada living with HIV/AIDS or working in the area of women and HIV/AIDS whose experiences are reflected in this paper. These interviews took place over a long period in 2002-2003, and, following some delays to this project, some informants were reinterviewed in 2005. The objective of these interviews and consultations was to determine which legal and policy issues had the greatest impact on the lives of women in Canada. A list of key informants is found in the acknowledgment.

This work builds on previous reports and analyses of the Legal Network related to women and HIV/AIDS. Past Network reports and papers on prisons, criminal law, complementary and alternative medicines, injection drug use, testing and confidentiality, and immigration all have discussed issues specific to women and have made recommendations aimed at improving care, treatment, and support of HIV-positive women as well as prevention initiatives for women. In 1999 and 2000, the Network produced reports on HIV testing in pregnancy and in reducing

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<sup>17</sup> Canadian Aboriginal AIDS Network, Canadian AIDS Society, Canadian AIDS Treatment Information Exchange, Canadian Treatment Action Council. *Summary of the Recommendations from the National Conference on Women and HIV/AIDS (Toronto, May 25-28, 2000)*. 2002.

women's vulnerability to HIV/AIDS using rights and the law.<sup>18</sup> Numerous articles in the Network's *HIV/AIDS Law and Policy Review* have examined the root causes of women's vulnerability to HIV/AIDS. The Network's report and information sheets on sex work and HIV/AIDS advocate for the health and human rights of a group of particularly vulnerable women. The Legal Network has also advocated in Canada and internationally for support for research on woman-controlled microbicides for HIV prevention as a matter of women's right to health. This report is intended to complement that earlier work and serve as resource for education and advocacy initiatives aimed at ensuring that policies and laws respect and promote human rights of women in Canada living with and vulnerable to HIV/AIDS.

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<sup>18</sup> These reports are available online at <http://www.aidslaw.ca/Maincontent/issues/women.htm>.



# HIV/AIDS among women in Canada: basic data and social determinants

The World Health Organization “social determinants of health” framework referred to above suggests that health outcomes are best understood as resulting not just from immediate clinical causes of disease but from social and environmental factors, poverty, unemployment, social support and exclusion, and exposure to violence and abuse. The 2004 Federal Initiative to Address HIV/AIDS in Canada espouses a similar approach when it says that the federal government “will make a larger and more effective contribution to addressing the complex social, human rights, biological and community barriers that continue to fuel the epidemic” in Canada.<sup>19</sup> Unfortunately, as noted below, there are few data that link poverty, violence, abuse, working conditions and other important social factors to HIV/AIDS in Canada, suggesting that the Federal Initiative, as well as provincial and territorial programs, should support the kind of research that informs a social determinants approach.

The most recent UNAIDS update on HIV/AIDS indicates that globally, of the 36 to 44 million persons living with HIV/AIDS, about 16 to 19.5 million are women or girls.<sup>20</sup> Based on the midpoints of these ranges, about 47% of persons over age 15 living with HIV/AIDS are women. The corresponding figure in sub-Saharan Africa is 57%, the highest in the world, following by the Caribbean at 49%.<sup>21</sup>

In Canada, the figure is lower, but the proportion of women among persons newly infected by HIV has increased markedly since the beginning of the epidemic.

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<sup>19</sup> Government of Canada. *The Federal Initiative to Address HIV/AIDS in Canada*. 2004: 6. Available at [www.phac-aspc.gc.ca/aids-sida/hiv\\_aids/federal\\_initiative/initiative/fi/pdf/fed\\_init\\_e.pdf](http://www.phac-aspc.gc.ca/aids-sida/hiv_aids/federal_initiative/initiative/fi/pdf/fed_init_e.pdf)

<sup>20</sup> UNAIDS. *AIDS Epidemic Update: December 2004*. 2004: 1. Available at [www.unaids.org/wad2004/EPI\\_1204\\_pdf\\_en/EpiUpdate04\\_en.pdf](http://www.unaids.org/wad2004/EPI_1204_pdf_en/EpiUpdate04_en.pdf).

<sup>21</sup> Ibid. at 5.

Although the epidemic in Canada was at first concentrated in gay men, there were small numbers of women testing positive for HIV as early as 1985.<sup>22</sup> Women and girls have over time accounted for a consistently increasing percentage of newly diagnosed HIV transmission, from 9.7% of new positive tests among persons over age 15 between 1985 and 1995, to 26.6% in the first half of 2004.<sup>23</sup> Among persons aged 15 to 29 years who tested positive in the first half of 2004, girls and women accounted for 42.6% of these results; in the under-15 group, girls accounted for 41% of reported positive HIV tests from 1985 to June 2004. Young women and girls are over-represented among persons living with HIV/AIDS in Canada, as is the case in Africa and the Caribbean.

The Public Health Agency of Canada estimates that there were about 7,700 (6,500 to 9,000) women living with HIV/AIDS in Canada in 2002, an increase of 67% from the 1996 estimate of 4,600. Before 1994, the proportion of women among adults living with HIV/AIDS was about 6%, but that figure increased to 15.8% in 1999 and 16.5% in 2002.<sup>24</sup> Heterosexual transmission is the dominant route of HIV infection among Canadian women. Injection drug use was estimated to be the means of transmission among about 20% of women diagnosed with AIDS before 1998, as much as 46% in 1998, and about 30% in the first half of 2004.<sup>25</sup>

Surveillance data from HIV testing of pregnant women in antenatal care settings indicates an overall HIV prevalence among pregnant women in Canada of 3-4 per 10,000. Rates in cities tend to be higher than the national average, with prevalence in Montreal at 15.3 per 10,000 and in Vancouver 4.7 per 10,000 by the most recent estimates of the government. It is not clear to what degree these estimates reflect variability of test-seeking or test availability from place to place.

HIV/AIDS is a problem of particular concern in Aboriginal communities in Canada, including among women. A study among pregnant Aboriginal women in British Columbia estimated HIV prevalence of about 31 per 10,000 in the period 2000-2002, compared to about one tenth that amount in the general population.<sup>26</sup> The Public Health Agency of Canada reports that in provinces and territories where ethnicity is reported with HIV tests, some 45% of Aboriginal persons having tested positive for HIV were women or girls, compared to 19.5% in the non-Aboriginal population from 1998 to June 2003.<sup>27</sup> Of AIDS cases reported in jurisdictions where ethnicity was identifiable, 24.6% were women among Aboriginal persons, compared to 8.5% among non-Aboriginal people through mid-2003. Aboriginal women are thus disproportionately affected by HIV/AIDS compared to other women, just as Aboriginal populations overall in Canada are incommensurately affected.<sup>28</sup>

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<sup>22</sup> Centre for Infectious Disease Prevention and Control (Canada). *HIV and AIDS among women in Canada, HIV/AIDS epi update*. 2003.

<sup>23</sup> Ibid; Public Health Agency of Canada. *HIV and AIDS in Canada: Surveillance report to June 30, 2004*. 2004:2.

<sup>24</sup> Centre for Infectious Disease Prevention and Control, op.cit., and *HIV and AIDS in Canada*, ibid. at 15.

<sup>25</sup> *HIV/AIDS in Canada*, ibid.

<sup>26</sup> Ibid at 4.

<sup>27</sup> Public Health Agency of Canada. HIV/AIDS among Aboriginal peoples in Canada: A continuing concern. in *HIV/AIDS epidemic update*. 2002:35-39. Available at [www.phac-aspc.gc.ca/publicat/epiu-aeipi/hiv-vih/aborig\\_e.html](http://www.phac-aspc.gc.ca/publicat/epiu-aeipi/hiv-vih/aborig_e.html).

<sup>28</sup> Ibid. According to PHAC, Aboriginal persons comprise 6% of the population of the provinces and territories where

In Canada, as in many countries, more women are living in poverty than men. The federal government estimates that in 2002, there were about 1.8 million adult women living in poverty and 1.35 million men.<sup>29</sup> Of single-parent families, 56% of those headed by women were living in poverty compared with 24% of those headed by men. Longitudinal studies concluded that in the 1990s, family structure was one of the most important determinants of sustained poverty among women, even more important than access to income support programs and other services. In particular, women's capacity to fall into or climb out of poverty is linked to the presence and income of other family members, most often men.<sup>30</sup> This finding underscores the likelihood that for women living at or near poverty levels, their calculus in such matters as challenging their sexual partners about condom use or fleeing violence and abuse must include the factor of an income on which they and their children may depend.

Unfortunately, there are no recent data from large-sample studies in Canada on the links among gender, poverty and HIV/AIDS. Two small studies of people living with HIV/AIDS in British Columbia (women) and New Brunswick (men and women) both found that about half of the persons surveyed indicated a significant change for the worse in their economic status since their HIV diagnosis.<sup>31</sup> A survey of people living with HIV/AIDS conducted by the Canadian AIDS Society in 1998 found that 74% of the 1400 respondents had a gross annual income of under \$29,000 and 45% under \$12,000, well below national averages.<sup>32</sup> The lack of sex-disaggregated data related to poverty and HIV/AIDS is a statement in itself about the degree to which gender analysis informs policy-making on HIV/AIDS.

Violence against women, including domestic violence and marital rape, is an important determinant of HIV/AIDS risk. According to Status of Women Canada, a staggering 51% of Canadian women report having experienced at least one act of physical or sexual violence since the age of 16, the large majority of them perpetrated by someone known to the woman.<sup>33</sup> The Family Violence Initiative of Health Canada reported that 8% of women in Canada had suffered violence from within the family in the period 1994-1999.<sup>34</sup> Aboriginal women were three times more likely than non-Aboriginal women to have been assaulted by a current or former spouse in this period. Status of Women Canada also estimated that young women in common-law unions were at relatively high risk of spousal assault and that 21% of women abused

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ethnicity is identified in HIV test data, and in these same jurisdictions, about 23% of persons living with HIV/AIDS were identified as Aboriginal.

<sup>29</sup> Statistics Canada. *Persons in low income before tax by number*. 2005. Available at [www.statcan.ca/english/Pgdb/famil41b.htm](http://www.statcan.ca/english/Pgdb/famil41b.htm).

<sup>30</sup> C Lockhead and K Scott. *The Dynamics of Women's Poverty in Canada*. Status of Women Canada. 2000: 41-43. Available at [www.swc-cfc.gc.ca/pubs/pubspr/0662281594/200003\\_0662281594\\_e.pdf](http://www.swc-cfc.gc.ca/pubs/pubspr/0662281594/200003_0662281594_e.pdf).

<sup>31</sup> CM Kirkham and DJ Lobb. The British Columbia Positive Women's Survey: A detailed profile of 110 HIV-infected women. *Canadian Medical Association Journal* 1998; 158:317-323; and C Olivier. Relationships between income level and healthcare, social well-being and mental health among persons living with HIV/AIDS. *Canadian Social Work* 2001; 3(1):46-58.

<sup>32</sup> Canadian AIDS Society. *HIV and the downward drift into poverty* (HIV and Poverty Information Sheet no. 5), 2004: 3. Available at [www.cdnaids.ca/web/backgrnd.nsf/24157c30539cee20852566360044448c/1542f5f47d522a2385256f5e006a0698!OpenDocument](http://www.cdnaids.ca/web/backgrnd.nsf/24157c30539cee20852566360044448c/1542f5f47d522a2385256f5e006a0698!OpenDocument).

<sup>33</sup> State of Women Canada. *Fact sheet: Statistics of violence against women in Canada*. 2004. Available at [www.swc-cfc.gc.ca/dates/dec6/facts\\_e.html](http://www.swc-cfc.gc.ca/dates/dec6/facts_e.html).

<sup>34</sup> Health Canada. *The Family Violence Initiative: Year five report*. 2002, p ii.

by spouses were assaulted during pregnancy. Alcohol abuse among spouses and low income are also noted as risk factors.<sup>35</sup> A 1998 study of 100 women living with HIV/AIDS in British Columbia in 1998 found that 69% of these women had experienced sexual assault as adults or sexual abuse as children or both.<sup>36</sup> Again, data in these government reports do not permit any analysis of the intersection of violence and HIV/AIDS among women in Canada.

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<sup>35</sup> Status of Women Canada. *Assessing violence against women: A statistical profile*. 2002, p 27.

<sup>36</sup> CM Kirkham and DJ Lobb. The British Columbia Positive Women's Survey: A detailed profile of 110 HIV-infected women. *Canadian Medical Association Journal* 1998; 158:322.



# Programs and policies addressing HIV/AIDS among women in Canada

In 2000, Health Canada convened a National Reference Group on Women and HIV/AIDS. Its role was to review programs, policy and research on women and HIV/AIDS in Canada and to make recommendations for future federal programs and policy priorities in this area.<sup>37</sup> The group met twice in 2000, after which it was dissolved and members were thanked for their service even though it had not finalized its recommendations.<sup>38</sup> It is not clear how or whether the group's deliberations were used to inform federal policy. At the time, Health Canada prepared a list of 31 projects or activities that it was supporting in the area of women and HIV/AIDS, including eight activities related to perinatal transmission, 10 related to violence against women, and several on Aboriginal women and women in prison.<sup>39</sup>

The Federal Initiative on HIV/AIDS was released in December 2004 as a strategic guideline for HIV/AIDS activities of Health Canada, the Public Health Agency of Canada, Correctional Services Canada, and the Canadian Institutes of Health Research. The Initiative replaces the Canadian Strategy on HIV/AIDS, Health Canada's strategic framework since 1998. With respect to several of its core strategies, the Federal Initiative highlights women as a particularly vulnerable population among several others. Women, along with gay men, drug users, Aboriginal people, federal inmates, and youth, are noted as priority vulnerable populations with respect to the need for enhanced front-line population-specific programs for prevention, care, treatment and support. Women and youth are, however, dropped from the list of priority groups for communications and social

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<sup>37</sup> Health Canada - HIV/AIDS Policy, Coordination and Programs Division, National Reference Group on Women and HIV/AIDS: Terms of Reference, p 1, April 2000 (unpublished memorandum).

<sup>38</sup> J Gahagan, Dalhousie University, personal communication, July 2005.

<sup>39</sup> Health Canada – HIV/AIDS Policy, Coordination and Programs Division, April 2000.



marketing campaigns to improve awareness and reduce stigma and discrimination.<sup>40</sup> At a presentation of the Federal Initiative to national AIDS organizations in January 2005, federal officials were asked about this discrepancy but did not offer an explanation. At this writing, it is not clear how resources will be allocated to the population-specific work laid out in the initiative.

A cornerstone of the Federal Initiative, according to the government's description, is an enhanced federal contribution to addressing the complex determinants of HIV/AIDS, including "social, human rights, biological and community barriers that continue to fuel the epidemic."<sup>41</sup> The Federal Initiative document does not indicate by what analysis women are highlighted as a vulnerable population, but it is accompanied by a "pan-Canadian" action plan entitled *Leading Together* that suggests some elements of a gender-based analysis. *Leading Together*, which is still in draft form at this writing, resulted from a multisectoral consultative process involving public, private and voluntary sector leaders and organizations. A hard-copy draft of *Leading Together* circulated for consultation in 2005 offers this analysis of women in Canada and HIV/AIDS, which is very similar in many respects to WHO's global analysis above:

Poverty often leads to situations where women trade sex for survival, and economic dependence limits women's ability to leave dangerous relationships or negotiate safer sex with their partners. Domestic violence, sexual violence, abuse and coercion affect women's ability to protect themselves.... The women who are most at risk may not have the knowledge, resources or power within their relationships to protect themselves from infection. Because women's ability to ensure that their partners use condoms or practice safer sex is often limited, every effort must be made to develop prevention tools that the women themselves can control and use to protect their health, such as microbicides and preventive vaccines. Canada must invest adequately in developing prevention strategies for women.<sup>42</sup>

Health Canada and the Public Health Agency of Canada (PHAC) report that their support to HIV prevention services includes numerous activities that target women. For 2003-2004, the activities they highlight include support to Stella, an organization in Montreal that provides services to sex trade workers; the development of counselling guidelines for sexual and reproductive health; and capacity-building activities for persons providing services to HIV/AIDS-affected youth and families.<sup>43</sup> In the more general area of women's health, PHAC supports an information clearinghouse through the Canadian Women's Health Network, and the federal and provincial governments collaborate to support four Centres of Excellence for Women's Health linked to universities across the country.

The federal government supports other programs that, while they do not have HIV/AIDS as a central focus, are related to determinants of HIV risk. PHAC, for

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<sup>40</sup> Government of Canada. *The Federal Initiative to Address HIV/AIDS in Canada: Strengthening federal action in the Canadian response to HIV/AIDS*. 2004, pp 11, 13.

<sup>41</sup> Ibid. p 6.

<sup>42</sup> Government of Canada, *Leading together: Canada's HIV/AIDS action plan 2005-2010*. 2005, p.41. At this writing, it is not known whether this passage will appear in the final version of *Leading together*.

<sup>43</sup> Health Canada Women's Health Bureau. Women and HIV/AIDS in Canada. Available at [www.hc-sc.gc.ca/english/women/facts\\_issues/facts\\_aids.htm](http://www.hc-sc.gc.ca/english/women/facts_issues/facts_aids.htm).

example, also coordinates the federal Family Violence Initiative, a program involving 12 departments and agencies of the government working in collaboration with the National Clearinghouse on Family Violence, which includes a focus on violence against women.<sup>44</sup> The program includes provision of public information on violence against women and support for research on the subject. In 2000, Health Canada commissioned a guide to counsellors on HIV/AIDS and violence against women.<sup>45</sup> Federal and provincial governments also support safe shelters for women and in some cases legal education and assistance.

The HIV/AIDS strategies and programs of Canada's provinces and territories vary in their commitments to a particular focus on women. The HIV/AIDS strategy of Quebec, for example, recognizes a growing HIV prevalence among women in the province and notes women as a key "target group" for interventions. Among the priority activities noted in Quebec's strategy document are workshops on negotiating condom use and self-esteem, which may be particularly geared to women and girls.<sup>46</sup> Aside from these and consideration of pregnant women, there is little other attention to women in the strategy.

British Columbia's HIV/AIDS strategy for 2003-2007 notes a 270% increase in HIV prevalence among women from 1987 to 2001 and a 40% decline among men.<sup>47</sup> The objectives of British Columbia's HIV/AIDS strategy include "to sustain effective systems of care for women living with HIV and ensure no infants are born with HIV over the next five years" and "to ensure HIV+ women from the most vulnerable groups access antiretroviral therapy at the same rate as women in the general population".<sup>48</sup> Thus, programmatic focus is on pregnant women and treatment for women in vulnerable populations such as Aboriginal communities and those in the sex trade, but prevention programs specifically for women are not mentioned.

Ontario's HIV/AIDS strategy paper of 2002 notes that women constituted about 20% of new HIV transmission in the province virtually throughout the 1990s and about 25% since 1997. In the period 1985-2000, about 20% of HIV infection among women in the province could be attributed to injection drug use, and about 20% occurred in women originally from countries where HIV is endemic.<sup>49</sup> The provincial strategy includes a complex analysis of social determinants of HIV risk. Gender is not developed in detail; it is mentioned that HIV-related stigma faced by women is compounded by "being financially dependent on a partner and the risk of violence in their relationships."<sup>50</sup> The innovative responses highlighted among the province's

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<sup>44</sup> See Public Health Agency of Canada. Reducing family violence: a comprehensive federal approach, at [www.phac-aspc.gc.ca/ncfv-cnivf/familyviolence/initiative\\_e.html](http://www.phac-aspc.gc.ca/ncfv-cnivf/familyviolence/initiative_e.html).

<sup>45</sup> C Neron, *HIV and sexual violence against women: A guide for counsellors working with women who are survivors of sexual violence*. 2000.

<sup>46</sup> Ministère de la Santé et des Services Sociaux du Québec. *Stratégie québécoise de lutte contre l'infection par le VIH et le Sida, l'infection par le VHC et les infections transmissibles sexuellement: Orientations 2003-2009*. 2004, pp 24, 30, 32.

<sup>47</sup> Ministry of Health Planning of British Columbia. *Priorities for action in managing the epidemics—HIV/AIDS in British Columbia 2003-2007*. 2003, p. i.

<sup>48</sup> Ibid. at 3, 4.

<sup>49</sup> Ontario Advisory Committee on HIV/AIDS. *A proposed strategy for Ontario to 2008*. 2002, p 17.

<sup>50</sup> Ibid. at 25.

HIV/AIDS programs do not include ones that target women, but the directions suggested for programming are based on a social-justice analysis that would address many of the root causes of HIV risk among women.

Manitoba's "Provincial AIDS Strategy" does not mention women as a group at particular risk except women in the sex trade and those who are partners of injection drug users.<sup>51</sup> Nova Scotia's "Strategy on HIV/AIDS" does not highlight women in particular, though it highlights the needs of caregivers, who tend to be women.<sup>52</sup> In 2003, the Advisory Council on the Status of Women of the government of Nova Scotia produced an excellent background paper on women and HIV/AIDS and has made available a great deal of information on violence and poverty faced by women.<sup>53</sup> New Brunswick's public health service web site includes information on HIV/AIDS services but appears not to have a particular focus on women. Recommendations to the Saskatchewan government from a community-based HIV Provincial Strategy Team in 2002 included special attention to women drug users but no other recommendations explicitly about women.<sup>54</sup>

Though not directly related to domestic programs, the Canadian International Development Agency (CIDA) has had a particular focus on gender equality and gender-based analysis in its programming of official development assistance related to HIV/AIDS. On World AIDS Day (December 1) 2004, CIDA announced a CAD 105 million initiative to support activities designed to address gender inequality linked to HIV/AIDS. Noting that "gender inequality is fuelling the spread of HIV/AIDS," Minister of International Cooperation Aileen Carroll announced support to development of woman-controlled microbicides, work on sexual and reproductive health by the United Nations Population Fund, and a small grants program for "innovative projects" on gender equality.<sup>55</sup> Linking CIDA's analysis of the global situation to the domestic reality, Carroll noted in announcing the initiative that "[e]ven in Canada, where AIDS was once considered a man's crisis, infection rates among women are climbing much faster than those among men. Why is this happening?... Let me give you three reasons: physiology, poverty and power."<sup>56</sup>

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<sup>51</sup> Manitoba Health. *Manitoba's Provincial AIDS Strategy*. 1996, p 15. Available at [www.gov.mb.ca/health/aids/strategy.pdf](http://www.gov.mb.ca/health/aids/strategy.pdf).

<sup>52</sup> Nova Scotia Provincial HIV/AIDS Strategy Steering Committee. *Nova Scotia's strategy on HIV/AIDS: Summary report*. 2003.

<sup>53</sup> Nova Scotia Advisory Council on the Status of Women, Gender and HIV/AIDS. *A backgrounder*. 2003. Available at [www.gov.ns.ca/staw/pubs2003\\_04/genderHIV\\_Sept2003.pdf](http://www.gov.ns.ca/staw/pubs2003_04/genderHIV_Sept2003.pdf).

<sup>54</sup> Alberta Provincial Strategy Team on HIV, Blood-borne Pathogens and Injection Drug Use. *At risk: Recommendations for a strategy on HIV, blood-borne pathogens and injection drug use*. 2002, pp 7-13.

<sup>55</sup> Canadian International Development Agency. Canada hears the voices of women on World AIDS Day (news release). December 1, 2004. Available at [www.acdi-cida.gc.ca/cida\\_ind.nsf/0/1E37D83E7D3D563985256F5C0079157B?OpenDocument](http://www.acdi-cida.gc.ca/cida_ind.nsf/0/1E37D83E7D3D563985256F5C0079157B?OpenDocument).

<sup>56</sup> A Carroll. World AIDS Day: Putting women at the centre of the fight Against AIDS (remarks for a presentation on World AIDS Day, Dec. 1, 2004). Available at [www.acdi-cida.gc.ca/cida\\_ind.nsf/vLookupSpeechEn/08A68009E1114A6385256F5D0049C4FD?OpenDocument](http://www.acdi-cida.gc.ca/cida_ind.nsf/vLookupSpeechEn/08A68009E1114A6385256F5D0049C4FD?OpenDocument).



# Findings from research and key informant interviews

## Conceptualization of prevention programs: ignoring the human rights and social context

A lot of women, even if they know the risk factors for this disease, are not in a situation where they can actually protect themselves – if they're in a situation with a partner who is violent, or they don't know that they're in relationships that ought to make them concerned. That certainly was my situation.

– Louise Binder, chairperson, Canadian Treatment Action Council<sup>57</sup>

As noted above, women were generally not the focus of HIV/AIDS prevention and care programs in the early years of the epidemic in Canada as they were perceived not to be at risk. Many of the women interviewed by the Legal Network for this report criticized the government at all levels for perpetuating this error of history – that is, for having either no programs focusing on women or programs that were inappropriate in their conceptualization of the situation and rights of women. A criticism raised by several key informants was that programs and prevention messages tend to focus on curbing particular behaviours such as sex without condoms, sex with multiple partners, or injecting drugs, rather than to be based on an appreciation of the social, economic and human rights-related factors that constrain or shape women's behavioural choices. That is, for example, does it make sense to spend resources to tell a woman about condom use when she might be in a situation where she faces violence or abuse if she raises the issue of condoms with her sex partner?

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<sup>57</sup> Quoted in Number of HIV cases up among Canadian women, *Canadian Press*, November 30, 2004. Available at [www.ctv.ca/servlet/ArticleNews/story/CTVNews/1101846754636\\_113?s\\_name=&no\\_ads=](http://www.ctv.ca/servlet/ArticleNews/story/CTVNews/1101846754636_113?s_name=&no_ads=).

Several women said explicitly that analyses of HIV/AIDS at the global level, which elucidate such factors as poverty, subordination of women, and violence against women as key determinants of HIV risk, are lacking in Canada's official analyses of the epidemic within its borders. They thus raised exactly the points that the government of Canada asserts that its new approach to HIV/AIDS will address.

Several key informants noted that prevention programs for women in Canada have relied on stereotypes of women affected by HIV/AIDS. Programs target women as drug users or sex workers or they focus on pregnant women as “vectors” of HIV transmission to children, but they are not informed by women's rights and women's subordination in a larger sense. The Canadian Medical Association has a consensus guideline on the treatment of HIV-positive women and their infants,<sup>58</sup> for example, but not of other women. In Canada as in many countries, much of the clinical literature on HIV prevention, testing and diagnosis focuses on pregnant women. The dominance of this focus helps determine access to prevention, treatment care and support services.

An understanding of gender-linked factors that may pose challenges for women – and men – independent of their status with respect to “traditional” high-risk characteristics is lacking. Louise Binder, chairperson of the Canadian Treatment Action Council, remarked in 2004: “We need prevention programs that are targeted to women, and let's get outside the AIDS box, and let's get to the places...where women go in order to reach them, with messages to these women. These messages need to be not only messages about HIV itself..., but also messages about violence, mental health programs, harm reduction programs and about all of the services that should be available to women to get out of the situations that put them at risk.”<sup>59</sup>

Similar concerns have been raised by researchers in Canada. Loppie and Gahagan assert that behind Health Canada's statistics is a largely untold story with two essential threads – that women in Canada as elsewhere “have been relegated to positions of social, political and economic subordination that are mediated by race and class” and that this subordination “inhibits women's capacity to protect themselves from exposure to HIV.”<sup>60</sup> They cite violence against women as a particularly neglected factor. In addition, they attribute the inadequate analysis behind programs to women's under-representation in decision-making and policy-making bodies, long-standing male bias in HIV/AIDS research and policy, and a reliance on “patriarchal models of sexual decision-making.”<sup>61</sup> This kind of critique has been raised by social scientists and public health experts with respect to HIV/AIDS programs for women for some years. As Campbell noted in 1995, HIV/AIDS prevention at that time was dominated by approaches that simply made the assumption that women had complete control over factors affecting their health

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<sup>58</sup> DR Burdge et al. Canadian consensus guidelines for the management of pregnancy, labour and delivery and for postpartum care in HIV-positive pregnant women and their offspring (summary of 2002 guidelines). *Canadian Medical Association Journal* 2003; 168(13):1671-1674.

<sup>59</sup> L Binder. Remarks made at Annual General Meeting of Canadian HIV/AIDS Legal Network and Interagency Coalition on AIDS and Development, September 12, 2004. Available at [www.phac-aspc.gc.ca/ncfv-cnivf/familyviolence/initiative\\_e.html](http://www.phac-aspc.gc.ca/ncfv-cnivf/familyviolence/initiative_e.html).

<sup>60</sup> C Loppie and J Gahagan. Stacked against us: HIV/AIDS statistics and women. *Canadian Woman Studies* 2001; 21(2):6.

<sup>61</sup> Ibid. at 7, 8.

rather than recognizing the circumstances, such as power differentials based on gender, that limit women's behavioural choices as they may seek to minimize HIV risk.<sup>62</sup>

One example of HIV/AIDS prevention activities for women being based on women as “vessels or vectors” is the complete dearth of HIV prevention information or programs for lesbians. Lesley Fleming, an HIV/AIDS researcher in Ottawa, noted that the idea that lesbians face no risk of HIV is so commonplace that doctors will not raise HIV-related issues once a woman identifies herself as lesbian, and many lesbians do not seek information on HIV transmission. But, she said, little is known about concentration of HIV in vaginal secretions or risks associated with penetrative sex toys, and educational materials fail to target lesbians with information on sharing needles.<sup>63</sup> There seems also to be no research on lesbians who have or have had sex with male partners.

The range of government-supported programs meant to address HIV prevention among women in Canada appears not to be the result of a coherent national strategy for addressing HIV/AIDS among women. Some provinces apparently do not even regard women as particularly at risk. HIV/AIDS programs that explicitly address the subordination that puts all women at risk of HIV appear to be rare in Canada.

## Human rights concerns in HIV testing and diagnosis of women

Since it was first realized that HIV could be transmitted from mother to child *in utero*, during childbirth and through breastfeeding, women have been at the centre of policy and programs on HIV testing – women, that is, as vessels for child-bearing and potential vectors of transmission to their children. In developing countries, until very recently, programs to prevent mother-to-child transmission focused only on ensuring that pregnant women had access to the antiretroviral drugs needed to reduce the risk that children would be born without HIV/AIDS, not on the more expensive matter of ensuring long-term antiretroviral treatment and other care for the HIV-positive mother. While Canada is in a position to ensure that both goals are met, there remains a concern that women in Canada are not receiving the information and counselling that are meant to accompany HIV testing.

As in the United States, public health authorities in some jurisdictions in Canada are turning to models of HIV testing that de-emphasize pre-test and post-test counselling and a requirement to obtain explicit informed consent from persons tested. Alberta, Northwest Territories, Nunavut, Newfoundland and Labrador have mandated “opt-out” HIV testing for pregnant women who have contact with the health system – that is, women are told that they will be tested for HIV as a matter of course and that they have a right to refuse this testing.<sup>64</sup> Other provinces' policies retain the established

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<sup>62</sup> See, e.g., CA Campbell. Male gender roles and sexuality: Implications for women's AIDS risk and prevention. *Social Science and Medicine* 1995; 41(2), esp. pp. 197-198.

<sup>63</sup> GS Grenier. Myth still exists that lesbians are not at risk. *Capital Xtra*, March 2002. Available at [www.capitalxtra.on.ca/queercapital/cx103/cx103\\_index.htm](http://www.capitalxtra.on.ca/queercapital/cx103/cx103_index.htm).

<sup>64</sup> HIV/AIDS Epi Updates, p 35.



model of voluntary testing initiated by the person to be tested, with informed consent and counselling. Recent results from Ontario, for example, show that 83% of women in the province accepted HIV testing in an “opt-in” system,<sup>65</sup> indicating that a concerted effort to offer testing regularly can yield good outcomes without compromising informed consent.

In Canada, as elsewhere, whether policies favour “opt-out” or client-initiated testing, attention is needed to ensure that informed consent, confidentiality and counselling are preserved as human rights-based elements of HIV testing espoused in Canadian policy as well as in UN recommendations.<sup>66</sup> Leonard and colleagues studied the HIV testing experience of pregnant women in Alberta, Ontario and Nova Scotia in an effort to inform the development of a federal policy on HIV testing of pregnant women in Canada, which currently does not exist as testing policy is left to provincial and territorial authorities. Summarizing the results of their extensive interviews with 105 women, the authors noted:

...there is clear evidence that the established Canadian principles of HIV counselling and testing, which require HIV testing to be carried out only after the person has given [her] voluntary informed consent in the context of pre- and post-test counselling, are not always maintained in...programmes that offer to test women during pregnancy. While the majority of the women interviewed did accept testing when it was offered, many reported that they did not experience the offer to test as voluntary and did not feel that they had given their specific informed consent to be tested. Many women interviewed also reported not having been given adequate information to assess the risks and benefits of HIV testing for themselves or for their unborn child.<sup>67</sup>

Of the women from Alberta in this study, many said they experienced the “opt-out” system without having been given a clear option to “opt out” of being tested.<sup>68</sup> The authors note with concern that a number of women in the study, particularly those not living in urban areas, had little information on reduction of the risk of mother-to-child transmission through antiretroviral prophylaxis, leading some to believe that aborting their pregnancies was the only way to avoid HIV transmission. In this study, women in all provinces said they needed access to more information on HIV/AIDS than what was offered to them in contacts with any health officials surrounding HIV testing.<sup>69</sup>

An earlier study of women in Ottawa and Montreal reached similar conclusions. In both Ontario and Quebec, where pregnant women should be offered an HIV test with counselling and informed consent, women recounted experiences in which they received too little information to justify the supposition that they could give

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<sup>65</sup> HIV/AIDS Epi Updates, p 36.

<sup>66</sup> Joint United Nations Programme on HIV/AIDS (UNAIDS) and Office of the High Commissioner of Human Rights. HIV/AIDS and human rights: International guidelines. Report of the second international consultation on HIV/AIDS and human rights. UN Doc. HR/PUB/98.1. 1998, paras 28(b), 28(c).

<sup>67</sup> L Leonard et al. HIV counseling and testing among pregnant women in Canada: Best practices. In: C Amaratunga and J Gahagan (eds). *Striking to the Heart of the Matter: Selected Readings on Gender and HIV*. Halifax: Atlantic Centre of Excellence on Women's Health, 2002: 65-74 at 67-68.

<sup>68</sup> Ibid. at 70.

<sup>69</sup> Ibid. at 70, 72.

informed consent, or they experienced some level of coerciveness and were reluctant to refuse. The experiences of two women are illustrative.

(1) I was given a requisition form with all manner of other tests on it. I recognized my test for my thyroid, and I think maybe one or two other tests on it. And I did notice “HIV” written in, which I wasn’t told about and didn’t question or ask why because I was just assuming it was mandatory at that point.<sup>70</sup>

(2) I sort of felt like, this is a bit obnoxious. But I’m not going to make a fuss because I know it is not an issue for me.... I mean, it’s a very delicate thing, your relationship with your obstetrician. Because as much as you want to stand up for yourself, the bottom line is you also want to please your obstetrician because you want him to be there for you.... I really want him to like me and I want him to come to my birth.... These guys are pressed for time and they don’t make guarantees.<sup>71</sup>

In addition to concerns related to informed consent, key informants for this project expressed their concern that stigmatization upon diagnosis with HIV was in many ways more profound for women than for men and that counselling was an essential tool for helping women to deal with it. They echoed the concerns of women around the world when they noted that when women test positive, they were more likely than men to face judgmental attitudes or implicit accusations of promiscuity or other bad behaviour. These judgments sometimes translate into the message that HIV-positive women lack the capacity to be good parents. Several noted that testing policies, including regular counselling to accompany testing, were not respected, a conclusion echoed in recent research in three provinces.<sup>72</sup> Some noted that the absence or curtailment of counselling hits certain women especially hard, including those living in poverty who may have well-founded fears of abandonment or rejection by persons on whom they are economically dependent, women from Aboriginal communities and women from countries where HIV/AIDS is endemic, who may face isolation or violence if it is known they are living with HIV.

For women who are not pregnant or whose contact with the health system is not through prenatal services, the availability of voluntary testing services with gender-appropriate counselling and assurance of confidentiality is crucial. As late as 1998, some studies found that women seeking testing and counselling in regular health facilities reported being tested without their knowledge, not receiving counselling, and being given test results over the telephone.<sup>73</sup> The quality of testing services and the confidence established with women in the delivery of these services is essential to women’s ability and willingness to follow treatment and care recommendations at a later stage.<sup>74</sup>

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<sup>70</sup> L Leonard et al. Summary of pregnant women’s experiences of screening for HIV in pregnancy: What they have to say about what constitutes an appropriate policy for the HIV testing of pregnant women in Canada – a pilot study. In: Health Canada. *Perinatal HIV transmission: Study results and implications for policy and program development*. 2001, pp 23-32 at 27.

<sup>71</sup> L Leonard and L Shap. A different kind of risk? – Pregnant women’s experience of HIV testing in pregnancy. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 5(1):18-21 at 20.

<sup>72</sup> Leonard et al., HIV counseling and testing.

<sup>73</sup> S Walmsley. The new antiretroviral “cocktails”: Is the stage set for HIV-positive women to benefit? *Canadian Medical Association Journal* 1998; 158:340.

<sup>74</sup> Ibid.



The Canadian HIV/AIDS Legal Network has evaluated Canadian HIV testing policies in detail from a legal and human rights perspective and concludes that informed consent, pre- and post-test counselling and confidentiality or anonymity must remain central to HIV testing. All pregnant women and those considering pregnancy should be offered HIV testing routinely. The Legal Network recommends that all HIV testing be voluntary and contingent upon obtaining specific and informed consent. This means that women should be provided with appropriately detailed information about the purposes, risks and benefits of HIV testing and of the interventions available to reduce the risk of mother-to-child transmission of HIV.<sup>75</sup> Pre- and post-test counselling of good quality should be a requisite part of HIV testing. The Legal Network recommends against any policy of HIV testing that compromises informed consent, counselling and the voluntary nature of HIV testing.<sup>76</sup> It recommends that pre-test counselling include advice to women that if they test positive, they will have access to a range of services, including treatment for themselves. It is also useful to inform them that many HIV-positive women do not know their HIV status and thus cannot take advantage of the health services that could potentially benefit them. Post-test counselling is equally important, including an occasion for counsellors and HIV-positive women to discuss partner notification and the implications of it.

The Legal Network disagrees with the Canadian Medical Association's recommendation that all pregnant women in Canada be tested routinely for HIV unless they take the initiative to decline testing. Firstly, in practice, routine testing is very likely to undermine the seeking of informed consent by health professionals and the giving of it by women. In human rights law, informed consent for medical procedures is rooted in the right to security of person, or the right of a person autonomously to control what happens to her body.<sup>77</sup> In Canada, courts have recognized this right and the decisive role of patients in controlling what is done to them in medical treatment or testing. Secondly, for pregnant women, any infringement of this right to security of person would, in either intent or effect, be *because* of the pregnancy and would be discriminatory in that only women can be pregnant. There is, in any case, a need for documentation of the actual practice of opt-out testing in places where it has been adopted as a matter of policy and for extensive training of health workers and women on the human rights protections to which women are entitled.

## Criminal law and disclosure of HIV status

In March 2005, a woman was charged with aggravated assault after she reportedly volunteered that she was HIV-positive to military investigators from the army base in Borden, Ontario, who were questioning her on a "minor unrelated matter".<sup>78</sup> It was later alleged that she had had unprotected sex with a soldier on the base, though the

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<sup>75</sup> Canadian HIV/AIDS Legal Network. *HIV testing and pregnancy: medical and legal parameters of the policy debate*. 1999, esp. pp2-4.

<sup>76</sup> Ibid.

<sup>77</sup> Ibid. at 25.

<sup>78</sup> I Teotonio, Military warns all bases of HIV case: Canadian soldiers around the world told to seek medical advice, *Toronto Star*, March 26, 2005.

facts of the case remain to be clarified. Subsequently, the woman was also charged in relation to a complaint from a second man, even though, in respect of this man, there is no dispute that a condom was used. The woman was portrayed in the press as a sexual predator and wantonly promiscuous. Military officials also saw fit to inform army staff across the country and the world of the woman's identity and HIV status, though it was unclear that they did anything to emphasize to soldiers their own responsibility for safer sex with sex partners they may encounter on military bases. As of July 2005, the 31-year-old woman is still being held in a maximum-security facility pending trial or a plea agreement with the Crown.

In May 2005, a woman in Hamilton, Ontario was charged with criminal negligence for allegedly not revealing her HIV status to hospital staff during the birth of her child. This is the first case, to the Legal Network's knowledge, in which criminal charges have been laid related to transmission of HIV from mother to child; all other such cases involved sexual transmission. The complete facts of this case are not clear. But it is clear that this kind of application of criminal law to HIV exposure or transmission can have enormous public health costs. As Richard Elliott of the Legal Network noted in a press statement:

Prosecuting a mother for not disclosing her HIV status to health care workers is just the kind of action that would drive others in her situation underground and away from the assistance they need. If women face criminal charges in these situations, it's a reason to avoid HIV testing and prenatal care, which harms both them and their babies. Do we really think that throwing this woman in jail is going to help either her or her children?<sup>79</sup>

These are the first cases in Canada, to the Legal Network's knowledge, where women have been charged with criminal acts due to non-disclosure of HIV-positive status, in line with the Supreme Court's 1998 *Cuerrier* decision. The judgment in the case of *R v Cuerrier* established that persons living with HIV/AIDS in Canada may be guilty of aggravated assault if they do not disclose that they are HIV-positive before engaging in unprotected sex.<sup>80</sup>

After the *Cuerrier* decision, the Legal Network noted that it would be "far-fetched" but not impossible for *Cuerrier* to be used as a basis for criminalizing HIV transmission from a woman to her fetus during pregnancy or labour, but that breastfeeding by an HIV-positive woman, as a matter of legal argument, could lead to prosecution of the woman. While the complete facts of the Hamilton case are not known, it is clear that at least one prosecutor finds the legal leeway to bring such a charge.

In the matter of sexual transmission, the ripple effects of *Cuerrier* are being felt acutely by both women and men in Canada, but for women they may be especially severe. Women, particularly those in abusive relationships and those in the sex trade, may be more likely than men to face sexual or physical violence if they

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<sup>79</sup> Canadian HIV/AIDS Legal Network. Criminal charges against HIV-positive mother inappropriate response (press release), May 27, 2005, Toronto.

<sup>80</sup> This section relies heavily on Canadian HIV/AIDS Legal Network. *After Cuerrier: Canadian criminal law and the non-disclosure of HIV-positive status*. 1999.

disclose that they are HIV-positive. In analyzing the *Cuerrier* decision, the Legal Network urged Canadian courts to adopt a contextual approach in their applications of the decision. For example, if a person honestly fears physical violence as a result of revealing her HIV-positive status, there should be no criminal liability if she does not disclose. But this issue has not been addressed by the courts, so it remains unclear how the law would deal with it, and it is thus not possible to give definitive advice to people living with HIV/AIDS about whether a fear of violence removes the obligation to disclose their status to a sexual partner.

The *Cuerrier* decision emphasizes that disclosure of HIV status is a legal duty for HIV-positive persons who are about to engage in acts that place others at *significant risk* of infection. The decision *suggests* that people might not have this duty if they use condoms; but courts have not decided definitively on this matter, so it remains a suggestion, albeit one from the highest court in the country. In this regard, women are also at a disadvantage because condom use is overwhelmingly male-controlled. An HIV-positive woman may wish to have sex with a condom but be unable to get her sex partner to agree. In such a case in the courts, her desire to use a condom would be a matter of her word against his. In the case of the woman charged in March 2005 in relation to alleged sexual encounters with two men from the military base in Borden, Ontario, the Crown chose to lay charges for alleged non-disclosure to one of the men even in the case of a condom having been used for vaginal sex. If a conviction were to be obtained (and stand) on such facts, it would essentially remove any suggestion of a “safer sex” defence in Canadian criminal law that AIDS organizations argued for before the Supreme Court in the *Cuerrier* case. *It would mean that any HIV-positive person would have to disclose his or her serostatus to a sexual partner even if he or she were practising safer sex.*

For HIV-positive women and men both, the *Cuerrier* decision, for all its good public health intent, is most troubling for its undermining of public health by scaring those people who should be most empowered to face their HIV status. Criminal penalties will deter those most at risk from getting tested for HIV. If people fear HIV tests and refuse to have them, they will not receive counselling about risky behaviour or find out if they are HIV-positive, or benefit from medical treatment and support services. “This decision [*Cuerrier*] is not about protecting people,” said Louise Binder of Voices of Positive Women and the Canadian Treatment Action Council. “We’re reaching the stage where we’re afraid that even if we tell lovers our status, it won’t be enough.”

Since the *Cuerrier* decision, the Legal Network, the Canadian AIDS Society and other organizations have conducted training workshops on the implications of the decision and have developed informational materials for people living with HIV/AIDS. The Federal/Provincial/Territorial Committee on AIDS prepared guidelines for public health professionals and other health care workers on handling cases of non-disclosure, which were published in March 2005 in the *Canada Communicable Disease Report*.<sup>81</sup> Training of law enforcement and public health officials remains an urgent need, to ensure that the coercive powers of state authorities are not used in an

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<sup>81</sup> Federal/Provincial/Territorial Committee on AIDS. Persons who fail to disclose their HIV status: Conclusions reached by an expert working group. *Canada Communicable Disease Report* 2005; 31(5):53-61. Available at [www.phac-aspc.gc.ca/publicat/ccdr-rmtc/05pdf/cdr3105.pdf](http://www.phac-aspc.gc.ca/publicat/ccdr-rmtc/05pdf/cdr3105.pdf).

overbroad or otherwise inappropriate fashion, and that criminal charges are never used except as a last resort.

## Treatment and care for women living with HIV/AIDS

Women tend to feel isolated for many reasons. Women also have to look after everybody else. A lot of women don't have the resources that men do. With so many burdens and obligations, it's harder for us to ask for help.

– Jane Strickland in *The Positive Side*, 2003<sup>82</sup>

When I decided to start HAART..., I was not prepared for potential side effects to the medication. I experienced nausea and vomiting for several months, followed by kidney complications. With a four-year-old son at home, I was run ragged. I seriously considered stopping the meds for a while so I could cook, clean and care for my son.... One of the most difficult decisions I ever made was to give my child a medication that had previously sent me to the hospital with an adverse reaction.

– Shari Margolese, 2004<sup>83</sup>

Women in Canada have been shown to be diagnosed with HIV later in the course of their disease than men, which may be a result of not being as readily referred for testing as men. They have been seen also to have lower rates of seeking treatment and poorer treatment outcomes, the latter possibly the result of being diagnosed later in the course of the disease. In a study of AIDS-related deaths in Vancouver in 1995-2001, for example, women were found disproportionately to have died without having received treatment.<sup>84</sup> Women interviewed for this paper raised a wide range of concerns about treatment and care of women living with HIV/AIDS in Canada. These related to access to treatment, the quality and content of treatment and care, and factors related to women's ability to adhere to treatment protocols. Not only women in especially difficult circumstances, such as women prisoners or women living on the street, but women living with HIV/AIDS in "traditional" households may face the challenge of balancing their own need for treatment with their caregiving roles, the duties they face in keeping households going, and stigma and discrimination that may come from seeking treatment.

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<sup>82</sup> J Strickland. Women's words. *The Positive Side* 2003; 6(2). Available at [www.catie.ca/PSWomen\\_e.nsf/28b8400200f016b185256c6f00611dce/7a396bd28db38e9a85256cee00569171?OpenDocument](http://www.catie.ca/PSWomen_e.nsf/28b8400200f016b185256c6f00611dce/7a396bd28db38e9a85256cee00569171?OpenDocument).

<sup>83</sup> S Margolese. Shari's story. In: Canadian AIDS Society. *Stories of leadership in the AIDS movement: a tribute to the women living for change*. 2004, p 10. Available at [www.cdnaids.ca/web/pressreleases.nsf/7df11ef9c5b7c745852568ff007d35e8/3473e8e63fa86c4185256e4e0075274a/\\$FILE/CAS%20womensweek.pdf](http://www.cdnaids.ca/web/pressreleases.nsf/7df11ef9c5b7c745852568ff007d35e8/3473e8e63fa86c4185256e4e0075274a/$FILE/CAS%20womensweek.pdf).

<sup>84</sup> E Wood et al. Prevalence and correlates of untreated human immunodeficiency virus type 1 infection among persons who have died in the era of modern antiretroviral therapy. *Journal of Infectious Diseases* 2003;188(15 Oct):1164-1170.

Gahagan and Loppie interviewed 53 women living in Ontario in 1999 who were taking antiretroviral drugs or had taken them and stopped. Their findings echo comments of our key informants. For these women, adherence to antiretroviral therapy was made difficult by isolation and lack of social support, sometimes linked to HIV/AIDS-related stigma; childcare and other family responsibilities that were not shared by men in their lives; and the absence of gender-appropriate information on treatment.<sup>85</sup> There are few quantitative studies that have examined barriers to treatment among women in Canada. In a sample of 110 HIV-positive women in British Columbia who were studied in the early years of antiretroviral therapy, 45% of women judged to be clinically in need of treatment were being treated.<sup>86</sup>

From their own experiences, women in Canada have expressed the urgent need for better treatment information tailored for women. As one noted, “When I found out I had HIV, all I got from the doctor was a pamphlet on men with AIDS. He didn’t have a clue where to send me for help.”<sup>87</sup> Informants in the Ontario study reported that such problems as weight gain, changes in menstrual cycles, loss of or changes in texture of hair, and lipodystrophy, which manifest themselves differently among men and women, were frequently not understood or recognized by their doctors. In the British Columbia study, only 28% of those surveyed said they perceived that their family physician at the time of HIV diagnosis had up-to-date information or training to deal with HIV/AIDS.<sup>88</sup> As Walmsley notes, results such as this bode ill for women’s ability to adhere to treatment as a good physician-patient relationship is a key determinant of compliance.<sup>89</sup>

Indeed, although antiretroviral treatment is clearly effective for both men and women, many fundamental questions remain about differences in side effects and effectiveness of antiretroviral treatment between men and women.<sup>90</sup> AIDS activists in Canada have repeatedly decried the lack of research focused on women’s treatment needs and the under-representation of women in drug trials in Canada.<sup>91</sup> Consensus guidelines on the care of HIV-positive pregnant women were published only in 2002,<sup>92</sup> and pregnant women are arguably the highest-priority women for clinicians. Much of the information that is available may not leave women with many options. For example, women may be told that protease inhibitors in their antiretroviral regimens interact negatively with birth control pills, but they may have few other contraceptive options, particularly if they cannot ensure condom use.<sup>93</sup>

<sup>85</sup> J Gahagan and C Loppie. Counting pills or counting on pills? What HIV+ women have to say about antiretroviral therapy. *Canadian Woman Studies* 2001; 21(2):118-121.

<sup>86</sup> Kirkham and Lobb at 320.

<sup>87</sup> Gahagan and Loppie at 119-120.

<sup>88</sup> Kirkham and Lobb at 321.

<sup>89</sup> S Walmsley. The new antiretroviral “cocktails”: Is the stage set for HIV-positive women to benefit? *Canadian Medical Association Journal* 1998; 158:339-41.

<sup>90</sup> See, e.g., A Garcia et al. *Treatment Issues for Women*. New York: AIDS Community Research Initiative of America (ACRIA), 2002, p 2. For sex differences in response to nucleoside reverse transcriptase inhibitors, see K Machon, Fighting fat, *HIV Australia* 2004/05; 4(2):20.

<sup>91</sup> Press statement in advance of the National Conference on Women and HIV/AIDS (untitled), May 25, 2000, available at [www.cdnaids.ca/web/PressReleases.nsf/0/79d16758ae5d6ee285256bc800490ff8?OpenDocument](http://www.cdnaids.ca/web/PressReleases.nsf/0/79d16758ae5d6ee285256bc800490ff8?OpenDocument).

<sup>92</sup> Burdge et al.

<sup>93</sup> Walmsley, p 341, and Garcia et al., p 19.



Lipodystrophy refers to changes in body fat distribution that are associated with antiretroviral therapy. Some experts have suggested that women are more likely than men to experience lipodystrophy, though others have interpreted the few studies available to be inconclusive on this point.<sup>94</sup> Women seem to be more likely to experience fat accumulation in the abdomen and breasts and overall weight gain, whereas men are more likely to undergo fat depletion in the face and limbs. In view of social stereotypes and pressures for certain ideals of physical appearance, women may be more likely to experience depression related to the physical changes associated with lipodystrophy.

As with many aspects of treatment side effects, the science of sex differences in lipodystrophy is undeveloped because HIV-positive women have been so underrepresented in large-sample studies,<sup>95</sup> which in turn speaks to the way society and policy-makers value women. In the late 1980s, one expert estimated that in North America, women represented only about 5% of people in HIV/AIDS drug trials, and some of the trials still required that women be sterilized or demonstrably infertile.<sup>96</sup> In the year 2005, the Canadian Association for HIV Research accepted 310 abstracts for its annual conference, of which 25 had a focus on women or gender differences. At the 2005 Conference on Retrovirus and Opportunistic Infections, an important international conference focusing on clinical science, of over 900 abstracts there were 40 specifically about women or gender, of which about half were related to pregnancy or mother-to-child transmission.<sup>97</sup>

In 1990, Darien Taylor wrote that women living with HIV/AIDS in Canada got some of their best information on care and treatment from informal sharing of personal anecdotes with each other.<sup>98</sup> At that time, she noted, in the absence of other information, women often took their cue on opportunistic infections from the experience of gay men, who tended to have very different patterns of opportunistic infections than those encountered by women. In 2005, it is shocking that informal sharing of treatment information remains such an important source of information in the absence of a women-centred body of science. There still has not been enough research on treatment of HIV/AIDS that has included significant numbers of women and been designed to understand treatment and prevention issues that are specific to women. Canada can set an example in rectifying this injustice.

In addition to the dearth of research-based clinical information and advice on treatment that is tailored to women, it is clear that women face other gender-related barriers to treatment access and treatment adherence. Poverty is an obvious constraint. Costs of childcare and transportation to make appointments at health facilities are a challenge for all women, but for those already struggling to meet survival needs, they may be prohibitive. This was a concern consistently raised by HIV-positive women and service providers alike in community-based study of treatment access conducted by Casey House in Toronto in 2001. One service

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<sup>94</sup> Project Inform (San Francisco), Lipodystrophy syndrome(s), Nov. 2001, available at [www.projinf.org/fs/lipo.html#women](http://www.projinf.org/fs/lipo.html#women).

<sup>95</sup> Ibid.

<sup>96</sup> R Denenberg, Treatment and trials. In: *Women, AIDS and Activism* (see note 8), p 74.

<sup>97</sup> K Webster, personal communication, June 2005.

<sup>98</sup> D Taylor. Testing positive. *Healthsharing* 1990; p 10.

provider described the case of a woman who was sick enough to be hospitalized and needed treatment, but “she couldn’t stay and get treatment because who would look after her kids? She is alone here, an immigrant with no family. There are many women out there in that position.”<sup>99</sup> The reluctance of women from some cultures, particularly those who are not highly educated, to ask questions of health care providers may contribute to reluctance to seek care or to seek relief from the side effects of treatment.

The unequal burden of childcare and other household and family responsibilities is a frequently cited factor in the global burden of HIV/AIDS on women. It figures prominently in research on Canadian women living with HIV/AIDS. Canadian women interviewed for this project cited the unequal burden shouldered by women of care for family members, partners, and children. For many HIV-positive women, that burden is not reduced when they are living with HIV/AIDS; allowances are not made for the extra attention needed to their own health. They are likely to face the same or more complicated difficulties in access to childcare assistance, along with the challenge of maintaining the health care needs of children and their own health simultaneously.

Some researchers have noted that women’s status vis-à-vis their husbands or long-term partners may be such that they neglect their own health in favour of focusing on that of their partner or children.<sup>100</sup> HIV-positive women who are caring for children living with HIV/AIDS may expend their energy and other resources first on their children, and it may not be possible for a woman and her child to be treated in the same facility. Some of the same barriers that keep women from being able to seek or adhere to long-term treatment programs may also keep them from being able to meet the time and transportation requirements of participation in research trials.

In addition to stigma faced by women living with HIV/AIDS, therefore, these women are likely to be handicapped by a wide array of logistical, financial, informational and discriminatory barriers to the highest attainable standard of care, which is their right. Programs cannot be expected to succeed in improving women’s access to high-quality treatment if they do not take explicit account of these day-to-day realities.

## Human rights and aboriginal women affected by HIV/AIDS

I think for a lot of women it’s scary when you find out [you’re positive]; you’re responsible for the whole world. You’re responsible for your children, your man, your home, for everything.

– First Nations woman, East Hastings area of Vancouver, 2000<sup>101</sup>

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<sup>99</sup> Casey House (Toronto). Casey House Access Project: final report. 2001, p 27.

<sup>100</sup> Walmsley, p 341.

<sup>101</sup> SJ Ship and L Norton. HIV/AIDS and Aboriginal women in Canada. *Canadian Woman Studies* 2001; 21(2):27.

About one in four cases of new HIV transmission generally in Canada occurs among women, but in Aboriginal populations, women account for about half of new cases. Among women in Canada generally, about 60% of HIV transmission is attributable to heterosexual sex with an infected partner and about 40% to injecting drug use; these numbers have shifted relatively slightly in recent years.<sup>102</sup> Among Aboriginal women, the percentages are almost reversed: an estimated 65% of reported AIDS cases from the beginning of the epidemic have been linked to injecting drug use, and most of the rest is associated with sex.<sup>103</sup> Among both women and men, Aboriginal persons living with HIV/AIDS are estimated to be infected at a younger age than in the general population (about 30% of Aboriginal people in Canada who tested positive for HIV between 1998 and June 2003 did so before the age of 30, compared to about 20% in the general population).<sup>104</sup>

HIV/AIDS among Aboriginal women cannot be understood without reference to poverty, gender power relations, violence and discrimination, including systemic racism in the delivery of health services. Aboriginal women are twice as likely to be living in poverty as their non-Aboriginal counterparts, and according to the Canadian Aboriginal AIDS Network (CAAN), they are more likely to be exposed everyday to substance abuse and spousal violence.<sup>105</sup> The Aboriginal Strategy on HIV/AIDS in Canada, developed by CAAN, notes that poverty and discrimination keep many Aboriginal women from acting on traditional HIV/AIDS education messages. For some, low self-esteem and putting the needs of children and other family members first may be linked to risk of exposure to sexual assault and other forms of violence.<sup>106</sup> Even in the absence of sexual assault, low self-esteem may contribute to vulnerability to unsafe sex. “[Many Aboriginal women] will not say anything; if they do not want to lose their partner, they will have sex with them without a condom,” said Alana-Dawn Phillips of the Mohawk nation, noting the need for prevention and education programs that are based on the cultural reality faced by Aboriginal women.<sup>107</sup>

A project of the National Indian and Inuit Community Health Representatives Organization in which Aboriginal women were interviewed in depth about their experiences of poverty and HIV risk concluded that those at greatest risk were “most likely to be products of families and communities devastated by spiraling cycles of multi-generational abuse, the long-term effects of the legacy of cultural disruption and residential schooling.”<sup>108</sup> Ship and Norton posit that this history of abuse combined with social and cultural upheaval in recent years has intensified subordination of women in Canadian Aboriginal communities.<sup>109</sup> Their interviews

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<sup>102</sup> HIV/AIDS Epi Updates, p 23.

<sup>103</sup> Ibid. at 50.

<sup>104</sup> Ibid. at 52.

<sup>105</sup> Canadian Aboriginal AIDS Network. *HIV/AIDS and Aboriginal women, children and families: A position statement*. 2004, p 4.

<sup>106</sup> Canadian Aboriginal AIDS Network. *Strengthening ties—strengthening communities: An Aboriginal strategy on HIV/AIDS in Canada*. 2003, p 26.

<sup>107</sup> Dennis Bueckert. High rate of HIV infection among women raises alarm. *Canadian Press*, 7 February 2002. Available at [www.canoe.ca/Health0202/07\\_hiv-cp.html](http://www.canoe.ca/Health0202/07_hiv-cp.html).

<sup>108</sup> SJ Ship and L Norton. HIV/AIDS and Aboriginal women in Canada. In C Amaratunga and J Gahagan, eds, *Striking to the Heart of the Matter* (see note 67), p 61.

<sup>109</sup> Ship and Norton, *Canadian Woman Studies*, p 25.



with HIV-positive Inuit women revealed among these women a common history of abuse as children followed by abuse by men later in life. Several of the women said they recognized that they used drugs or alcohol as a way of coping with abuse.<sup>110</sup>

Laverne Monette, coordinator of the Ontario Aboriginal HIV/AIDS Strategy, told us that for Aboriginal women, HIV-positive or not, caring for themselves is very often secondary in their minds to caring for their children. She noted a historical legacy of lingering fear among these women that their children will be taken away from them by the authorities, contributing to these women's prioritization of care for their children. A 2004 CAAN position paper on women, children and HIV/AIDS echoes this point, noting that Aboriginal women who use injection drugs have an especially deep fear of seeking services because they feel vulnerable to losing their children. In Monette's view, this tendency is exacerbated by health systems that focus on HIV in the baby but not the woman herself. This observation was also made by numerous Inuit women interviewed by Ship and Norton. As one of them said:

Your first priority is your child. All the money that you get if you live on welfare or have a job goes to your child, to your child's well-being. Sometimes you get a little bit for yourself... money, time out or a chance to sit and share with other women.<sup>111</sup>

The Aboriginal Strategy on HIV/AIDS in Canada also recognizes this phenomenon and asserts the prime importance of women's empowerment as a key element of facing HIV/AIDS in Aboriginal communities. "The need is one of building up respect and honour for women, and supporting them in whatever decision they make, including pregnancy terminations if that is their informed choice," it notes.<sup>112</sup>

CAAN's position statement on women and children underlines "a startling lack of gender-specific, Aboriginal-specific HIV/AIDS resources, programs and services."<sup>113</sup> Because of inadequacy of health care services for Aboriginal women as well as a history of sexism and racism in government services, Monette said, Aboriginal women may tend not to seek services such as HIV testing or care until they are very sick and "all other options are exhausted." She also decried the double standard in Aboriginal communities that stigmatizes women who carry condoms as promiscuous, undermining HIV prevention possibilities.

CAAN's 2004 position statement called for gender-specific research in the Aboriginal community so that the real experiences of Aboriginal women living with HIV/AIDS and living in situations of high risk can be elucidated and can inform policy and program development. It also suggested the establishment of a Positive Aboriginal Women's Network for national leadership, more investment in peer-driven programs for Aboriginal women, and a national conference on Aboriginal women and HIV/AIDS.<sup>114</sup>

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<sup>110</sup> Ibid. at 27.

<sup>111</sup> Ibid.

<sup>112</sup> CAAN, *Strengthening ties* at 26.

<sup>113</sup> CAAN, *Position statement* at 3.

<sup>114</sup> Ibid. at 4, 8-9.

## Human rights, HIV/AIDS and women in the sex trade

Society has always looked down on working women. You can't tell anybody about it. You can't tell the doctor or the police. You should be able to tell doctors so you are medically safe and the police so you can be protected physically.

– Sex trade worker in Vancouver, 2004<sup>115</sup>

Sex workers in Canada live under the burden of stigma and abuse that faces their counterparts around the world. Workers in the sex trade, unlike other populations at high risk of HIV/AIDS, do not appear as a high-priority vulnerable population in the new Federal Initiative on HIV/AIDS. Yet it is clear that, though they are a heterogeneous group, many women in the sex trade face extreme risk factors daily, including violence of all kinds, sexual coercion and poverty. Not surprisingly, studies in Canada conclude that women sex workers experience more assaults, rapes and arrests than male sex workers and are more likely to be robbed.<sup>116</sup> Lowman, who tracked violent crime against women sex workers in Canada through the 1990s, concluded that murders of sex workers were rising alarmingly,<sup>117</sup> and that was without considering the horrific spate of murders of women sex workers in Vancouver in recent years for which the alleged perpetrators are being tried at this writing.<sup>118</sup>

Researchers in Canada who have based their findings on first-hand interviews with women sex workers have gone to some length to dispel what they consider to be myths about this population. Most research in Canada suggests great heterogeneity among women sex workers from one location to another. The level of drug use among women sex workers, for example, apparently varies greatly from an estimated under 10% in Montreal to as much as 50% in the Atlantic provinces.<sup>119</sup> Sex workers as “vectors” of HIV transmission is also apparently an unjustified stereotype as several research studies have concluded that condom use among sex workers, when they can control it, is high with their clients, if not with regular sex partners in their personal lives. A longitudinal study of drug users in Vancouver, which included numerous sex workers, concluded that sex workers’ risk in this setting was almost exclusively from regular partners and not clients.<sup>120</sup> The percentage of women sex workers who are street-based also seems to vary greatly from city to city in Canada. There is strong agreement that street-based sex workers are the most vulnerable to violence and other harms.

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<sup>115</sup> Pivot Legal Society. *Voices for dignity: A call to end the harms caused by Canada's sex trade laws*. 2004, p. 20.

<sup>116</sup> FM Shaver. Traditional data distort our view of prostitution (research presentation), Université du Québec à Montréal, 27 September 1996

<sup>117</sup> J Lowman. Violence and the outlaw status of (street) prostitution in Canada. *Violence Against Women* 2000; 6(9):987-1011.

<sup>118</sup> CBC News. Pickton trial date delayed again, 20 December 2004. Available at [www.cbc.ca/story/canada/national/2004/12/20/pickton041220.html](http://www.cbc.ca/story/canada/national/2004/12/20/pickton041220.html).

<sup>119</sup> See, e.g., Shaver (note 116).

<sup>120</sup> PM Spittal et al. Risk factors for elevated HIV incidence rates among female injection drug users in Vancouver. *Canadian Medical Association Journal* 2002; 166(7):899.

Engaging in sex work is not illegal in Canada.<sup>121</sup> Rather, the law criminalizes several aspects of the sex trade, including “communicating” in a public place for the purposes of promoting or seeking sex work; providing directions, taking or showing someone to a “bawdy house”; procuring, or obtaining a person to furnish sexual services to another person; or living off the proceeds of sex work. As a result, as the Pivot Legal Society in Vancouver noted, many sex workers “face criminal consequences for engaging in what is an otherwise legal activity.”<sup>122</sup>

In early 2003, Parliament resolved to review the federal laws related to sex work, including through hearing testimony on the consequences of the laws for sex work and sex workers. In late 2004, the parliamentary Standing Committee on Justice re-established a Subcommittee on Solicitation Laws. The subcommittee conducted hearings in March 2005, including testimony of sex workers in Vancouver, Montreal, Halifax, Winnipeg, Edmonton and Toronto.<sup>123</sup> At this writing, the subcommittee’s conclusions are not yet public.

For purposes of this paper, an important point about the law is that evidence suggests it heightens HIV risks faced by women sex workers. As Lowman notes, these risks are both direct and indirect. Because the law is such that many sex workers would face criminal sanctions for their everyday activities, they have little expectation that the police will protect them from violence and every expectation that the police will arrest or fine them if given the chance.<sup>124</sup> Sex workers are thus highly vulnerable to violence, robbery and other abuse from which the police might otherwise provide some level of protection. When the bawdy house provision and other laws are enforced, women sex workers are likely to be led to meet their clients in more dangerous locations that make them even more vulnerable to assault and other danger. The bawdy house prohibition also impedes sex workers from organizing and managing their own work premises, thus keeping them from being able to organize for occupational health and safety protections.

A recent and elegantly documented study by the Pivot Legal Society on the impact of the solicitation laws on sex workers echoes some of these critiques. As one worker noted:

Working girls end up going into hiding places just to stay away from the harassment of the police. That’s dangerous; girls are getting killed out there. A lot of girls go...to beach areas and wooded areas...to keep away from police, and it’s dangerous because you don’t know if the john will bring you back.<sup>125</sup>

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<sup>121</sup> This section relies heavily on Canadian HIV/AIDS Legal Network. *Sex, work, rights: Reforming Canadian criminal laws on prostitution*. 2005.

<sup>122</sup> Pivot Legal Society, p. 3.

<sup>123</sup> House of Commons, Subcommittee on Solicitation Laws of the Standing Committee on Justice. Subcommittee to travel to several Canadian cities for its study on solicitation laws (press release), 23 February 2005. Available at [www.parl.gc.ca/committee/CommitteePublication.aspx?COM=9243&SourceId=102199](http://www.parl.gc.ca/committee/CommitteePublication.aspx?COM=9243&SourceId=102199).

<sup>124</sup> Lowman, pp 21-22.

<sup>125</sup> Pivot Legal Society, p 17.

The Pivot study also highlights the difficulty that low-income sex workers in particular often have in enforcing condom use by their clients, a situation it concludes is also exacerbated by women's vulnerability to violence and abuse because of the law. A number of the women Pivot interviewed said they would be better able to enforce condom use if they could work indoors rather than on the street, but the "bawdy house" provisions of the law prevent this.<sup>126</sup>

An in-depth analysis of sex work, HIV/AIDS and the law by the Canadian HIV/AIDS Legal Network in 2005<sup>127</sup> recommends that the bawdy house and communications provisions of the Criminal Code be repealed because of the risk they pose to sex workers. It further urges that the entire body of Canadian law related to prostitution be reviewed, including an assessment of the impact of federal, provincial and municipal law on sex work, and that this review include the meaningful participation of sex workers.

## Women who use drugs and HIV/AIDS

Women always get the short end of the stick. International Women's Day means nothing to a woman living on the streets, addicted to drugs and selling sex for a place to sleep and something to eat. If we really want to turn this epidemic around, we must redress the power and economic inequalities between men and women.

– Ann Livingston, coordinator, Vancouver Area Network of Drug Users<sup>128</sup>

Women who inject drugs in Canada as in the rest of the world are at extremely high risk of HIV and many other physiological and psychological harms and of human rights abuse. Injection drug use accounted for about 46% of new HIV transmission among women in Canada in 2002.<sup>129</sup>

Researchers in Vancouver found in 2002 that women drug users had higher HIV prevalence and 40% higher rates of seroconversion than men.<sup>130</sup> They attributed this result in part to women's greater likelihood of being assisted in injection because of their smaller veins and because men often control the injection process, and partly to women's greater physiological vulnerability to HIV transmission during unprotected sex. An earlier study in Vancouver found women drug users three times more likely than men to borrow needles from a regular sexual partner and concluded that this phenomenon was more resistant to change than other needle-sharing.<sup>131</sup>

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<sup>126</sup> Ibid. at 19.

<sup>127</sup> *Sex, work, rights*.

<sup>128</sup> Canadian Treatment Action Council. Canadian women with HIV/AIDS have little cause for celebration on International Women's Day (press release). 8 March 2004. Available at [www.ctac.ca/english/pdf/media\\_release\\_Intl\\_Womens\\_Day\\_2004.PDF](http://www.ctac.ca/english/pdf/media_release_Intl_Womens_Day_2004.PDF).

<sup>129</sup> HIV/AIDS Epi Updates, p 25.

<sup>130</sup> Spittal et al., pp. 894-899.

<sup>131</sup> SA Strathdee et al. Social determinants predict needle-sharing behaviour among injection drug users in Vancouver, Canada. *Addiction* 1997; 92(10): 1341.

Low condom use among injection drug users is a continuing concern, and not only for those drug users who report trading sex to support a drug habit. Health Canada cites studies from Winnipeg, Regina, Vancouver and Victoria indicating very inconsistent condom use among drug users with both regular and casual partners.<sup>132</sup> Some researchers have suggested that for women, this pattern may be linked to low self-esteem that itself may be a risk factor for initiating narcotic drug use, though others have refuted this idea.<sup>133</sup>

For both men and women, drug laws and police conduct in enforcing them may contribute to HIV/AIDS risk, but they may affect women in particular ways. The pan-Canadian action plan *Leading Together* observes that “drug laws in Canada force drug activity underground, causing drug users to avoid prevention and harm reduction programs that could reduce their risk. When drug users are arrested, most end up in prison rather than treatment, which increases their risk of infection.”<sup>134</sup> As noted above, because women are scattered in relatively small numbers throughout the prison system and do not seem to constitute the critical mass that is required to spur the creation of comprehensive programs, they may be particularly disadvantaged in their access to drug treatment and other services in prison.

Police conduct toward drug users may pose particular threats for women. For example, the extensive police crackdown against drug dealers in April 2003 in Vancouver, which resulted in the arrest of many drug users who were not dealers, reportedly led drug users to rush their injections and to inject alone in isolated locations for fear of being found by the police.<sup>135</sup> Women’s greater tendency to require assistance from other users in injecting means it is likely they were particularly disadvantaged during the crackdown.

Assisted injecting is also not allowed in Vancouver’s safe injection facility, a policy that especially disadvantages women. Wood and others, working with the Vancouver Injection Drug User Study (VIDUS), reported that women in that sample were more than twice as likely than men regularly to require assistance in injecting, and of these almost twice the proportion of women as men reported that this was because they didn’t know how to inject properly.<sup>136</sup> Needing help to inject was demonstrated by these researchers to be a risk factor for syringe sharing and thus for HIV and hepatitis risk. In a study conducted before the opening of the safe injection site, Kerr and others found that women to a greater degree than men said that they would be less likely to use the facility because of the prohibition of assisted injecting.<sup>137</sup> As Wood and others note, needing assisted injecting is a problem that is difficult for traditional syringe exchange services to address.<sup>138</sup> A safe injection facility, where one-on-one

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<sup>132</sup> HIV/AIDS Epi Updates, pp 75-76.

<sup>133</sup> See, e.g., S Boyd and K Faith. Women, illegal drugs and prison: views from Canada. *International Journal of Drug Policy* 1999; 10:196-98, 203-04.

<sup>134</sup> *Leading Together* (Jan. 2005 version), p 30.

<sup>135</sup> Human Rights Watch. *Abusing the user: police misconduct, harm reduction and HIV/AIDS in Vancouver*. 2003, pp 19-21.

<sup>136</sup> E Wood et al. Requiring help injecting as a risk factor for HIV infection in the Vancouver epidemic. *Canadian Journal of Public Health* 2003; 94(5):355-359.

<sup>137</sup> T Kerr et al. Potential use of safer injecting facilities among injection drug users in Vancouver’s Downtown Eastside. *Canadian Medical Association* 2003; 169(8): 759-763.

<sup>138</sup> Wood et al. at 358.

education with a health professional and peer education are possible, should be an ideal place both to address the root causes of assisted injection and to assist those who need help. The latter, in any case, is impossible under the current rules of the Vancouver facility.

Boyd and Faith assert that women drug users may be reluctant to seek medical help, even during pregnancy, for fear of being placed under official surveillance as drug users or losing their children.<sup>139</sup> They also note that women drug users in Canada may face discriminatory exclusion from health and social services for which they are likely to have a great need, such as shelters for battered women.<sup>140</sup>

## Incarcerated women and HIV/AIDS

I was 18, turning 19, confined in a little prison cell in a remand centre. I was heavy into needles (drugs my only friend).... One day a friend told me I had better get tested.... My friends, even my own brother, turned on me because I have HIV. Jail was rough. And I was alone. HIV was a big thing back then—it was thought of as AIDS, and people were scared.... It has been 10 years, and I am doing great. I now run a support group that is for inmates that are faced with being HIV+.... I know that there are inmates out there that need to know that they are not alone.

— Mary Parisian, 2004<sup>141</sup>

Men, women and transgender persons in prison in Canada are all at high risk of HIV transmission and of poor access to support, care and treatment for HIV/AIDS. HIV prevalence among prisoners is difficult to calculate overall in Canada, but it was estimated by the Public Health Agency of Canada to range from 1% to 15% in the late 1990s.<sup>142</sup> There are gender-specific factors, however, that may figure in the risks and service lapses faced by women compared to men. In several studies, HIV prevalence has been shown to be higher among incarcerated women than among incarcerated men in Canada.<sup>143</sup>

Anne Marie DiCenso, executive director of the Prison HIV/AIDS Support Action Network (PASAN) in Toronto and a key informant for this project, told us that for women in Canadian prisons, it is a struggle to get the same level of access to HIV/AIDS services either as women outside prison or as men inside prison. “They are supposed to have prevention from community-based organizations, but often none is available,” she said, noting that some women’s prisons are in such isolated locations that no organizations serve them. She noted that since women are

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<sup>139</sup> Boyd and Faith, p 198.

<sup>140</sup> Ibid. at 204.

<sup>141</sup> You are not alone. *For Your Information* (Voices of Positive Women newsletter) 2004; p 2.

<sup>142</sup> Public Health Agency of Canada. HIV-HCV co-infection in Canada as of December 1999. Available at [www.phac-aspc.gc.ca/hepc/hepatitis\\_c/pdf/hivhcvreport/results2.html](http://www.phac-aspc.gc.ca/hepc/hepatitis_c/pdf/hivhcvreport/results2.html).

<sup>143</sup> Ibid. and Correctional Service of Canada. *HIV/AIDS in prisons: final report of the Expert Committee on AIDS and Prisons*. 1994, p 8.



dispersed among numerous prisons such that there are relatively small numbers of them in a given institution, they are neglected in service provision. This point was cited by the Canadian HIV/AIDS Legal Network in the “report card” on Canadian prisons and HIV/AIDS that it issued in 2002: since women are often housed in small units of much larger men’s prisons, they do not constitute the critical mass that seems to be needed to justify women-centred programs and facilities.<sup>144</sup>

DiCenso noted that very basic information on HIV/AIDS and hepatitis C, including that bleach provided in prisons does not sufficiently sterilize needles to prevent hepatitis C transmission, is unavailable to many women. Some women also fear asking for bleach to do laundry, thinking that just making the request will label them as HIV-positive or having hepatitis. In addition, she noted, women are not informed of their rights. “Women in prison think [HIV] testing is mandatory because of the [coercive] way it is offered,” she said, even though they have the right to testing only with informed consent. As another example, women living with HIV/AIDS are frequently unaware that if they are to be released, Correctional Service Canada is obliged to provide them with a supply of their medications to see them through to their first doctor’s appointment outside prison. In this and many other circumstances, women may experience interruptions in their treatment that pose a high risk of dangerous complications, including eventual drug resistance.

A significant percentage of Canada’s women in prison are there because of narcotics drug charges. Writing in 1999, Boyd and Faith concluded that women in Canadian prisons have poor access to addiction treatment if they wish to overcome their addiction and, indeed, that many women not previously addicted to drugs become users while in prison.<sup>145</sup> There is little in more recent research to suggest that this has changed.

With financial support from Health Canada, PASAN conducted an extensive 2003 study on women and HIV/AIDS in Canadian prisons in which 40% of women in federal custody were interviewed about their experiences with respect to HIV/AIDS risks, care and support. The study, “Unlocking Our Futures,” paints a bleak picture of poor access to services, information and support among women vulnerable to or living with HIV/AIDS and hepatitis C in Canadian prisons. It reports on gender-linked risk factors that have been little appreciated in program and policy development. Some 9% of the women interviewed, for example, said they had engaged in slashing or cutting of their own skin or other forms of self-injury, a figure the authors believe may be an underestimate.<sup>146</sup> Tattooing and body-piercing were also common among women in the study, and 19% of the women said they were currently injecting drugs. Most of the women had very little information on HIV or HCV risks associated with any of these practices.

In addition to perceiving that HIV tests were mandatory, many women in the PASAN study reported an absence of counselling of any kind before or after HIV tests or

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<sup>144</sup> Canadian HIV/AIDS Legal Network. *Action on HIV/AIDS in prisons: too little, too late – A report card*. 2002, p. 23.

<sup>145</sup> Boyd and Faith, pp 197-198.

<sup>146</sup> AM DiCenso et al. *Unlocking Our Future: A National Study on Women, Prisons, HIV and Hepatitis C*. Prisoners HIV/AIDS Support Action Network. 2003, p. 32.

otherwise. An alarming two thirds of the women who had been tested for HIV reported that they remembered no counselling with the testing.<sup>147</sup> Women in prison are probably more likely than their counterparts in the general population to have faced violence and abuse; counselling accompanying HIV diagnosis is particularly important for these women, both for their own self-esteem and protection and for knowing how to manage the disclosure of their status in prison and beyond. Counselling by other women, a service that seems in especially short supply in the experiences of women in the PASAN study, is particularly useful. One woman depicted her experience as lacking both counselling and any kind of initiative to provide useful information:

When it's blood-work day, you go down and you get the blood work done. If it's negative, you don't get a phone call. You never see the information unless you ask. You never see it. You just take their word. There are some women in here that nobody has phoned.<sup>148</sup>

In spite of the paucity of counselling, women in this study took up offers of HIV and HCV testing at a relatively high rate. Those few women who had been able to take advantage of counselling by trained women counsellors from NGOs described those experiences as uplifting and meaningful.

Women living with HIV or HCV in the PASAN study reported very mixed experiences of medical care and cited numerous problems – concerns about confidentiality of their medical records, availability of doctors and nurses, finding health staff who would answer their questions – that are probably not unlike those encountered by men in prison. Some care-related issues are unique to women. Menstruating women have a need for dietary iron, for example, and anemia risk may be heightened by antiretroviral drugs. All of the women in the study who cited poor diet as an important factor in their health were living with HIV or HCV.<sup>149</sup> Two of the women said they decided not to take medications for HIV or HCV because they could not get access to foods that would help them counteract the side effects of their medications or because they could not get more frequent small meals, as recommended in their treatment protocols. The authors noted that women at some facilities experienced better diet and more supportive medical care, but standards of care appeared to be very inconsistent from institution to institution.

As the Canadian HIV/AIDS Legal Network's 2002 report card on prisons and HIV/AIDS in Canada asserts: "Few jurisdictions are able to state that they have developed and implemented HIV/AIDS education and support programs designed specifically for women. Indeed, few jurisdictions could identify a response to HIV/AIDS specifically designed to meet the needs of women."<sup>150</sup> All evidence suggests that incarcerated women are a population highly receptive to information, counselling, and support for reducing harmful behaviours, and that correctional authorities in Canada are missing a golden opportunity by not ensuring greater access to good-quality services.

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<sup>147</sup> Ibid. at 36.

<sup>148</sup> Ibid. at 34.

<sup>149</sup> Ibid. at 47.

<sup>150</sup> *Action on HIV/AIDS in prisons: too little, too late*, p 23.



## Women in Canada from countries in which HIV is endemic

The Public Health Agency of Canada estimated that in 2002, some 7% to 10% of persons living with HIV/AIDS in Canada and 6% to 12% of persons newly infected in that year were persons born in a country where HIV is endemic.<sup>151</sup> These estimates are stated as a range partly because many HIV tests are conducted without information on ethnicity or national origin, and many persons from endemic countries are estimated to be HIV-positive without knowing it. Ontario is home to many persons living with HIV/AIDS who come from countries where HIV is endemic. From 1997 to 2002, HIV prevalence in this population in Ontario increased by 90%, the highest increase in any “exposure category” followed in the province.<sup>152</sup> This increase was seen among both men and women. Women from these countries constituted one quarter to one third of newly diagnosed women in Ontario from 1990 to 1999, but from 2000 to 2002, they accounted for 43% of HIV diagnoses. Men from countries where HIV is endemic accounted for 7-9% of all diagnoses among men in 1996-2000 and about 15% in 2001-2002.<sup>153</sup>

Researchers and community leaders bemoaned the absence of attention to this population in the Canadian HIV/AIDS Strategy, the framework for federal government action on HIV/AIDS until the release of the Federal Initiative in December 2004.<sup>154</sup> The Federal Initiative notes “people coming from countries where HIV is endemic” as a vulnerable population that will receive attention under the new framework,<sup>155</sup> though it is not clear at this writing what level of resource allocation this attention entails.

Some community leaders have suggested that social and economic subordination poses great risks for women in Canada who are from countries where HIV is endemic. Vuyiswa Keyi, a nurse of southern African origin who has directed several NGOs representing the interest of Africans in Canada, told the CBC in 2003 that many women of African origin in Canada become HIV-positive without knowing it because their husbands are not inclined to disclose their own HIV status.<sup>156</sup> She said the cultural imperative to have children in this community may contribute to men’s non-disclosure.

Women, for their part, may have good reason in addition to cultural factors not to challenge their husbands. Women who migrate to Canada under the terms of the family reunification policy in federal law are required to be under the aegis of a sponsor for three years in the case of a legal spouse as sponsor or for ten years in

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<sup>151</sup> HIV/AIDS Epidemic Update at 4.

<sup>152</sup> RS Remis et al. *Report on HIV/AIDS in Ontario 2002*. Ontario Public Health Branch. 2003, para 5.

<sup>153</sup> Ibid. at Table 1.5a.

<sup>154</sup> See, e.g., B Goldman. AIDS among African immigrants to Canada, *CBC News*, 22 September 2003, available at [www.cbc.ca/news/background/aids/canada.html](http://www.cbc.ca/news/background/aids/canada.html); and *Globe and Mail* examines ‘alarming rise’ in HIV prevalence among African, Caribbean immigrants in Canada, Kaiser Daily HIV/AIDS Report, 5 October 2004, available at [www.kaisernetwork.org/daily\\_reports/rep\\_index.dfm?hint=1&DR.ID=26070](http://www.kaisernetwork.org/daily_reports/rep_index.dfm?hint=1&DR.ID=26070).

<sup>155</sup> Federal Initiative, pp 7, 11.

<sup>156</sup> B Goldman (note 154).

other cases.<sup>157</sup> This factor may add to women's reluctance to seek HIV information or a test as they may fear rejection or abandonment by their sponsoring family member. Lower rates of medical insurance coverage among women from HIV-endemic countries may also be an impediment to their seeking health services.<sup>158</sup> Whatever the reason, researchers have noted that children from these communities are greatly over-represented in the statistics on mother-to-child transmission of HIV in Canada. In Ontario from 1992 to 2002, an estimated 70-80% of children who became HIV-positive through perinatal transmission were in families from HIV-endemic countries,<sup>159</sup> with attendant consequences for women who are then charged with the care of these children and may face stigma and blame for giving birth to an HIV-positive child.

Even for immigrants not covered by the family reunification program, immigration law may be an impediment to seeking HIV testing, prevention or care services. Applicants for permanent residence in Canada who are not seeking refugee status are required to undergo an assessment of whether they would place "excessive demand" on the Canadian health and social service system.<sup>160</sup> In principle, someone living with HIV who is in good health and not taking antiretroviral medication should not be judged as placing excessive demands on the health system. Persons taking antiretrovirals, on the other hand, would normally be judged to present an excessive burden to the system and can be refused entry or deported, even if their medications are covered by private insurance. Persons living with HIV/AIDS and not in good health but not taking antiretrovirals may also be judged to be medically inadmissible. Refugees and persons awaiting determination of an asylum case are exempt from this determination, but new migrants may not know this. Applicants for permanent residence who are family members, including spouses (and same-sex partners), of the citizen or resident of Canada who is sponsoring them are also exempt from the "excessive demand" criterion.

Clear information about immigration rules is unlikely to be readily accessible for many women from endemic countries, some of whom may not be fluent in English or French or may not know whom to ask for such information. But rumours are likely to abound, and mass media presentation of HIV/AIDS and immigration issues may fuel fears of stigma and deportation. In May 2004, Canada's *National Post*, for example, trumpeted the tripling of HIV-positive immigrants from 2002 to 2003 (the actual increase was from 276 to 677, or an increase by a multiple of 2.4) and editorialized that it is hard to understand how non-refugee HIV-positive immigrants could be seen as anything other than "an added burden for Canada's strained health care system."<sup>161</sup> The editorial noted that 13% of HIV-positive immigrants

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<sup>157</sup> House of Commons, Standing Committee on Citizenship and Immigration. *Building a nation: The regulations under the Immigrant and Protection Act*, part 2A. 2002. Available at [www.parl.gc.ca/InfoComDoc/37/1/CIMM/Studies/Reports/cimmrp04/10-chap2-e.htm#SPONSORSHIP%20UNDERTAKINGS](http://www.parl.gc.ca/InfoComDoc/37/1/CIMM/Studies/Reports/cimmrp04/10-chap2-e.htm#SPONSORSHIP%20UNDERTAKINGS).

<sup>158</sup> KS O'Connor and SE MacDonald. Aiming for zero: preventing mother-to-child transmission of HIV. *Canadian Medical Association Journal* 2002; 166(7):909.

<sup>159</sup> Remis et al. at Table 3.4a.

<sup>160</sup> For a more complete guide to immigration law and regulations pertinent to people living with HIV/AIDS in Canada or seeking to enter Canada, see Canadian HIV/AIDS Legal Network. Questions and answers: Canada's immigration policy as it affects people living with HIV/AIDS. 2005, available at [www.aidslaw.ca/Maincontent/issues/immigration.htm](http://www.aidslaw.ca/Maincontent/issues/immigration.htm).

<sup>161</sup> M Friscolanti. Number of HIV-positive immigrants to Canada triples in one year, Immigration Department says, *National Post* 13 May 2004 at A1.

were prevented from entering or staying in Canada in 2003, suggesting that the admission of the others, mostly refugees, showed that Canada was taking seriously its “humanitarian responsibilities” with respect to people living with HIV/AIDS. The article quoted a retired foreign affairs officer who had lobbied for refugees to be subjected to the same medical admissibility regulations as non-refugees. Media stories such as these are likely to fuel fear of stigma and rejection among new or potential immigrants.

Immigration procedures, moreover, do not always happen according to regulations. One HIV-positive woman told researchers at Casey House in Toronto:

I went through two years of hell. I didn’t have OHIP [Ontario Health Insurance Plan]. I lost all my documentation [while homeless]; I lost my landed immigration papers. Finally I got my birth certificate, and they still wouldn’t do anything, so I had to get a lawyer and now I have my identification and everything. But I didn’t have blood work done for two years.<sup>162</sup>

In the same survey, service providers in Toronto noted that people with insecure immigration status too often present for treatment only when they are very ill and that it is frequently difficult to find doctors who will treat these patients.<sup>163</sup>

In Canada, most women from countries where HIV is widespread are from Africa or the Caribbean. Racism is part of these women’s daily lives along with other human rights challenges they face. The federal government estimated that in the 1990s, women of African and Caribbean origin were twice as likely as other women in Canada to be “persistently poor” over several years.<sup>164</sup> The challenges faced by all women living with HIV/AIDS or caring for family members with HIV/AIDS are likely to be greater in this population because of both poverty and economic dependence of women on other family members.

Social taboos against homosexuality in African and Caribbean communities may also add to HIV risk among both men and women. For gay or bisexual men, their arrival in Canada may provide the first opportunities to seek sex with men without facing high risk of violence or social disdain, but norms from their countries of origin may still keep them from revealing their sexual orientation to their wives. Several women of African origin living in Nova Scotia raised this point in research conducted by Planned Parenthood there in 2004. As one of them said:

The community still hasn’t come to grips with homosexuality so like I was saying earlier, I know guys that are gay but don’t want anyone to think that they’re gay, so they’re sleeping with women too. Do you know what I’m saying?<sup>165</sup>

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<sup>162</sup> Casey House, p 33.

<sup>163</sup> Ibid.

<sup>164</sup> Status of Women Canada. *The Dynamics of Women’s Poverty in Canada*, p 41.

<sup>165</sup> Keeping, p 41.

A similar phenomenon among African American men in the U.S. has been documented and hypothesized to be a major risk factor for HIV/AIDS among men and women in many U.S. cities.<sup>166</sup> Other women in the Planned Parenthood study said they thought that churches, which are influential in African communities, could be helpful in raising awareness of this problem, at least those churches where speaking about homosexuality is not taboo.

The 2001 Casey House study on treatment access in Toronto underscored language barriers for women from endemic countries – not just strictly whether they understood English or French, but also the words used to talk about sex and sexually transmitted diseases, which may be unfamiliar or offensive for these women.<sup>167</sup> In addition, as one service provider said, “Handing out a translated pamphlet is not the only education needed, especially for people from traditionally oral cultures. There is a need for personal contact.”<sup>168</sup>

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<sup>166</sup> See, e.g., B Denizet-Lewis. Double lives on the down low. *New York Times Magazine* 3 August 2003, pp 28 ff.

<sup>167</sup> Casey House, pp 24-25.

<sup>168</sup> Ibid. at 25.



## Canada's obligations under national and international law

The *Canadian Charter of Rights and Freedoms* prohibits discrimination based on sex and guarantees equal protection of the law without regard to sex. The Charter applies to all levels of government, including provincial and municipal, and to all government acts (executive, legislative or judicial).<sup>169</sup> It does not apply to discriminatory acts by private citizens or institutions. The *Canadian Human Rights Act* (CHRA) of 1977 prohibits discrimination by federally regulated institutions in the private sphere. With respect to both the Charter and the CHRA, courts have interpreted HIV/AIDS to be a disability on the grounds of which people are protected from discrimination, along with sex. Provincial and territorial law covers discrimination complaints not in the mandate of the Charter or CHRA. The anti-discrimination statutes in all provinces and territories prohibit discrimination based on sex. While they do not include explicit prohibition of discrimination based on HIV status, all jurisdictions effectively ban such discrimination.

On paper, then, a woman living with HIV/AIDS in Canada has recourse to mechanisms that provide protection from discrimination based on both sex and HIV status. In practice, it is challenging for many individuals, particularly those who cannot afford legal counsel, to make use of these structures. The Legal Network has called for governments at all levels to strengthen access to legal services and representation for people living with HIV/AIDS, including adequate funding for legal aid services, support for community-based organizations that help people defend their rights, and campaigns to raise awareness of human rights and their protection in Canada.

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<sup>169</sup> This section relies heavily on R Elliott. Protection against discrimination based on HIV/AIDS status in Canada: the legal framework. *HIV/AIDS Policy and Law Review* 2005; 10(1): 20-31.

Canada is a party to the *International Covenant of Civil and Political Rights*, which also contains guarantees of non-discrimination based on sex.<sup>170</sup> Canada is also a party to the *Convention on the Elimination of All Forms of Discrimination Against Women* (CEDAW). CEDAW does not make any reference to HIV/AIDS, but its article 12 enjoins states to “take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services...”.<sup>171</sup> Like all state parties to CEDAW, Canada is required to report at least every four years on actions it has taken to respect the provisions of the Convention. Canada’s fifth and last report on CEDAW, all 252 pages of it, was considered by the CEDAW Committee in 2003. This voluminous work describes numerous federal and provincial initiatives aimed at advancing gender equality in all sectors. The federal part of the report contains one paragraph on HIV/AIDS, noting that women are a priority group for programs, and one paragraph citing the process of developing the Canadian Strategy on HIV/AIDS as an example of women’s participation in policy decision-making.<sup>172</sup> Accounts of provincial activities also included in this document did not generally feature HIV/AIDS, with the exception of Quebec’s section of the report, which highlighted measures put in place to ensure policy attention to women and children affected by HIV/AIDS (paragraphs 753-756). In this report, Canada also recounts its efforts to reduce poverty among women and violence against women.

Canada has also ratified the *Covenant on Economic, Social and Cultural Rights*, which guarantees the right of all people to the “highest attainable standard of health.” Article 2 of the Covenant specifies that the right to health and all other rights therein are conferred without discrimination based on sex and other criteria.<sup>173</sup> As with all rights in this Covenant, the right to health is meant to be realized by each state party “progressively...to the maximum of its available resources” (Article 2.1). That is, states are required only to demonstrate that they are moving in the direction of full realization of this right.

To clarify the concrete meaning of this right, particularly in light of the “progressive realization” provision, the UN Committee on Economic, Social and Cultural Rights issued a “general comment” on the right to health in 2000. General Comment no. 14 takes the broad view of determinants of health that is also reflected in Canada’s new Federal Initiative on HIV/AIDS – that is, it understands “health” to comprise social and economic determinants of health, including violence against women and other factors related to the subordination of women.<sup>174</sup> According to the General Comment, women should be regarded as a vulnerable group with respect to access to health services because of gender inequality, and states should, among other things, base

<sup>170</sup> *International Covenant on Civil and Political Rights*. United Nations General Assembly, Res 2200S(XXI). 16 December 1966.

<sup>171</sup> *Convention on Elimination of All Forms of Discrimination Against Women*. United Nations General Assembly, Res 34/180. 18 December 1979 at Article 12(1).

<sup>172</sup> Government of Canada. *Canada’s fifth report on the United Nations Convention on the Elimination of All Forms of Discrimination Against Women*, UN document CEDAW/C/CAN/5. 2002, paras 323, 333. Available at <http://daccessdds.un.org/doc/UNDOC/GEN/N02/364/78/IMG/N0236478.pdf?OpenElement>.

<sup>173</sup> *International Covenant on Economic, Social and Cultural Rights*. UN General Assembly Res 2200A(XXI). 16 December 1966, at Article 2.

<sup>174</sup> UN Committee on Economic, Social and Cultural Rights. General Comment No. 14: The right to the highest attainable standard of health, Art 12, E/C.12/2000/4, 11 August 2000, paras 10, 11.



program and policy development on gender analysis and collect or generate sex-disaggregated data in their monitoring of health service provision and utilization.<sup>175</sup> As the comment notes:

...there is a need to develop and implement a comprehensive national strategy for promoting women's right to health throughout their life span....A major goal should be reducing women's health risks, particularly lowering rates of maternal mortality and protecting women from domestic violence. The realization of women's right to health requires the removal of all barriers interfering with access to health services, education and information, including in the area of sexual and reproductive health.<sup>176</sup>

State parties to the *Covenant on Economic, Social and Cultural Rights* are required to report every five years on progress toward achieving its goals. Canada's most recent report to the UN on this Convention in 1998 featured extensive information on women's health but mentioned HIV/AIDS only in passing.<sup>177</sup>

In addition to these binding international treaties, Canada has endorsed the United Nations' *HIV/AIDS and Human Rights: International Guidelines* of 1997.<sup>178</sup> While not legally binding, the International Guidelines are highly regarded as a standard and widely used globally by policy-makers and advocates. Guideline 8 encourages states to "support the establishment of national and local forums to examine the impact of the HIV/AIDS epidemic on women," including consideration of women's roles "at home and in public life," women's ability to negotiate safer sex, "strategies for increasing educational and economic opportunities for women," and training health professionals and others involved in providing services to women on women's special needs.<sup>179</sup> The Guidelines further recommend that states "should support women's organizations to incorporate HIV/AIDS and human rights issues into their programming."<sup>180</sup>

The Declaration of Commitment that resulted from the UN General Assembly Special Session on HIV/AIDS in June 2001 enjoins UN member states by 2005 to implement national strategies that promote women's rights generally, "promote the shared responsibility of men and women to ensure safe sex," and "empower women to have control over...matters related to their sexuality to increase their ability to protect themselves from HIV infection."<sup>181</sup>

Canada reported on its progress related to goals in the Declaration of Commitment in 2002. In response to the question in the report guidelines "Does the country have a national policy/strategy for the promotion and realization of the rights of women

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<sup>175</sup> Ibid. at para 20.

<sup>176</sup> Ibid. at para 21.

<sup>177</sup> United Nations Economic and Social Council. Third periodic report: Canada. UN document E/1994/104/Add.17 20 January 1998, para. 330.

<sup>178</sup> *HIV/AIDS and Human Rights: International Guidelines* (note 68).

<sup>179</sup> Ibid. at para 38(e).

<sup>180</sup> Ibid.

<sup>181</sup> UN General Assembly. Declaration of Commitment on HIV/AIDS: Global crisis – global action, UN doc A/RES/S-26/2, 2001, para 59.

who are affected or at risk of HIV infection?”, the government responded that it did not have such a policy but that gender discrimination is prohibited by law.<sup>182</sup> The report also notes that Correctional Service Canada is “obliged by law” to provide gender-specific programming and that it had a draft strategy on incarcerated women and infectious diseases. A CSC official said in April 2005 that work on this strategy paper had been deferred, but that HIV/AIDS peer education and counselling support for women was available, and women in prison could also apply to the CSC Special Initiatives Program for funding for activities related to HIV and HCV prevention and education.<sup>183</sup>

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<sup>182</sup> Government of Canada. *2002 Report to the Secretary General of the United Nations on the UNGASS Declaration of Commitment on HIV/AIDS*. 2002, section 4.2. Available at [www.hc-sc.gc.ca/datapcb/iad/ih\\_ungass2-e.htm](http://www.hc-sc.gc.ca/datapcb/iad/ih_ungass2-e.htm).

<sup>183</sup> Electronic mail message from Mary Beth Pongrac, Correctional Service Canada, 13 April 2005.





## Conclusion and recommendations

Canada has made significant investment in fighting HIV/AIDS on the one hand and in improving the health and status of women on the other, but somehow these two efforts have not enjoyed a fruitful intersection. The new Federal Initiative and action plan for the public and private sector represent a crucial opportunity to build women's own capacity to fight HIV/AIDS by improving their economic, social and human rights status as well as ensuring high-quality HIV/AIDS services tailored to their needs. The evidence in this report indicates that making women and HIV/AIDS a policy priority requires special measures that arise from a recognition of women's overlapping vulnerabilities to both HIV/AIDS and human rights abuse – what Toronto-based Voices of Positive Women refers to as “intersecting forms of oppression.”

It is striking that the factors noted by the World Health Organization at the beginning of this paper are so pertinent to the situation of women in Canada living with and affected by HIV/AIDS. One might suppose that in putting together a fact sheet on “human rights, women and HIV/AIDS”, the WHO was especially concerned about countries with poor records of commitment to human rights and women's rights. Canada cannot be counted in that number. Canada has consistently put forward its commitment to human rights-based approaches to HIV/AIDS. And yet women living with HIV/AIDS in Canada appear to remain highly vulnerable to a wide range of human rights abuses.

Evidence in this report suggests that women in Canada face discrimination based on sex and other forms of discrimination in access to HIV/AIDS services and that conditions of work, poverty, abuse and social exclusion affect their HIV/AIDS risk and their access to care and treatment. Women are too often unable to realize their right to full information about HIV/AIDS testing and treatment. Programs available to them may be of inadequate quality simply because they are not designed with women in mind. Women disproportionately face violence in and outside the home, and – in the cases of sex trade workers and drug users – the violence they face and the HIV/AIDS risk that goes with it may be exacerbated by existing laws. Women who live with both poverty and HIV/AIDS are especially disempowered in their struggle against the disease.

The experiences recounted and the research summarized here indicate, in short, that with respect to HIV/AIDS, women in Canada are far from being able to enjoy the highest attainable standard of health. The fact that this paper relies on so many small-scale, older, qualitative studies is telling in itself. Research dollars, like adequate program dollars, have clearly not followed Canada's public commitment to a human rights-based approach to HIV/AIDS with respect to women.

The many and varied HIV/AIDS-related human rights abuses faced by women in Canada require urgent action on many fronts. We endorse many of the recommendations of the National Conference on Women of 2000, the large majority of which have not been addressed, but would like to highlight here a smaller number of actions that should be high priorities as resources are allocated for federal programs under the Federal Initiative and more broadly under the new pan-Canadian action plan.

- There is an urgent need for more qualitative and quantitative **program- and policy-oriented research** on human rights abuses and other challenges faced by women in Canada with respect to HIV/AIDS as well as new research on women's prevention, diagnosis, treatment, care and support needs. The surveillance system proposed in the Federal Initiative should, from the start, put high priority on producing sex-disaggregated data and data on determinants of HIV/AIDS risk and access to care, treatment and support that are especially pertinent to women's situations and doing so without undermining confidentiality and privacy of persons participating in surveys. Every effort must be made to include the most marginalized women in research and to base research on their lived experiences. Standardization of methods to ensure comparability of data across provinces and territories should be a priority. If the Federal Initiative and the broader work proposed in *Leading Together* are to realize their strongly stated promise of focusing on determinants of health, including for women, these determinants must be sufficiently articulated to inform programs and policies. Existing research should be compiled and analysed without undue delay so as not to hold up program development, while new research involving women in participatory ways should be developed. More women-centred research should, for example, allow the Public Health Agency of Canada or the Canadian Medical Association to complement existing CMA guidelines on treatment of HIV-positive pregnant women with a broader guide to state-of-the-art treatment of women living with HIV/AIDS. Any further development of a national HIV/AIDS research strategy must make women-centred research a high priority.

- There should be **more and better HIV/AIDS programs for women** under the Federal Initiative and under provincial and territorial aegis than was the case under the Canadian Strategy on HIV/AIDS. There should be funds in the Federal Initiative and at other levels of government **explicitly earmarked for HIV/AIDS prevention, diagnosis, care, treatment and support for women**, including during the period of scaling up of Federal Initiative funding through 2010. Provinces and territories in Canada that have not developed programmatic and policy guidelines on women and HIV/AIDS should do so as a matter of high priority, and the federal government should back up the rhetorical commitment in the

Federal Initiative with new resources for well conceived programs. HIV/AIDS programs targeting women should be based on gender analysis of determinants of HIV/AIDS risk and access to care, treatment and support.

- **Prevention programs** must take account of the complex factors that impede women's behavioural choices and should be based on analyses of the full range of social determinants of HIV/AIDS for women in Canada. One way to be sure this happens is to ensure funding for peer-driven programs so that women have access to service-providers and information that speaks credibly to them. Not just the content of information and counselling but the places where it can be found should take account of women's time and resource constraints. Research on social determinants of HIV/AIDS among women is sorely needed.

- **HIV testing** of pregnant women, whether in provinces that have adopted "opt-out" policies or elsewhere, must include informed consent, pre-test and post-test counselling and confidentiality of test results. Without these elements, opt-out testing should be regarded as inconsistent with the human rights of women. Health care providers should be trained toward this end. Post-test counselling for HIV-positive women should include state-of-the-art guidance on treatment and on which treatments are appropriate for pregnant women. The capacity to provide counselling of women by women from their community should be supported to the greatest degree possible. Testing policy should also account for the context of HIV risk for pregnant women, including the possibility of offering testing to sexual partners of pregnant women.

- **Treatment programs** should take account of constraints women face in child care, transportation, and other practical demands as well as the fears and stigma they may live with. More efforts must be made to be sure all women living with HIV/AIDS benefit from all available information about the specific effects of antiretroviral medications and other treatment on women. Women-centred organizations should have the resources to facilitate support groups, knowledge exchanges and other effective measures. Information that is specific to ethnic and cultural realities is needed. **Encouraging women's voluntary participation in drug trials should be a high priority.** The Public Health Agency of Canada should develop and oversee the implementation of targets for women's participation in drug trials. Government and other sponsors of drug trials should work closely with organizations representing HIV-positive women to mobilize women volunteers for these trials.

- Under the new Federal Initiative on HIV/AIDS, **Correctional Service Canada** will receive a major boost in funding for HIV/AIDS programs, culminating in an annual budget of \$4.2 million by 2009. With this level of resources, excellent programs reaching all women in federal custody are feasible and must be instituted, along with monitoring and evaluation that involves civil society and ensures transparency. Provincial correctional authorities should make HIV/AIDS

and other infectious disease services for women a high priority. CSC should establish a process of policy consultation with organizations representing women living with HIV/AIDS. CSC should generally establish a transparent process of consultation with community-based organizations to inform its decision-making related to HIV/AIDS.

- **Women who inject drugs** should be the explicit focus of programs of education and support. The safe injection facility in Vancouver and any other such sites that may be opened should permit assisted injection so as to allow women requiring this assistance to have it in a safe place while they can be supported with woman-centred information on safe injecting.

- Canada's commitment to empowering women in their struggle against HIV/AIDS must include **addressing poverty** and related basic needs among women. There is an urgent need for programs and policies that enhance the economic independence of women, including income support for women whose main work is caring for others and reduction of discrimination and lower pay standards for women who work in salaried jobs. Support to women caregivers is especially needed as many of them are likely to be without pensions and other employment benefits. As part of its new HIV/AIDS initiative, the federal government should lead the effort to find strategies to ensure that women living with or affected by HIV/AIDS are included in social service programs without short-changing other women. Poverty and HIV/AIDS among women should be a high-priority matter for intersectoral policy making at the federal, provincial and territorial levels and for the interministerial HIV/AIDS policy group formed as part of the Federal Initiative.

- **Curbing violence** against women and girls must become a more urgent priority of government at all levels. The link between violence and HIV/AIDS should be further studied, and research results should inform policies and programs. The links among violence, HIV/AIDS and the law, particularly for sex workers and drug users, should be made explicit in policy and program development processes. The federal government should provide to the parliamentary Subcommittee on Solicitation Laws a gender-based analysis of the impact of these laws on HIV/AIDS. The "bawdy house" and "communications" sections of the Criminal Code related to sex work should be repealed, and there should be a major review of the laws governing prostitution in Canada that would include systematic consultation with sex workers and groups that represent them.

- The availability of an effective **microbicide** will save the lives of women in Canada as well as in other parts of the world. Investment in microbicide research and preparation for registration and distribution of microbicides should be high priorities for governments in Canada at all levels.

- **Improving access to and effectiveness of human rights institutions** in Canada is crucial to enabling women and persons living with HIV/AIDS to call on legal protections against discrimination. Legal assistance services for persons living with HIV/AIDS and those vulnerable to the disease should be more available, and support is needed for providers of these services to have the capacity to address the needs of women.

- The “**global leadership**” component of the Federal Initiative on HIV/AIDS should include resources that would enable women’s organizations in Canada to network and share experiences with women living with and vulnerable to HIV/AIDS around the world.

The actions associated with these recommendations should figure in a coherent Canadian strategy for addressing HIV/AIDS among women, which should be the result of a sustained process of consultation with women’s organizations and women living with HIV/AIDS. With a new national HIV/AIDS initiative that involves all sectors and increased funding, it would be a scandal for Canada to have to say again to the United Nations in its next report on progress against HIV/AIDS that it has no formal strategy on women and HIV/AIDS.