Manifesto Backgrounder

Blueprint for Action on Women and Girls and HIV/AIDS

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INTRODUCTION

"Acquired Immunodeficiency Syndrome (AIDS) has killed more than 25 million people since it was first recognized in 1981, making it one of the most destructive epidemics in recorded history."[1] "[In 2005,] 2.8 million [people] lost their lives to AIDS."[2]

"An estimated 38.6 million people worldwide were living with [the Human Immunodeficiency Virus] HIV in 2005. An estimated 4.1 million became newly infected with HIV."[3] In 2005, 48% of all known HIV positive people were women over 15 years old, about 17.3 million people.[4]

"Of people living with HIV, only one in ten has been tested and knows that he or she is infected."[5] "In Canada, there were an estimated 58,000 people living with HIV infection, including AIDS, at the end of 2005. Of these, approximately 15,800 or 27% were not aware of their infection."[6] The immensity, and the dangerous public health implications, of the unseen pandemic are staggering.

"Three-quarters of all women (15 years and older) living with HIV are in sub-Saharan Africa… Women comprise an estimated 13.2 million—or 59%—of adults living with HIV in Africa south of the Sahara."[7] "HIV infection levels among pregnant women are 20%—or higher—in six southern African countries (Botswana, Lesotho, Namibia, South Africa, Swaziland and Zimbabwe)."[8] "[For example, in Swaziland]…HIV prevalence among pregnant women attending antenatal clinics rose from 4% in 1992 to 43% in 2004."[9] "In several southern African countries, more than 75% of all HIV positive young people are women."[10] "[I]n sub-Saharan Africa…[y]oung women aged 15-24 are between two to six times as likely to be HIV positive than men of a similar age."[11]

Around the world, women represent: 59% of all adults living with HIV in sub-Saharan Africa[12], 53% in the Caribbean[13], 47.5% in North Africa and the Middle East[14], 46.7% in Oceania[15], 30% in Latin America[16], 29.7% in South and South-East Asia[17], 28% in Eastern Europe and Central Asia[18], 28% in Western and Central Europe[19], 28% in East Asia[20] and 25.8% in North America[21].

"Physiologically…, during heterosexual sex, it is easier for the virus to be transmitted from male-to-female… A higher concentration of HIV is found in semen…; a greater volume of seminal fluid is transmitted…; and women have a much larger area of mucous membrane…through which seminal fluid can be absorbed… Additionally, women with a history of sexually transmitted infections are particularly physically vulnerable to HIV."[22] "Coercive sex can lead to lesions that increase risk and these vulnerabilities are dramatically more pronounced for girls and young women… [M]any estimates are in the range of two to four times higher risk for women."[23]

"The rights and status of women and young girls demand special attention… It is often women with little or no income who are most at risk [of HIV infection]. Widespread inequalities including political, social, cultural and human security factors exacerbate the situation for [them]."[24] Almost 70% of the world's poor are women. Women face varying degrees of labour discrimination throughout the world. They have more limited access to the labour market and the average pay for women is lower than it is for men. Globally, women average 15% of seats in parliaments, while they require at least 30% of political positions to exercise real influence on political processes.[25]

Marriage and women's fidelity does not guarantee protection against infection. "More than 40% of new infections in Cambodia and Thailand are among women whose only sexual partner was their husband… A study in India found that 90% of HIV infected women were married, monogamous and had only one sex partner in their lives: their husbands."[26]

"In Canada, women represent an increasing proportion of those with positive HIV test reports and, in 2005, accounted for 25% of positive HIV tests."[27] "Heterosexual contact and injection drug use (IDU) are the two major risk factors for women's HIV infection. The proportion of positive HIV test reports in women due to heterosexual contact has increased over time, from 47.5% for the period 1985-1999 to 58.3% in

2005. The proportion attributed to IDU varied between 27% and 40% during this period, with a slightly decreasing trend over time."[28] "Some studies found this risk to be greater among female than male IDU due to gender differences associated with injection practices…"[29] namely that women who require assisted injecting are at a greater risk for HIV infection.

"Canadian women's proportion of all reported adult AIDS cases has increased over time, from 6.6% before 1996 to 21.7% in 2005. Of all reported AIDS cases among women up to December 31, 2005, 67.1% were attributed to heterosexual contact, 24.2% to IDU and 8.5% to recipients of blood or blood products."[30]

"When compared to other age groups, the proportion of positive HIV test reports attributed to females is highest among [Canadian] youth. In 2005, women aged 15-29 years accounted for 35% of tests, which is an increase from 14.1% for the 1985 to 1995 time period."[31] "Women in other age groups (i.e. 30-39, 40-49 and over 50) accounted for approximately 20 to 25% of positive HIV tests."[32]

"In 2005, of positive HIV test reports and reported AIDS cases attributed to Aboriginal peoples [in Canada], women accounted for 60% and 38.9% respectively. HIV test reports show that IDU is a leading exposure category for Aboriginal peoples; from 1998 to 2005, IDU accounted for 58.9% of positive HIV test reports."[33] "Women represented 52% of positive HIV test reports attributed to the HIV-endemic exposure category between 1998 and 2004 and 42% of AIDS cases during the same time period."[34]

"[In the United States,] an estimated 83% [of women newly diagnosed with HIV/AIDS between 2001 and 2004] were African American or Hispanic."[35] "AIDS is the number one cause of death for black women aged 25 to 44 in the U.S., beating out heart disease, cancer and homicide."[36]

Despite the challenges posed by these statistics, "[t]here is ample evidence that HIV does yield to determined and concerted intervention. Sustained efforts in diverse settings have helped bring decreases in HIV incidence among men who have sex with men in many Western countries, among young people in Uganda, among sex workers and their clients in Thailand and Cambodia, and among [IDU] in Spain and Brazil. Now there is new evidence that prevention programmes initiated some time ago are currently helping to bring down HIV prevalence in Kenya and Zimbabwe, as well as in urban Haiti."[37]

In order for programmes and policies to be effective, they must be comprehensive. The Concise Oxford English Dictionary (9th edition) defines *comprehensive* as "complete; including all or nearly all elements, aspects etc." According to UNAIDS, "[a]chieving universal access [to prevention, care, treatment and support] will require co-ordination of different approaches. Prevention, treatment, care and impact mitigation goals will have to be pursued simultaneously, not sequentially or in isolation from each other. Countries will need to focus on programme implementation, including strengthening of human and institutional resources, and initiate strategies that allow for the greatest possible level of integration of services.

All of this must be done with great urgency. It forms part of a larger, more long-term challenge. Bringing HIV/AIDS under control will require tackling with greater resolve the underlying factors that fuel these epidemics—including societal inequalities and injustices. It will require overcoming the…serious barriers to access that take the form of stigma, discrimination, gender inequality and other human rights violations. It will also require overcoming the new injustices created by AIDS, such as the orphaning of generations of children and the stripping of human and institutional capacities. These are extraordinary challenges that demand extraordinary responses."[38]

Noluvo, an HIV positive woman from Cape Town, South Africa, shares her thoughts on HIV/AIDS. Please substitute the word God with whatever word, if any, you use for the divine, and apply whatever gender, if any, you conceive the divine to be.

> I'm not ashamed of being HIV positive, because I believe God gives you sickness for a reason. He gave it to me so that I could teach and educate the young ones not to fall into the trap that I

fell into. For those who are already HIV positive, my role is to let them know that there is a good, long life after testing positive. I have conquered AIDS; all that is left is HIV.

To those who are infected, I would like to say HIV is controllable and you can live your life to the fullest. To those who are affected, be supportive, do not discriminate or be judgmental because HIV affects us all. The only thing that we can do is stand up and fight this virus together and I'm certain we can conquer it.[39]

The Blueprint for Action on Women and Girls and HIV/AIDS is a Coalition of HIV positive women, Canadian and international HIV/AIDS organisations, women's health care advocates and organisations and health care providers. The Coalition seeks to ensure that governments and key stakeholders are held accountable for their response to the HIV/AIDS pandemic as it affects women and girls in Canada and around the globe.

The Blueprint Manifesto was launched across Canada and internationally on World AIDS Day, December 1, 2005. Updated annually, it is a living document, open to incorporate anything significant that was missed or to reflect any shifts in the epidemics. The Manifesto calls for a comprehensive, multi-stakeholder response to the HIV/AIDS epidemics in Canada and around the world.

Mirroring the Manifesto's structure, the Backgrounder is an arrangement of primary and secondary sources that support the Manifesto's issues and demands.

Immediate actions must be taken by all to stem the rapid spread of HIV/AIDS among women and girls and to effectively treat and support those who are infected and affected. They are our grandmothers, mothers, sisters, daughters, co-workers, friends, lovers and neighbours. As women and girls become increasingly infected and affected by HIV/AIDS, so do we all. Every one is responsible. Each one of us has a role to play.

BLUEPRINT FOR ACTION ON WOMEN AND GIRLS AND HIV/AIDS

This Blueprint Manifesto is a comprehensive strategy to stop the HIV/AIDS epidemic among women and girls (including transgendered women) globally that requires adequately funded, sustained and ongoing response from all stakeholders.

LEGAL, ETHICAL AND HUMAN RIGHTS

In many countries, women and girls have few, if any, legal rights and, even in countries where we do, our rights are trampled on daily.

> I went to India with Christian Aid to support and learn about the work of Sanlaap, a grassroots' organisation working with sex workers and children who had been trafficked for sexual exploitation. I visited one of their shelter homes for girls, called Sneha which means affection, where 48 girls ages 10 to 18 had been rescued by the police after being trafficked.
>
> Children who are rescued have to undergo a mandatory HIV/AIDS test; sadly 28 of the 48 girls in the shelter were already infected with the virus. I had a very upsetting conversation with a group of girls who told unspeakable stories of abuse, cruelty and betrayal. One of the girls was visibly upset and after much hesitation she described how men who look sick, emaciated and often covered with scabs would come to solicit their services at the brothel.
>
> She was sobbing when she told me how the children would beg the madam not to sleep with these men, because they feared they would contract [HIV]. However, the madam wouldn't hear their pleas and if they refused, they would be abused, beaten and burned with cigarettes. She was talking about herself but she didn't dare tell me because she would have had to admit that she had contracted [HIV]. In India and elsewhere, there is a myth that HIV can be cured by having sex with a virgin.
>
> If any of the girls succeeded in escaping and went to the police to seek protection, they were likely to be returned to the brothel by an officer bribed by the madam, and if they returned to their villages their fathers would refuse to take them back.[40]

"Protecting the human rights of women and girls also protects them from HIV [infection and the impact of AIDS]. More than any other disease in recent decades, HIV/AIDS has exposed the social inequities that make girls and women more likely to become infected, but women need more than rights in order to protect themselves. They need to know that they have such rights, that they can act in their own self-interest and that they will be supported by their communities and governments…

[In many parts of the world, women and girls' human rights] conflict with traditional practices such as early and forced marriage, female genital cutting (FGC) and 'widow cleansing' (a traditional practice in which widows are expected to have sexual relations, often with a relative of their late husband, in order to secure property within the family)…" All of these traditional practices violate women's human rights and increase their likelihood of HIV infection.[41] HIV infection risk is increased as young women are often married to older, more sexually experienced men who are more likely to be HIV positive; young wives are often unable to make demands of older husbands; and sexual protection is used less frequently.[42] FGC increases the likelihood of HIV infection due to possibly unclean instruments used during cutting, and increased likelihood of tearing and scarring during sexual intercourse or childbirth.[43] Widow cleansing puts women at risk of HIV infection from sexual contact. In the case where the husband died of AIDS, the "cleanser" is also at risk.[44]

"In many countries, women often have difficulty finding and keeping paid work or earning a wage equivalent to men's. In some regions, they are not allowed to inherit or own property or are discouraged from doing so, meaning that a woman without male protection has very few ways to support herself or her children."[45] The poverty induced by these situations leads women to desperate situations that greatly

increase their risk of contracting HIV, including remaining in abusive relationships, being unable to negotiate safer sex and having sex to survive.

"By failing to enact and effectively enforce laws on domestic violence, marital rape, women's equal property rights, and sexual abuse, and by tolerating customs and traditions that subordinate women, governments are enabling [AIDS] to continue claiming the lives of women and girls."[46]

"[W]hile women [and girls] 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 [prevention, testing and] treatment of HIV/AIDS… [W]omen living in poverty, women who inject drugs, Aboriginal women, [incarcerated women,] women…sex [workers], [young women and girls] and many women who come from countries where HIV is endemic are particularly vulnerable to HIV/AIDS, but vulnerability extends to all women who [are] not aware of their own risk and who [are] not able to control all of the elements that add up to safer sex or safer drug use." [47] "[T]he subordination that Canadian women face is most often a complex interaction of sexism and discrimination linked to other status (for example, recent immigrant, detainee, [street involved], ethnic or racial minority, sex worker, drug user, lesser income-earner, or worker in a caring profession not valued by the community) with direct [and indirect] consequences [on] their ability to protect themselves from HIV infection or to gain access to care, treatment and support services."[48]

HIV positive people in Canada have a legal obligation under criminal law to disclose their HIV status to sexual partners prior to engaging in sex that would put their partner at significant risk of HIV infection. This likely has a disproportionately negative impact on women, especially those women who are in abusive relationships. Current case law in Canada makes it unclear whether the fear of violence removes the legal obligation to disclose one's status to a sexual partner. Women are at a further disadvantage because condom use is overwhelmingly male-controlled. If an HIV positive woman wishes to have sex with a condom but is unable to get her partner to agree and the case goes to court, her desire to use a condom would be a matter of her word against his.[49]

Sexual and reproductive rights are human rights. Dozens of developing countries still face massive contraception shortages as a result of the United States' 2001 policy that denies U.S. development aid to international family-planning programmes that counsel abortion or advocate for changes to abortion laws. Many international family planning organisations, such as Marie Stopes International and International Planned Parenthood Federation, refused to sign the conditions of the policy and forfeited millions in family planning funding. This has led to the closure of health clinics throughout the developing world. As a result, many developing countries are gripped by an overwhelming shortage of birth control supplies. The U.S. has also stopped sending condoms to organisations that do not comply with the policy. As a result, men can't find condoms, which leads not only to unwanted pregnancies but HIV transmission. Women become unwillingly pregnant because they have run out of birth control, and if they are HIV positive, they risk passing HIV to their babies. Some turn to back-alley abortions, where HIV transmission again looms, and where their lives are often lost.[50]

In Ethiopia, four community health clinics closed due to the funding loss. Three of them were in the poorest parts of Addis Ababa and one was in a rural location. These one-room clinics staffed by a nurse offered vaccines to children, birth control to women, vitamin A supplements, malaria treatment and treatment for sexually transmitted infections (STIs) and HIV/AIDS.[51]

Because over 7,000-8,500 daily new HIV infections are among young people, adolescent sexual and reproductive rights need particular attention. "A frequent response to adolescents' vulnerability to HIV infection consists of attempts to 'keep them away from sex.' Teenagers may be denied school-based sex education because adults fear provision of such knowledge will promote sexual experimentation and activity. For the same reason, their ability to access sexual and reproductive health (SRH) services may be curtailed. Nevertheless, such restrictions have neither stopped teenagers from engaging in sexual activity nor protected them from exposure to [HIV infection or other STIs]… A first step towards effectively protecting adolescents from HIV/STI infection is to acknowledge that considerable numbers of young people around the world are sexually active… A second step is ensuring that these young people

receive [comprehensive] sex education so that they are informed about the reproductive processes[, …]the positive and negative consequences of sex[, and ways to prevent the negative consequences. A third step is to provide youth with the means to put knowledge into practice, by providing them with tools, such as condoms, to stop HIV and other STIs.]

It is…useful to situate a gender-based approach to examining SRH needs within a human rights framework… *The Right to be Free from Torture and Ill-treatment* includes the right to protection from violence, sexual exploitation and abuse. *The Right to Information and Education* relates to comprehensive information on the various factors that…affect sexual and reproductive health. *The Right to Freedom of Thought* includes freedom from texts, including religious texts, that are used to restrict access to SRH care. *The Right to Equality and Freedom from all Forms of Discrimination* includes the right to decide to be sexually active or not and with whom. *The Right to Life* means that no woman's life should be [at risk due to] pregnancy and unsafe abortion. *The Right to Liberty and Security of Person* implies freedom from female genital cutting, forced pregnancy, forced sterilization or forced abortion… *The Right to Freedom of Assembly and Political Participation* includes the right to advocate that communities and governments prioritize SRH rights."[52]

Historical events and colonization have led to deplorable systemic racism and to the violation of human rights of Aboriginal peoples [in Canada (First Nations, Métis and Inuit) and] across the world. This has had a severe impact on susceptibility to HIV, particularly for women and girls.

"In the 77 years between 1892 and 1969, generations of Aboriginal children in Canada were sent to government-sponsored residential schools run by the Roman Catholic, Anglican, United, Presbyterian and other churches. The physical and sexual abuse suffered by many of these children — along with the imposed alienation from families, communities and cultures — left scars that have been passed on from generation to generation. This legacy of abuse and intergenerational trauma is now well recognized."[53]

"Assimilation was the central goal of Canadian federal policy. In 1920, Duncan Campbell Scott, then Deputy Superintendent-General of the Department of Indian Affairs stated: 'Our object is to continue until there is not a single Indian in Canada that has not been absorbed into the body politic and there is no question, and no Indian Department'."[54]

"Canada was not alone in its attempts to assimilate Aboriginal people through the education system. While educational policies and the criteria under which children were removed varied, many thousands of Indigenous children in the United States and Australia were taken away from their families and placed in boarding or mission schools. Colonialism took different forms in New Zealand and Greenland: if judged by the lower socioeconomic and health status of Indigenous people compared to non-Indigenous citizens, the consequences of colonialism were equally damaging."[55]

"[A]t least two key areas have been impacted: damage to cultural identity, including loss of language, traditions and connection to family and community; and damage to the individual, resulting in shame, rage, lack of trust and engagement in negative coping patterns, including substance abuse, among others. Marginalization and isolation are further by-products of the legacy."[56] "The amount of grief work required to overcome such personal and cultural histories is immense, especially…considering inadequate support mechanisms or time to grieve before the next loss happens. In short, systemic discrimination, disruption, weakening of the family-based social system, internalized shame, combined with the multi-generational effects of physical and sexual abuse and addictions,…contribute to risk behaviours that lead to HIV infection."[57]

"Aboriginal people in Canada [continue to] suffe[r] from the ongoing effects of cultural denigration, racism, and colonialism. The legacy of [these] experience[s] is apparent: on average, Aboriginal people have higher rates of incarceration, higher rates of suicide, drug and alcohol use, more poverty, and poorer health than the non-Aboriginal population of Canada. These are risk factors for HIV."[58] "Aboriginal women are twice as likely to be poor than their non-Aboriginal counter-parts, and they are more likely to live in an environment where substance abuse and spousal violence are widespread… These

socioeconomic conditions are strongly associated with a positive HIV test result for Aboriginal women and they contribute to the creation of…living environments in which techniques used to simply survive often include high-risk behaviours such as rural to urban migration, homelessness, sex work, injection drug use, and alcohol abuse."[59]

> I got it from injection drug use. And the problem that I'm having today is that most of society doesn't want to accept HIV and AIDS as a reality. And yet they expect me to accept it. And I'm supposed to stand up and be proud as a woman and let other people know so that they can be scared of me and call me names and call me down and treat me bad. I really agree with what you're saying before about that we're not dealing with just the epidemic of HIV and AIDS, we're dealing with feelings and things that happened in the past, residential schools and physical, mental and sexual abuse because I've been through all of them… I refused to deal with it before and that's why I turned to using cocaine… I didn't know who to talk to and I didn't know how to tell other people what happened to me, what somebody else did to me. And this disease has forced me into a corner, into standing up and fighting for my life. It's been really difficult and I've been hiding for a long time.[60]

<u>WE DEMAND</u>:

- ***Leadership and immediate action from all levels of government globally, to create, implement and meaningfully enforce laws that prohibit human rights violations against women and girls, including institutionalized women and girls, and to protect all women and girls equally from human rights violations through the development, implementation and strong enforcement of laws, policies and practices.***

Between April and June 1994, an estimated 800,000 Rwandans were killed in the space of 100 days. "The…genocide…left Rwanda deeply damaged in numerous ways. It was a nation being rebuilt by women who, [due to their lack of inheritance rights,] were farming land they had no legal right to own. The 1999 Rwanda Inheritance Law is an effort to change this by giving widows the right to inherit their deceased husband's property and granting equal inheritance rights to male and female children. Despite the importance of recognizing girls' and women's rights in this area, implementation has been hindered by the fact that customary law still holds sway in parts of the country and women are disinherited. Rwandan human rights activists warn that a nationwide campaign to inform men and women about women's rights to own property is essential if the law is to have an impact.

Ultimately, implementation and enforcement are essential. The political will to implement laws that have been passed is critical to ensuring women's human rights. But political will is easily deflected… It has long been recognized that ensuring women's human rights is essential to growth and development. Now, with HIV/AIDS decimating nations, guaranteeing those rights is essential for survival. It is up to policy makers to ensure that these human rights have pride of place alongside more commonly acknowledged development goals."[61]

"It is a shame that a crisis of the proportion of HIV/AIDS is necessary to focus attention on human rights abuses of women and girls…, but it would be unconscionable for governments to miss this opportunity. …[G]overnments and donors alike must begin to see protection and fulfillment of the rights of…women and girls as a central strategy in the fight against HIV/AIDS. This means more than occasional rhetorical flourishes or poorly funded gender components in larger projects. It means real resources, real coordination across sectors and real participation by women in decision-making. Without this commitment, the conspiring forces of HIV/AIDS and gender inequality…will win the day."[62]

"Women, men and transgendered persons in prison are all at high risk of HIV transmission and poor access to support, care and treatment for HIV/AIDS… In several studies, HIV prevalence has been shown to be higher among incarcerated women than among incarcerated men in Canada."[63] "Conditions reigning in most prisons make them extremely high-risk environments for HIV transmission, leading them to be called 'incubators' of HIV infection, as well as of hepatitis C and tuberculosis… [I]n the United States it is estimated that women prisoners are 15 times more likely to be HIV positive than women in the

general population."[64]

"People retain the majority of their human rights when they enter prison, losing only those that are necessarily and explicitly limited because of their imprisonment. They retain such rights as freedom from cruel and inhuman punishment, and the right to the highest attainable standard of health and security of the person. Courts in many parts of the world have ruled that governments actually have greater obligations to prisoners than to the general public because governments are the sole source of essential services provided to prisoners, including health care."[65]

WE DEMAND:

- ***The creation of human rights bodies, supported by governments globally, that protect women and girls' rights with strong enforcement powers.***

One idea to protect women's and girls' human rights comes from Stephen Lewis, the United Nations (UN) special envoy for HIV/AIDS in Africa. He proposes that women and girls need their own UN agency. "[W]e could…mount an unbridled campaign to demand that gender equality be legislated and enforced..."[66]

"Where the rights and needs of women are concerned, the gap between rhetoric and reality remains a yawning chasm… On a daily basis, the UN should be identifying, investigating, documenting, and accusing those who are involved – especially governments – in the continuing, systemic discrimination against women."[67] "[I]t should be the role of the UN family to shame, blame and propose solutions, all the while yelling from the rooftops that inequality is obscene. Only then will change have a chance."[68]

"[He]…believe[s] a new agency could…be rooted in an amalgamation of the United Nations Development Fund for Women (UNIFEM), the UN Population Fund (UNFPA) and the Division for the Advancement of Women (DAW), currently placed in the Secretary-General's office. It would have to be headed by an Under-Secretary-General, and funded no less than the level of [United Nations Children's Fund] UNICEF; that is to say, something close to $2 billion a year."[69]

A problem with international agencies is also pointed out by Mr. Lewis: "It speaks volumes that so many countries feel they can ignore the prescriptions of [CEDAW] with impunity; there are simply no enforcement mechanisms…"[70]

This idea still requires a lot of analysis and consultation with women, particularly HIV positive women, from around the world. This level of consultation would be an opportunity to explore all available options to effectively deal with the issues of gender equality, human rights violations and HIV/AIDS.

Due to the lack of enforcement mechanisms by UN agencies, regional and national human rights bodies must protect and fulfill women's human rights with strong and effective enforcement powers.

WE DEMAND:

- ***Leadership and immediate action from all levels of government [in Canada and] globally to redress the impacts of colonization and racism that are fuelling this epidemic for Aboriginal people.***

"…[D]ecolonization [is] a process that involves addressing historic trauma and unravelling the tragic after-effects of colonization. Historic trauma theory argues that individuals can be traumatized by events that occurred before their birth. Thus, a relationship exists between history, the social, economic and political environments, and individual experiences. It follows that therapeutic approaches to healing that incorporate Indigenous history will more effectively address root causes. At the same time, many individuals need therapeutic help to heal from deeply personal wounds or to address depression, addiction or the effects of physical and sexual abuse… [H]ealing from historic trauma…brings history and culture together with personal healing in a journey that is both individual and collective in nature…"[71]

"Learning about the history of colonization, mourning the losses and reconnecting with traditional cultures, values and practices are becoming recognized stages of the healing process. Indigenous people in the United States, Australia[,] New Zealand [and] Canada are all addressing historic trauma, both at a theoretical level and within therapeutic practice…

Solid arguments can be made in favour of embedding healing practices in the specific cultures, traditions and languages of Indigenous people, nations, tribes and communities. At the same time, pan-Aboriginal approaches and the sharing of Indigenous healing traditions across cultures are growing phenomena… [N]o single approach is applicable across all nations and communities… [Further, s]pecific strategies are needed for Indigenous people who do not have strong cultural ties…

[M]any healing programmes incorporate, adapt and blend traditional and Western approaches. Traditional ceremonies, medicines and healing practices are being incorporated into the therapeutic process while Indigenous values and worldviews are providing the programme framework. Some core values, such as holism, balance and connection to family and the environment, are common to Aboriginal worldviews across cultures; others are clearly rooted in local customs and traditions."[72]

"Failure on the part of governments to formally recognize and affirm Indigenous rights and to accept responsibility for past policies aimed at assimilating Indigenous peoples is an impediment to healing, both symbolically and with respect to the development of policies and programmes that support individual and community healing."[73]

"The central lesson learned about promising healing practices is the immense value and efficacy of incorporating history and culture into holistic programmes based on Indigenous values and worldviews."[74] "While such approaches challenge governments that compartmentalize funding through departments (health, education, housing, etc), they are natural to Indigenous service providers."[75]

<u>WE DEMAND</u>:

- ***Immediate decriminalization of sex work by all governments globally and in Canada.***

"Sex workers have the same human rights as everyone else, particularly rights to education, information, the highest attainable standard of health, and freedom from discrimination and violence, including sexual violence."[76]

"[In Canada, p]rostitution means exchanging sex for money and other things of value (such as meals, housing, or drugs). Prostitution is legal in Canada and it is legal to be a sex worker[, b]ut it [i]s hard for sex workers actually to engage in prostitution without breaking the law and risking criminal charges. The *Criminal Code* makes almost every activity related to prostitution illegal and prohibits prostitution in almost every public or private place."[77]

"Sex workers (usually women) receive much harsher penalties than clients (usually men) do when they are convicted under the communicating section [of the *Criminal Code*]… According to information gathered over 30 years by Statistics Canada, women get sentenced to prison more often than men, get longer prison sentences than men, do not get probation as often as men [and,] if they do get probation, usually get twice as long, and are not offered diversion programmes such as "john school" nearly as often as men."[78]

"[M]any women in the sex trade face extreme risk factors daily, including violence of all kinds, sexual coercion and poverty. [S]tudies in Canada conclude that women sex workers experience more assaults, rapes and arrests than male sex workers and are more likely to be robbed. Lowman, who tracked violent crime against women sex workers in Canada through the 1990s, concluded that murders of sex workers were rising alarmingly."[79]

The criminalization of sex work "reinforces the stigma associated with prostitution and pushes sex workers to the margins of society. [This] reinforces attitudes that sex workers 'deserve what they get'

when they are beaten up or murdered, makes prostitution part of an illegal market and pushes people involved in prostitution and other illegal activities, such as the drug scene, together, creates an environment in which brutal forms of exploitation of sex workers can take root, creates a relationship of conflict between sex workers and police, means sex workers often have to work more to pay fines if they are charged and convicted, and makes it more difficult for sex workers to get other sorts of work because they have a criminal record."[80]

Furthermore, "laws criminalizing the sex industry reduc[e] the effectiveness of measures designed to prevent the spread of sexually transmitted diseases[, including HIV/AIDS]. The most successful means of achieving health outcomes for sex workers is peer-based education conducted through sex worker organisations."[81] This includes harm reduction measures for sex workers who are also injection drug users. "An ongoing study involving IDU in different areas across Canada found that, in 2003, about 40% of female IDU reported engaging in commercial sex work. It also showed that about 92% always used condoms with their male client partners, but almost a third never used condoms with their casual partners and condom use was infrequent with their regular partners."[82]

Decriminalization of sex work will facilitate HIV/AIDS prevention and treatment.

There is a direct causal link between violence against women and girls and the infection of women and girls with HIV/AIDS.

"Violence against women is a global health crisis of epidemic proportions and often a cause and consequence of HIV."[83] "At least one out of every three women has been beaten, coerced into sex, or otherwise abused in her lifetime, according to a study based on 50 surveys from around the world."[84] "Violence and the threat of violence dramatically increase the vulnerability of women and girls to HIV by making it difficult or impossible for women to abstain from sex, to get their partners to be faithful, or to use a condom. Violence is also a barrier for women in accessing HIV prevention, care, and treatment services."[85]

"The consequences of violence against women go far beyond immediate physical damage… Psychological damage, and the threat of further violence, erode a woman's self-esteem, inhibiting her ability to defend herself or take action against her abuser… Some of the long-term effects of violence… are abuse of alcohol and drugs, depression, other mental health disorders and suicide. The repercussions of violence against women reverberate throughout the family and community. Studies show that children exposed to violence are more likely to become both victims and perpetrators."[86]

"Violence against women is a fundamental violation of their human rights and is fuelled by longstanding social and cultural norms that reinforce its acceptability in society – by both men and women." "Growing evidence from around the world shows that a large proportion of women and girls are subjected to violence by family members, acquaintances and strangers." "Numerous studies from around the globe show the…links between violence against women and HIV. These studies demonstrate that HIV infected women are more likely to have experienced violence, and that women who have experienced violence are at higher risk for HIV."[87]

"Rape…is prevalent throughout the world… In the USA, it has been estimated that one in three women will be sexually assaulted in her lifetime… However, [rape] is greatly under-reported because of the stigma attached to it, and even more rarely punished… Estimates from France suggest that out of 25,000 cases of rape committed every year, only 8,000 are reported to the police."[88] A mid-1990's Vancouver, Canada study showed that convictions are rare: "of 462 cases reviewed, only 33% resulted in charges being laid and only 11% in convictions."[89] "The link between rape and HIV transmission is well documented… Repeated rape by a partner appears to be a particular risk factor for HIV. The overwhelming majority of rape victims…are women and girls."[90]

"Sexual violence against women—which can expose them to both HIV/STI infection and unwanted pregnancies—is an outcome of prevalent gender biases that imply women's sexuality is not their own to control; indeed, marital rape is still not seen as a crime in many countries. Much more needs to be done

to enable women to cope as survivors of violence, including expanding access to psychological care, legal aid, and medical care, including measures to deal with the consequences of sexual assault (post-exposure prophylaxis, emergency contraception and legal abortion)."[91]

Intimate partner violence, whether physical, sexual or psychological, is linked to HIV infection. Globally, between 10 and 69% of women report physical abuse by an intimate partner at least once in their lives. Between 6 and 47% of adult women worldwide report being sexually assaulted by intimate partners in their lifetime. Intimate partner violence and HIV intersect both directly and indirectly. The possibility exists of direct transmission through sexual violence. Indirectly, HIV may be transmitted by increased risk-taking behaviours by women who have experienced violence, by their reduced ability to negotiate condom use and by their partnering with riskier and/or older men. Further violence may be the consequence of being HIV positive.[92]

One result of the colonial legacy is that intimate partner violence is more common among Canadian Aboriginal women than non-Aboriginal women. "[They] were three times more likely than non-Aboriginal women to have been assaulted by a current or former spouse [in the period 1994-1999.]"[93]

Sexual violence increases in wars and other conflict situations. "Rape has been used as a deliberate strategy to brutalize and humiliate civilians and as a weapon of war or political power. It is likely that all forms of violence against women, including intimate partner violence, increase during conflicts and this may be linked to a ready availability of weapons, high levels of frustration among men and a general breakdown in law and order… In Liberia, towards the end of the five year civil war, 49% of women 15 to 70 years old who were surveyed reported experiencing at least one act of physical or sexual violence by a soldier or fighter… In the Democratic Republic of Congo, a Human Rights Watch report describes that the civil war has created a context in which abusive sexual relationships are more accepted and where many men – civilian or combatant – regard sex as a service easy to get by using force."[94]

"Such violence thrives because too many governments turn a blind eye and allow violence against women to occur with impunity. In too many countries, laws, policies and practices discriminate against women…and make them vulnerable to violence. In too many parts of the world, women are trapped in a cycle of poverty, which breeds violence. Too often gender roles and societal structures reinforce the power of men over women's lives and bodies. In too many communities, religious leaders and the media promote roles, attitudes and customs that seek to subordinate and subjugate women… Human rights are universal – violence against women has made human rights abuse universal."[95]

"[Our purpose] is not to portray women as victims and stigmatize men as perpetrators; it is to condemn the act of violence itself. That will require all of us to change, not only as organisations and institutions, but as individuals."[96]

<u>WE DEMAND</u>:

- ***Immediate development, implementation, and strong enforcement of laws, policies and practices by governments globally that prohibit violence against women and girls and their families. Law enforcement agencies charged with enforcing them must do so rigorously.***

"Using international human rights law as a framework for addressing violence against women presents a methodology for determining government obligations to promote and protect the human rights of women. It also points to the mechanisms available for holding ratifying governments to account if they fail to meet those obligations."[97]

There are numerous human rights documents that guarantee women the right to be free from violence: the International Bill of Human Rights (including the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights, and the International Covenant on Civil and Political Rights), the UN Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), the International Convention on the Elimination of All Forms of Racial Discrimination and the UN Convention on the Rights of the Child. General Recommendation No. 19 by the CEDAW Committee

defines violence against women as a form of discrimination and defines the rights and freedoms impaired or nullified by violence against women. The UN Declaration on the Elimination of Violence against Women, the Beijing Declaration and Platform for Action, and the UN Convention against Transnational Organized Crime are further international commitments applicable to human rights law.

The Rome Statute of the International Criminal Court, finalized in 1998, has been a significant development in addressing crimes of violence against women. Several forms of violence against women, including rape and trafficking, were included in the Rome Statute as war crimes and crimes against humanity. In addition, gender-based persecution was included as a crime against humanity. It contains progressive provisions relating to the participation and protection of [survivors] and witnesses…and for reparation of [survivors of violence].

There are also regional treaties and agreements which have been drafted and adopted by governments, such as the Inter-American Convention on the Prevention, Punishment and Eradication of Violence against Women and the African Union's Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa.[98]

"States are required under international human rights law to 'respect, protect and fulfill' human rights… [G]overnment officials, or those acting with the authorisation of the state, must not commit acts of violence against women… States must also protect women's rights… [by instituting] laws, policies and practices that protect [survivors] of violence, provide them with appropriate remedies and bring the perpetrators to justice… Finally, states must fulfill these rights, by ensuring the appropriate infrastructure to support these laws, policies and practices, and to render them effective. Moreover, states must report on the progress of laws and policies designed to eliminate discrimination and violence against women and modify features that are ineffective."[99]

"The recent adoption of an Optional Protocol to CEDAW… offers women a direct means for seeking redress at the international level for violations of their rights under CEDAW. It is a mechanism that allows [survivors] of violations or those acting on their behalf (including non-governmental organisations) to make a complaint directly to the CEDAW Committee when all domestic avenues of redress have been exhausted or are ineffective… It also allows the CEDAW Committee to undertake investigations of systemic abuses."[100]

Impunity must be rooted out. "In response to growing activism, many countries have engaged in legal reform processes, as well as in training members of the criminal justice system. However…even when the law prohibits violence against women, social institutions, cultural norms and political structures in every country sustain and maintain it, making the law a dead letter. Impunity remains the norm because of inadequate implementation, monitoring, documentation and evaluation of the law."[101]

"The greatest challenge to [violence against women] has come from individual women and women's groups who have stood up and spoken out, often at the cost of their lives. They have organized themselves to demand justice. They have called for their human rights to be respected, protected and fulfilled. Thanks to their efforts, important breakthroughs have been made in terms of international treaties and mechanisms, laws and policies. But these achievements continue to fall dismally short of the real needs because the promises they contain remain just that. International treaties and mechanisms are only useful if they are implemented properly. Otherwise they are simply hot air. Laws and policies only offer protection if they are respected. Otherwise they are just printed words. Human rights are real only if they provide real equality and equal protection… [T]he challenge still remains to bring about change that will make a real difference in the lives of women."[102]

"Violence against women is universal but not inevitable. A recent World Health Organisation report points out that communities that condemn violence, take action to end it and provide support for survivors, have lower levels of violence than communities that do not take such action. In a comparative study of 16 countries, researchers found that levels of partner violence are lowest in those societies with community sanctions (whether in the form of legal action, social approbation or moral pressure) and sanctuaries (shelters or family support systems)."[103]

Internationally, world leaders, organisations and individuals must publicly pledge to make the Universal Declaration of Human Rights a reality for all women. All governments should ratify and implement CEDAW and its Optional Protocol, without reservations. They should ratify the Rome Statute of the International Criminal Court, and adopt implementing national legislation to end impunity for violence against women, including in armed conflicts. They should agree on an international Arms Trade Treaty to stop the proliferation of weapons used to commit violence against women.[104]

UN and regional organisations should assist countries to develop action plans to end violence against women and set up monitoring mechanisms[105], maximize coordination between HIV/AIDS and violence prevention and mitigation services, and remove barriers to integrating these essential services. They must provide funding and technical support to civil society groups seeking to stop violence against women and to reduce its impact on access to HIV/AIDS services, and provide funding for research and evaluation of programme strategies that reduce violence against women and its links to HIV. Bilateral and multilateral funding mechanisms must increase support for programmes that address the relationship between violence against women and HIV.[106]

Nationally, governments must abolish all laws that facilitate impunity for the rape or murder of women, criminalize consensual sexual relations in private, restrict a woman's right to choose her partner and restrict women's access to reproductive health care and family planning. They must adopt and enforce laws that protect women, ensure that violence in the family is treated the same as assaults in other contexts, and that rape and other violence against women is criminalized. National and local authorities must fund and support measures to enable all women to live free from violence, such as civic education programmes, training, and systems to support and protect [survivors] of violence and women's human rights defenders. Governments, financial institutions and corporate actors must counter women's impoverishment by ensuring equal access to economic and social rights, including food, water, property, employment and social entitlements and by safeguarding social safety nets, particularly in times of economic stress and dislocation.[107]

National governments must integrate strategies to reduce violence against women into national HIV/AIDS plans, and strategies that increase access to HIV/AIDS services within violence prevention efforts must be developed and funded. They should also ensure that organisations addressing violence against women are represented on national HIV/AIDS councils and other relevant fora to ensure that the link between violence against women and HIV is effectively addressed within the design and implementation of national HIV/AIDS programmes.[108]

Locally, communities must work to create a supportive environment for women that addresses violence by building community structures and processes that protect women, provide assistance to survivors of violence, raise awareness about violence against women, and ensure that women human rights defenders are free to carry out their work. Women must have equal access to decision-making in local governments and community structures. Religious bodies and traditional and informal authorities must denounce and desist from any action that encourages or tolerates violence against women and must respect women's human rights.[109] Health services, including those focused on HIV/AIDS, provide an important and potential entry point for identifying and responding to women who experience violence and cross-training is essential.[110]

Each individual must challenge negative images of women and resist mass media, advertisements and school curricula that reinforce discriminatory attitudes and perpetuate violence against women and girls. Communities should work with those most affected by violence to develop and implement local strategies to address violence against them.[111] Educational entertainment that informs young people about social and health issues, including violence and HIV, should be developed.[112]

RESEARCH

Women and girls of all cultural backgrounds and life experiences are effectively absent from the HIV/AIDS research agenda and research decision-making at all levels.

"[W]omen have historically been excluded from participating in…research because of concerns about: damaging either the fœtus or the woman's reproductive capacity; harming the newborn through breast-feeding; the influence of hormonal cycles; or failing to recognize that diseases and conditions might affect men and women differently… Such exclusions retard the advance of knowledge, deny potential benefits to women and…expose women to heightened risk. For example, the exclusion of women as research subjects raises serious concerns regarding the generalizability and reliability of some research data; and research data on drug dosages, the effects of devices, treatments, cultural norms, moral development and social behaviour obtained from male-only studies likely will not be generalizable to women. As a result, data for women are lacking and often must be inferred, despite important differences that may render such inferences inaccurate, and treatments or interventions based thereon more harmful. The inclusion of women in research is essential if men and women are equally to benefit from research. It advances both the commitment to justice and to rigorous scholarly and scientific analysis."[113]

"[A]lthough 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. HIV/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. Consensus guidelines on the care of HIV positive pregnant women were not published until 2002, and pregnant women are arguably the highest-priority women for clinicians."[114]

"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… 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. In 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 Retroviruses and Opportunistic Infections, of over 900 clinical science abstracts, 40 were specifically about women or gender, of which about half were related to pregnancy or mother-to-child transmission."[115]

The 2004 UNAIDS South Asia Inter-Country Team and UNIFEM South Asia Regional Office rapid scan showed that "the understanding of gender and HIV/AIDS in the region has been limited to information accessed at ante-natal clinics provided by public health systems. In a context where access to such services is itself severely affected by power relations of gender…this has meant that the way in which the gender dimensions of the epidemic have been understood and addressed have largely been limited to the experiences of women in their reproductive roles [who can access the clinics]. In addition, and to a limited extent, the experiences of women in sex work have been addressed through targeted interventions, but this approach has limitations as large numbers of people may place themselves at risk, but not identify themselves with "high-risk" groups. As such, a large number of women…have not been significantly addressed in the understanding and response to the HIV/AIDS epidemic."[116]

In Canada, there is a lack of human rights analysis of HIV risk factors for women. "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."[117] "Research dollars, like adequate programme dollars, have not followed Canada's public commitment to a human rights-based approach to HIV/AIDS with respect to women."[118]

"Despite the fact that Aboriginal women are over-represented in HIV/AIDS statistics, there is still very little gender-specific, Aboriginal-specific research being done. Little is known about the experiences of Canadian Aboriginal women living with HIV/AIDS, the circumstances that lead to their infection, what happens to them after diagnosis, the circumstances that lead to treatment (or not), and the experiences with and of their families and children."[119]

The fact that "two of Canada's largest provinces, Ontario and Quebec, do not routinely collect and/or report ethnic information on their positive HIV tests" [120] reveals the lack of attention paid to understanding the true picture of Canada's HIV/AIDS epidemics and developing culturally and linguistically relevant strategies to effectively address them. The Public Health Agency of Canada continues that "this is a limitation for conducting surveillance on ethnicity as these two provinces together account for over two-thirds of all positive HIV test reports. These two provinces also include two large urban centres, namely Toronto and Montreal, that are ethnically diverse. The omission of these provinces impedes the ability to accurately describe the epidemic among ethnic sub-groups."[121]

Globally, "[d]isaggregation of data by sex and age for use in shaping programme interventions remains a challenge. According to the UNGASS Report in 2003, only 21% of countries were able to provide disaggregated data on core indicators."[122]

<u>WE DEMAND</u>:

- ***Comprehensive research on HIV/AIDS that specifically addresses questions of importance to the health of women and girls from all cultural groups and life experiences, impacted by this epidemic, including questions regarding prevention, diagnosis, care, treatment and support. This agenda must be developed by relevant stakeholders including researchers, research funders, HIV+ women and girls, institutions doing research and research coordinating bodies.***

"There is no single HIV/AIDS epidemic. Even within a country itself, epidemics can be extremely diverse… [S]trategies need to address the diversity of epidemics and must be evidence informed, through accurate epidemiological and behavioural information."[123]

"Whether intentional or inadvertent, the exclusion of some from the benefits of research violates the commitment to societal justice. A commitment to distributive justice in research [, such as articulated in the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS),] imposes obligations on, and concerted activities by, researchers, institutions and Review Ethics Boards (REBs). All have important roles to play in ensuring a fairer distribution of the benefits and burdens of research. As the following TCPS articles make clear, distributive justice imposes on researchers and REBs a duty not to act in a discriminatory fashion. Sometimes it may impose positive duties to include disadvantaged groups in research involving human subjects.

Article 5.1

a. Where research is designed to survey a number of living research subjects because of their involvement in generic activities… that are not specific to particular identifiable groups, researchers shall not exclude prospective or actual research subjects on the basis of such attributes as culture, religion, race, mental or physical disability, sexual orientation, ethnicity, sex or age…

Article 5.2

Women shall not automatically be excluded from research solely on the basis of sex or reproductive capacity.

…[W]omen have been automatically excluded from research on the basis of sex or reproductive capacity. Article 5.2 rejects such an approach as a discriminating and unethical use of inclusion or exclusion criteria. Rather, in considering research on pregnant women, researchers and REBs must take into account potential harms and benefits for the pregnant woman and her embryo, fœtus or infant. The ethical duty to assess the harms and benefits of research thus extends to the special case of research involving pregnant or breast-feeding women."[124]

Australia's *Human Research Ethics Handbook* states that "[w]omen should not be excluded from study populations on the basis of gender or reproductive stage… [I]t is not always clear who is to make the judgment that the risk to woman or fœtus is unacceptable. Human Research Ethics Committees

(HRECs) should consider the participation of the women concerned, or representative community groups, in the decision-making process."[125]

The following statements apply to women's research in general and different populations in particular:

> Recommendation #13 – Researchers and funding agencies must take a greater interest in Aboriginal women, children and families.
>
> Research efforts, in collaboration with community-based organisations, need to be focused on Aboriginal women living with HIV/AIDS. Qualitative as well as quantitative data are required…
>
> A National Conference on Aboriginal Women and HIV/AIDS must be organized. This will highlight the issues that Aboriginal women must deal with, act as an impetus for further research, and give HIV positive women an opportunity to network with each other and with researchers.[126]

"[A]s far as possible, *all* HIV positive women should be offered meaningful opportunities to be actively involved in all medical, socio-economic or other research which is undertaken concerning women living with the virus, regardless of age, religion, culture, socioeconomic background, parental status, length of knowledge of HIV positive status, or sexuality. [HIV positive women] are uniquely placed to contribute [their] knowledge, skills and experience to all research conducted on this issue… [O]nly through involving HIV positive women in all stages of research will a clearer picture emerge of the issues facing HIV positive women. This information is long overdue [and] critical if we are together to find a way of reducing the effects of the virus on women, and ultimately eradicate the spread of [HIV] to future generations."[127]

<u>WE DEMAND</u>:

- ***Involvement of women and girls from all cultural backgrounds and life experiences in all HIV/AIDS research that is proportional to our representation in this global epidemic.***

"[D]istributive justice…imposes duties neither to neglect nor discriminate against individuals and groups who may benefit from advances in research."[128]

"The most pressing problems in women's health often involve women from marginal or vulnerable social groups. When these women are included in research, a different set of ethical considerations need to be considered so that the research process itself does not increase their disadvantages… [R]esearch issues identified as particularly important for women's health commonly involve vulnerable groups, including women exposed to violence and occupational health risks and women enduring the exacting demands of their roles as carers. These problems are aggravated by the negative stereotyping to which all women are subjected, as well as by low socioeconomic status. Such difficulties are further compounded [for] Aboriginal women or women from non-English speaking backgrounds… When assessing research proposals involving vulnerable groups of women, HRECs should consider the ways in which these women will be required to participate in the research. Study designs should use methods of data collection that minimise intrusion into the women's lives. The informed consent process then becomes the means of addressing any remaining, unavoidable intrusion(s)."[129] Some examples of research techniques that minimise intrusion into women's lives include offering a wide variety of times that suit women's needs, having childcare offered on-site, and allowing women to report from home.

For African and Caribbean women living in Toronto, "[r]esearch needs to explore the needs of girls and young women, the context within which infection occurs and look for accurate epidemiological markers to determine target groups within communities."[130] "More research needs to be done to document the status, prevalence and impacts of the HIV/AIDS epidemic on African and Caribbean women and their communities. Epidemiological markers can show which subsets of these populations are affected by the disease and can also determine access to care, treatment, support and prevention. Understanding facilitators of vulnerability/risk reduction can provide useful evidence upon which to base effective programmes and services."[131]

"[G]iven the lack of information about the health of women in general, and vulnerable groups of women in particular, there is a need for researchers to review the way in which they disseminate research findings. Dissemination of results in peer-reviewed literature adds to the stock of scientific knowledge but has little direct impact on vulnerable communities who act as research participants."[132]

"There is a need for community involvement when developing resources and outreach strategies to maximize use of programmes[,] services [and] resources."[133]

"More research and programme evaluation on a wide variety of Aboriginal HIV/AIDS issues by trained community based Aboriginal researchers is necessary. Research areas include injection drug use among Aboriginal people, limited antiretroviral use, alternative health maintenance practices, new and alternative models of addiction treatment [and] models of mental health services." [134] Taking into consideration the context of colonial legacy experienced by Aboriginal peoples will help find the roots of problems. Addressing the ongoing effects of the legacy will help propose the new models and solutions required.

<u>WE DEMAND</u>:

- ***Ownership and direction by women and girls research participants in all research.***

While the following two guidelines do not specifically name women and girls from diverse backgrounds, their language can be applied to them.

"The emphasis on the partnership between governments, communities and researchers has been central to Australia's successful HIV/AIDS strategies. In this context, emphasising a separation between the interests of researchers on the one hand and research participants on the other is counter productive. The problem is particularly acute in social research, where much of the most successful Australian HIV/AIDS related social research has been conducted on the basis of a reflexive relationship between researchers and researched… [R]esearch priorities have been determined in relation to the individual and collective needs of the populations and communities most affected by HIV/AIDS[.] [R]esearch findings have come out of the experience of individuals and communities[.] [R]esearch results have been taken up at community level in responding to the impacts of HIV/AIDS, in turn creating new research needs in a cyclical process. The ethical implication of these research paradigms is that role clarification should be valued, but disinterest and objectivity may hinder the research process more than help it."[135]

"Ownership, control, access and possession (OCAP) is a political term that is being used by Aboriginal Peoples to highlight the right to self-determination in the area of HIV/AIDS research… It indicates that Aboriginal peoples have relinquished the notion of "being researched", and have taken up the call to become active participants in the research process." Ownership means that there is authority over the research process and the products of research. Control means that Aboriginal people are in charge of the process. Access means that research findings will be shared and used by the community where the research is done, to help improve programming and policy in the research area. This involves translation and interpretation of terms as needed. Possession means the right to possess the findings of research.[136]

<u>WE DEMAND</u>:

- ***Monitoring of all research to ensure that it is conducted ethically, adheres to culturally specific research principles, with HIV+ community members from the communities being researched serving on all Ethics Review Boards.***

"Justice connotes fairness and equity. Procedural justice requires that the ethics review process have fair methods, standards and procedures for reviewing research protocols, and that the process be effectively independent."[137]

"For the expertise essential to effective ethics review, REBs…need to involve academic or community members from representative groups, or advisory committees drawn from relevant communities."[138]

"[O]nly through involving HIV positive women in all stages of research will a clearer picture emerge of the issues facing HIV positive women… [A] 'stakeholders' research advisory group' which consists of diverse members of the community [or communities] concerned and those who wish to conduct the research with them[, should be created]. The idea is that *all* those concerned should be viewed as researchers."[139]

Because of women's and girls' historical, socio-economic and cultural inequality women and girls do not control HIV/AIDS research methods.

The fact that, historically and to this day, women of child-bearing age are excluded from drug trials, that women of all ages are excluded due to concerns about female hormones, that women are excluded due to sex in inclusion/exclusion criteria, that the young and the elderly are excluded, and that some researchers continue to fail to recognize that diseases, conditions and drugs may affect men and women differently[140] reveals that women do not control HIV/AIDS research methods and are absent from the history of their development. The fact that "[m]uch current research also ignores the effects of the research process itself on the psychological and economic well-being of the individual women concerned" is further evidence.[141]

Women involved in research methods write policies like the following:

> **Collection of gender-specific data**
> It is the responsibility of researchers to systematically collect gender-specific data as part of every clinical trial in order to identify any clinically important differences between men and women that may, or may not, exist. Regardless of whether or not they are proven to exist, it is still a biologically plausible possibility that they do and that the effects of both the body on the drug, and the drug on the body, may be significantly different between men and women.
>
> **Women's reproductive capacity**
> Women involved in clinical trials should be viewed as women first, rather than as potential mothers, just as men are seen as men and not just potential fathers.[142]

<u>WE DEMAND</u>:

- ***Development of women and girls-initiated forms of HIV/AIDS prevention, particularly microbicides, including a dissemination plan which will allow affordable, free and unlimited access to these methods.***

"Globally, the vast majority of HIV infections are transmitted through heterosexual sex. If men and women had an equal say in their sexual relations, then abstinence, condoms and mutual monogamy, the so-called 'ABC approach', could make a considerable dent in the incidence of HIV transmission. However, the unequal gender relations that characterise most relationships, particularly in cultures where the epidemic is growing the fastest, result in women and girls having little control over the conditions under which sexual intercourse takes place. This limits the effectiveness of current prevention strategies, as is clearly evidenced by the growing number of new infections each year. A female-initiated HIV prevention strategy is needed – one that does not interfere with sex and is not necessarily contraceptive. Microbicides would be one such HIV prevention strategy."[143]

"Microbicides are products that could be applied topically to the vagina to reduce the transmission of HIV during sexual intercourse. Microbicides could take the form of a gel, cream, film, suppository, sponge or vaginal ring that releases the active ingredient gradually, or even a new formulation or delivery method yet to be invented."[144] Microbicides are currently in development and are still being tested. With sufficient funding, they are expected to reach the market in approximately five to seven years.

"Male and female condoms, when used correctly, remain the most effective means for preventing sexual transmission of HIV and other infections. Condom promotion efforts have led to their increased use…and their use and distribution should be encouraged. However, it is also vital to appreciate that…condoms

may not always be used. Within marriages and long-term relationships, condom use remains low and is unlikely to rise… Condoms block both HIV and conception, and are not a viable option for couples who wish to conceive. In other situations, couples may not be able to use them because they indicate a lack of trust… [P]revailing gender norms often mean that women lack the power to convince male partners to use condoms. In studies [from] Papua New Guinea, Jamaica and India, women reported that bringing up…condom use, with its…implication that one of the partners has been unfaithful, can result in violence. Economic dependence and fear of sexual violence also often compel women and girls to accept unsafe sex… There are also cultural and religious oppositions to condom use to consider. The limits of these current prevention strategies illustrate the need for an expanded range of new prevention options, particularly ones that women can initiate or control."[145]

"The female condom is the first woman-initiated barrier method that protects against HIV and STIs as well as pregnancy… In addition to benefiting women's sexual and reproductive health, the female condom contributes to women's sense of empowerment, especially if supported by education and informational activities. Unfortunately, access to the female condom has been somewhat limited and its uptake has been negatively affected by a number of factors including cost, which remains the major barrier to access. The public sector must play a role in making female condoms widely available and affordable, as well as generating awareness of their benefits. Guaranteeing accessibility requires a sustained commitment to providing ongoing support for users and providers, through informational materials, promotional messages and training."[146]

"No one prevention technology is sufficient to address the HIV/AIDS pandemic. [M]icrobicides [are a] part of what should be a full spectrum of HIV prevention options. While male and female condoms are the only tools currently available to prevent sexual transmission of HIV, we envision the toolbox expanding as other options are proven safe and effective." The full HIV prevention spectrum could include: [prior to exposure] behaviour change, vaccines, pre-exposure prophylaxis, sterile syringe access and drug addiction treatment, STI screening and treatment, [point of transmission] male and female condoms, anti-retroviral (ARV) therapies to reduce mother-to-child transmission, microbicides, cervical barriers, [treatment] ARV therapies, opportunistic infection therapies, basic care/nutrition and post-exposure prophylaxis.[147]

"[M]icrobicides can only make a lasting impact on the AIDS epidemic if they are widely accessible in heavily affected [communities and] countries… The International Partnership for Microbicides (IPM) seeks to identify products for development and testing that inherently cost little to produce. IPM has already established all necessary agreements with commercial partners to ensure its right to make products available in developing countries. IPM is working to identify regulatory strategies to facilitate swift review of new microbicides by regulatory agencies in key developing countries as well as the United States and Europe. And IPM is collaborating with donors and international organisations to establish adequate financing mechanisms to support global microbicide access."[148]

The Global Campaign for Microbicides, through its active engagement of community members, states that "[t]he microbicides field is committed to expediting the widespread availability of any effective product, reaching those who are most in need first… Most microbicide leads currently in testing are projected to be relatively inexpensive – similar to the cost of a condom… In most cases, the applicators and shipping cost more than the product itself. Efforts are underway to reduce these costs even further through innovative designs and identifying capacity to manufacture products in developing countries."[149]

Because poverty is a factor fuelling HIV transmission for women and girls, and since poverty is a factor in women and girls' inability to negotiate condom use, all relevant stakeholders must plan to make women-initiated prevention tools, including microbicides, available without cost to women and girls unable to afford them. Women and girls who are geographically distant must also be considered.

STIGMA AND DISCRIMINATION

All women and girls with HIV/AIDS face profound stigma and discrimination in many aspects of their lives. Stigma and discrimination is compounded by factors including racism, sexism, classism, heterosexism and poverty. These forms of stigma and discrimination fuel epidemics globally.

> I remember clearly one day when my son was playing together with my neighbour's child, the parent of the child drew him away abruptly. The parent shouted to the child "Don't play with him any more. His mother was infected with [HIV]." I didn't know what to say. It might be anger. It might be a sense of helplessness. I was worried about my son. I moved to other places to work and my son has transferred to another school.[150]

"Stigma refers to an unfavourable 'mark' placed on a person or group, and [is] reflected in attitudes, beliefs and policies directed toward that person or group by others because of a perceived characteristic of the person or group. Stigmatization is a social process of devaluation… [It] is expressed in fear, avoidance, shame, blame, and judgment. The stigma associated with HIV/AIDS is complex. It draws out what people think and how they feel about an incurable virus, sickness, and death; about sexual activity and sexually transmitted disease; about homosexuality, sex work, drug use, gender, and race/ethnicity."[151]

"Stigma taps into existing prejudices and patterns of exclusion and further marginalizes people who might already be more vulnerable to HIV infection. HIV stigma and the resulting actual or feared discrimination have proven to be perhaps the most difficult obstacles to effective HIV prevention. Stigma and discrimination simultaneously reduce the effectiveness of efforts to control the global epidemic and create an ideal climate for its further growth... Fear of stigma can also dissuade people living with HIV from playing a vital front role in HIV prevention efforts. Stigma prompts people to act in ways that directly harm others and deny them services or entitlements—actions that take the form of HIV-related discrimination. Stigma prevents many people from negotiating safer sex, taking an HIV test, disclosing their status to their partners or seeking treatment, even when prevention services are made available."[152]

"[W]hen women test positive, they are 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… [T]hose living in poverty…may have well-founded fears of abandonment or rejection by persons on whom they are economically dependent…"[153]

"HIV/AIDS is feared in many Aboriginal communities and, as a result, stigma and discrimination against those who are HIV positive is frequent. The Aboriginal Nurses Association of Canada points out that 'the worst punishment that can happen in an Aboriginal community is banishment and this is happening to people with HIV/AIDS.'"[154]

For many women living in Toronto from Africa and the Caribbean, "the cultural and religious beliefs/practices of these communities perpetuat[e] gender inequality as an acceptable norm… [T]hese… inequalities translate into power imbalances… [S]ome women were reluctant to access services for fear of being stereotyped and discriminated against."[155] " Women expected that they would experience stigma and discrimination and were willing to do anything to avoid it. The fear of being ostracized and isolated contributed to denial, silence and secrecy."

> You are dead if you have HIV. There is no level of discrimination, if it is out you are finished, nobody will touch you, nobody will touch your children…you are as good as dead and you can't discriminate against a dead person. People who are discriminated against are people who have a chance to be discriminated against; with this women don't have a chance, they become a cast out.[156]

"Systemic discrimination based on race, gender, culture, religion and other characteristics of difference have continually marginalized African and Caribbean women and their communities. These differences intersect with HIV-related stigma and discrimination to further compound their ability to access and utilize HIV/AIDS information and services. African and Caribbean women felt at the mercy of different systems within the family, community and the larger systems when they were accessing care. It took women many years to learn how to navigate these multiple systems, if at all, to access services."[157]

Human Rights Watch's document "A Test of Inequality: Discrimination against Women Living with HIV in the Dominican Republic" reveals:

> [When I lived at home] I had to clean the bathroom whenever I used it, I had to wash my plates separately. [My mother] told me not to touch my children. She threw me out. My uncle gave me some land where I built a shack… without water, without light, without a [constructed] floor…[158]

"[Gabriela López worked at a free trade zone job.] "They did a test. They did not tell me what it was. They just took my blood, right there. Then they fired me. I had been working for three months." In the hotel industry, she said the company apparently relied on hearsay to guess her HIV status and then fired her… López now maintains herself and her children through random jobs. "Day after day I have this difficulty, are they going to accept me or not… My son says 'Mommy, I want a cookie," but I don't have anything."[159]

"Yolanda Pie did not return for regular prenatal checkups after she was subjected to HIV testing without consent at her three-month checkup at a public hospital in Santo Domingo in 2003:

> When I went back with labour pains, there was no time for a cesarean section, he [the doctor] turned his back on me [and said] "I don't want to be infected." When the baby was just about to fall on the floor, he caught him underneath… They did not clean me or anything. It's as if you are a dog.[160]

<u>WE DEMAND</u>:

- ***Implementation by governments globally of public education and awareness campaigns to end stigma and discrimination against women and girls with HIV/AIDS.***

"Domestic law in the Dominican Republic prohibits the administration of HIV tests as a condition for work, but the law is not implemented, and many workers Human Rights Watch spoke to did not even know the testing was illegal."[161] Laws are passed, yet no one knows of the law or their rights, social mores hold sway, and impunity rules. Sustained and informed public education and awareness campaigns are important parts of the solution.

In order to change public attitudes and gain greater public support for HIV positive people [and] those vulnerable to HIV, political and community leaders must make public statements of support for HIV positive people or those vulnerable to HIV. They must speak out against intersecting forms of stigma and discrimination affecting people living with HIV/AIDS [and] vulnerable to HIV, including discrimination against Aboriginal people, gay, lesbian, bisexual and two-spirited people, ethnic minorities, immigrants and refugees, people on low income or social assistance, people who use drugs, sex workers, women, prisoners and trans people. Governments must fund national and community organisations to conduct year-round campaigns with strong local community involvement to change negative attitudes towards HIV positive people [and] those vulnerable to HIV.[162]

Non-stigmatizing, informed media coverage of HIV/AIDS, HIV positive people and people vulnerable to HIV is needed. National and community organisations must be funded to develop programmes, staff, tools and training to develop media relations, inform media coverage of issues affecting their populations and respond to media misrepresentations. A review of media coverage of HIV/AIDS suggests that the most effective journalism integrates the following three elements: the perspectives of people living with

HIV/AIDS, the larger cultural, economic and political context which shapes the epidemic and the science of HIV.[163]

In response to the epidemics of HIV, hepatitis C and overdose deaths in the Downtown Eastside of Vancouver, the Vancouver Area Network of Drug Users (VANDU) was formed in 1997. Their earliest work involved setting up drug use discussion groups in the heart of the open drug scene in Oppenheimer Park. They used popular education techniques that determined needs and responded with facts about overdoses, HIV rates and accompanying epidemics. Members learned about public health initiatives implemented elsewhere like supervised injection sites, heroin prescription, low-threshold methadone maintenance and housing for users. It was from these meetings that members became involved in local decision-making and politics. VANDU brought hundreds of policy makers, healthcare professionals, researchers and others face-to-face with the realities of the Downtown Eastside. Through public presentations and back alley tours, VANDU actively countered the stereotypes that perpetuate the stigmatization of people who inject drugs.[164]

The Sonagachi AIDS Project, a successful sex workers project in Kolkata, India, "carried out extensive advocacy campaigns and individual lobbying with policy makers and opinion builders at all levels to persuade them of the legitimacy of the Project's approach, and to convince them that sex workers were entitled to equal rights concerning health and life. The Project targeted local opinion makers, elected representatives, ministers, political party officials, human rights organisations, women's groups, trade unions, bureaucrats, intellectuals, other NGOs, and bilateral and multilateral donor agencies. As a result, the Project gained public recognition and wide acceptance, which gave it enough credibility to challenge some of the fundamental structural constraints that marginalize sex workers and increase their vulnerability."[165]

"HIV/AIDS should be made visible to African and Caribbean women and their communities [in Canada] to raise awareness and reduce stigma and discrimination against those infected and affected while acknowledging the impacts of the epidemic on individuals, families and their communities at large."

> I've been doing work around HIV and AIDS for about 12 years…this is something that has impacted me, my life and my family. It is something that lives in my community… I've become an example and some sort of role model. If I am able to offer a model of communicating about HIV/AIDS it makes it easier for someone else. For example, when we're doing HIV/AIDS education with newcomers who are in various programmes that are available for them, they are very reluctant to talk about this thing. We know that on the continents all of us have lost loved ones…It's up to us to say that it's been present in our lives, and here is how I'm trying to deal with it, here's how I'm trying to address it…We have to protect ourselves because there is so much stigma around HIV/AIDS…So many of us are coming from a history of displacement, a history of conflict and strife, and we're trying to make the best of a brand new opportunity in Canada…For many of the brothers and sisters that are living with HIV themselves, it is that voice of courage that we need to keep alive and pass on.[166]

<u>WE DEMAND</u>:

- ***Inclusion of HIV/AIDS education as a subject of all school curricula mandated by governments and educational institutions.***

"Education about HIV/AIDS is necessary for reducing stigma and discrimination – twin pillars that support the continued spread of the disease and undercut care and support for the infected and affected… Formal school education and non-formal programmes for youth reach into communities and families in ways that no other services do… There is a growing body of evidence that education empowers individuals to take decisions that are more life-affirming."[167]

It is necessary to "[p]rovide comprehensive HIV/AIDS and sexual education information beginning in primary schools [and to i]ntegrate HIV/AIDS education into curricula, with special attention to the needs of girls. This should include addressing gender norms."[168]

A Plan of Action for Canada to reduce HIV/AIDS-related stigma and discrimination recommends "culturally sensitive, age-appropriate, accurate and non-judgmental education and support for children and youth with regard to their sexuality and the sexuality of others, sexual activity and the skills to practise sex safely, HIV/AIDS and sexually transmitted infections, alcohol and other drugs, and how to reduce their potential harms, and human rights in the context of the HIV/AIDS epidemic (e.g. the rights of people living with HIV/AIDS, of women and girls, of gay, lesbian, bisexual and transgendered people, of people who use drugs)." Provincial and territorial departments of education must ensure that schools deliver curricula on these subjects. *A Plan of Action* also recommends that departments of health ensure that HIV prevention is integrated into existing sexual and reproductive health services for youth and adults, and that harm reduction is integrated into existing information, outreach and treatment services for youth and adults who use drugs.[169]

Women's Health in Women's Hands makes the following recommendation to reduce HIV/AIDS-related stigma and discrimination: "[i]ncrease education for the general population to raise awareness regarding the consequences of stigma and discrimination and to promote an attitude change about HIV/AIDS and cross-cultural groups."[170]

WE DEMAND:

- ***Leadership from the private sector to develop, implement, sustain and strongly enforce policies prohibiting discrimination against HIV+ employees in the workforce, or those who have HIV+ family members, and to provide ongoing HIV/AIDS awareness campaigns for their employees.***

Governments, employers and unions must "promote and enforce laws and policies protecting the rights of people living with HIV/AIDS and those vulnerable to HIV in the workplace."[171] "Policies and education about HIV/AIDS in the workplace are meant to ensure that the rights of HIV positive people—including the right to freedom from harassment and discrimination and the right to accommodation—are protected, respected and fulfilled."[172]

"Programmes to educate workers about HIV/AIDS and protect the rights of people living with HIV/AIDS have an effect not only in the workplace but also in the community. They can help to prevent HIV transmission and to improve care, treatment and support of people living with HIV/AIDS. Recognizing this, the International Labour Organisation (ILO) has developed a *Code of Practice on HIV/AIDS and the World of Work* [that] was developed and has been endorsed by governments, employers and workers…"[173] Its key principles include recognition of HIV/AIDS as a workplace issue, non-discrimination, gender equality, healthy work environment, dialogue, cooperation and trust between employers, workers and governments, prohibition of HIV/AIDS screening as a requirement for employment, confidentiality, prohibition of HIV status as cause for termination, fulfillment of accommodation, prevention, care and support.[174]

"Workplace education, routine precautions, post-exposure procedures, and voluntary testing – not mandatory testing – should be the standard practice in occupations where there is risk of exposure to potentially infectious bodily fluids."[175]

WE DEMAND:

- ***Public acknowledgement by all levels of government[in Canada] of the direct causal relationship between colonization, stigma and discrimination and Aboriginal women and girls' susceptibility to HIV/AIDS. Governments must redress this historical legacy by providing resources to Aboriginal peoples, including First Nations, Inuit and Métis, to develop appropriate solutions.***

What differentiates discrimination against Aboriginal people living with or affected by HIV/AIDS is the history of oppression and social disintegration experienced by First Nations, Métis, Inuit [and other Aboriginal] communities."[176] The combination of racism, homophobia, and AIDSphobia means Aboriginal people living with or affected by HIV/AIDS are one of the most marginalized groups in Canada."[177] Add women and girls' overall marginalization and Aboriginal women and girls are further ostracized.

Due to the continuing effects of the legacy, "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… A project…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 [from] families and communities devastated by spiralling cycles of multi-generational abuse, the long-term effects of the legacy of cultural disruption and residential schooling.'"[178]

Aboriginal people living with or affected by HIV/AIDS experienc[e] discrimination from a variety of sources, "from band administrators and community members to health practitioners and the public at large. Discrimination is often associated with misunderstandings or lack of knowledge about HIV/AIDS, is often reinforced by other social problems and other forms of discrimination, and finds its roots in a history of oppression and cultural disintegration."[179]

"Two issues with respect to discrimination and the epidemic need to be distinguished: the personal impact of discrimination on Aboriginal people living with or affected by HIV/AIDS, and the way that discrimination contributes to the prevalence of risk factors for HIV infection among Aboriginal people. The systemic and individualized discrimination experienced by Aboriginal people generally, and by Aboriginal people associated with HIV/AIDS in particular, contributes to the disproportionate impact of HIV/AIDS on Aboriginal communities."[180]

"Misinformation about HIV/AIDS contributes to discrimination both within Aboriginal communities and in the rest of Canada. Education efforts must continue in First Nations, Métis, and Inuit communities. It is widely recognized that education is a crucial component in both addressing the discrimination that often accompanies HIV/AIDS and in reducing the spread of HIV. It is important, however, that HIV/AIDS education initiatives for Aboriginal people take into account broader health and social issues, including the impact of a foreign culture on community practices and traditions, the effects of residential schools and assimilationist policies, and the high incidence of other health problems."[181] HIV positive Aboriginal women must participate in the development and implementation of HIV/AIDS education in order to represent and address their particular challenges and points of view.

"The involvement of Aboriginal leaders in HIV/AIDS issues is important to help overcome homophobia, AIDSphobia, and reluctance to deal openly with sexuality and lifestyle issues… Leadership is also necessary at the provincial and federal government levels to address HIV/AIDS issues for Aboriginal people"[182]—particularly since different national, provincial/territorial and Aboriginal governments and policies create jurisdictional barriers.[183] These jurisdictional barriers can be overcome through leadership, including the commitment to sustained funding, involvement of Aboriginal leaders, community members and HIV positive people, including women, and coordination across jurisdictions.

"Failure on the part of governments to formally recognize and affirm Indigenous rights and to accept responsibility for past policies aimed at assimilating Indigenous peoples is an impediment to healing, both symbolically and with respect to the development of policies and programmes that support individual and community healing."[184]

"Due to their personal experience with HIV/AIDS, Aboriginal AIDS workers and Aboriginal people living with or affected by HIV/AIDS have a particularly significant contribution to make to the development of a legal, educational, and health-care framework addressing HIV/AIDS issues." Denise Lambert, a community educator in Alberta, provided an example of the benefits of Aboriginal control and expertise in the design and delivery of HIV/AIDS programmes and services. "Lambert's personal knowledge of the communities she visits allows her to convey HIV/AIDS information in a way that responds to the needs of each community and respects their views and traditions. The expertise of Aboriginal people in issues affecting their communities is the greatest resource in the effort to control the spread of HIV and reduce HIV/AIDS-related discrimination."[185]

DIAGNOSIS AND TREATMENT

Women and girls lack access to testing, are denied testing, are under-diagnosed and are diagnosed too late for successful treatment interventions. This is exacerbated by racism, classism, misogyny, and other forms of discrimination against women and girls.

"Data from the most recent demographic surveys in several [sub-Saharan African] countries indicate that less than 10% of people in these countries know whether they have been infected with HIV. Much wider knowledge of serostatus is essential if many millions of people are to access treatment, care and prevention."[186] Since three-quarters of the world's infected women live in this region, the number of women not accessing HIV testing is immense.

"Even where treatment is free, basic costs like diagnostic tests or transportation to the hospital may be out of reach of women."[187] "Brazil has universal health care and runs one of the world's most successful anti-HIV programmes… Nevertheless, many rural women are still underserved… 'In some states, 90% of pregnant women don't go for prenatal care because it's too far off. So you're not bringing women into prenatal care and therefore you're not testing them and introducing them to HIV programmes.'"[188]

"Women in Canada have been shown to be diagnosed with HIV later in the course of their disease than 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."[189] "[They] face a number of barriers…:

- There is still a perception that only men who have sex with men, drug users, and sex workers are at risk for HIV. This has prevented women from seeking testing. It has also led physicians not to offer testing to women whom they do not perceive to be at risk for HIV.
- Some women have even been refused testing by their physician on the assumption that they are not at risk, or have been required to answer questions about drug use and sexual activity before they are given access to a test…
- …Women who are not pregnant or of childbearing age have found it difficult to access HIV testing.
- Women often live in situations of abuse and economic dependence and are fearful of the potential repercussions of testing. Women who test HIV positive may experience negative consequences that most men who test positive do not have to deal with – one study showed that 52% of women who tested positive feared their partners would leave them, and 12% expected to be assaulted – many were indeed subjected to violent acts by their partner.[190]

"Because of the inadequacy of health care services for Aboriginal women as well as a history of sexism and racism in government services, [LaVerne Monette, coordinator of the Ontario Aboriginal HIV/AIDS Strategy,] said [that] 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.'"[191]

"Aboriginal people face greater barriers to accessing HIV testing than other Canadians. In some parts of the country, an Aboriginal person may have to travel long distances to get tested… Further, many communities are visited by a health nurse only sporadically… Because reserves are small communities, people may be reluctant to use the local health centre due to concerns about confidentiality. Mainstream facilities in cities often do not take into account cultural differences between Aboriginal and non-Aboriginal people, making these facilities less accessible to Aboriginal people."[192]

"[T]here is a distinct lack of Aboriginal women-specific information on HIV testing and treatment options. Many Aboriginal women find out their HIV status when they become pregnant or develop complications during pregnancy. This increases the risk of mother to child transmission because it reduces the window of opportunity for…treatments to be effective… [M]ore than 1/3 (38.6%) of Aboriginal women receive treatment late in their pregnancy (in the third trimester or during labour/childbirth) compared to 9% of non-Aboriginal women. When Aboriginal women seek HIV tests outside of pregnancy, research shows that

they test significantly later than non-Aboriginal women for HIV. 75% of HIV tests for Aboriginal women who tested positive were administered late in the development of the infection, compared to 45.2% of non-Aboriginal women."[193]

WE DEMAND:

- ***Appropriate laws, policies, practices and services for women and girls experiencing violence and for their families.***

"Many women risk being subjected to violence and abuse upon disclosing their HIV status, especially when they are the first to be diagnosed and are blamed for bringing the virus into the household. "When women are infected with HIV they often face physical and emotional violence," said Ludfine Anyango, a woman living with HIV and the national HIV/AIDS coordinator of ActionAid Kenya." A report on HIV and partner violence in Dar es Salaam, Tanzania showed that a serious barrier to disclosure for women is fear of a violent reaction from male partners, that HIV-infected women are at more risk of partner violence, and that many women lack autonomy in decisions about HIV testing and are compelled to seek permission from their partners.[194]

"A report [from] Cambodia pointed to fear of domestic violence as a contributing factor in the low numbers of women accessing voluntary HIV counselling and testing services at antenatal clinics. A multi-country WHO review found that fear of violence was a barrier to HIV disclosure for an average of 25% of participating women, with rates reaching as high as 51% in Kenya. A study in Uganda found that women were often powerless to access AIDS services because their husbands physically attacked, threatened, and intimidated them."[195]

As mentioned previously, the threat of violence is a deterrent to women testing in developed countries like Canada and not just in developing countries. "The broader problems of abuse and economic dependence of women need to be addressed to create a climate in which women will be less fearful of the potential consequences of testing."[196]

In order to help meet the challenges of women experiencing violence, health workers should be trained to recognize signs of gender-based violence and to provide appropriate counselling and referral services to social, legal and community-based support groups. Women should be trained and employed as health care providers to increase the confidentiality and comfort level of women and girls seeking diagnosis and/or treatment. [C]ouple counselling should be encouraged to better ensure the involvement of male partners.[197]

Law enforcement and judicial personnel, as well as educators and health care providers, should receive expanded training on the link between gender-based violence and HIV/AIDS in the enforcement of women's and children's rights, and in investigating and prosecuting sexual violence, child abuse, domestic violence and violence against sex workers.[198]

WE DEMAND:

- ***Culturally and linguistically relevant testing sites with services provided by health-care providers trained in HIV testing protocol, including comprehensive pre- and post-test counselling, voluntary testing and informed consent.***

> When my results came back positive, I was completely unprepared for that result because I went into total shock. After leaving the clinic I got into my car to drive home but soon found I had driven for miles in the wrong direction. After I finally got home I got out of my car to find my trousers were soaking wet, I'd literally wet myself whilst driving. I went into a period of 'psychological death' for five months after which I made a conscious decision to get up and 'live'.[199]

"Since 2004, WHO and UNAIDS policy has recommended that an HIV test be routinely offered to people in all clinical and community-based health care settings in which HIV is prevalent and antiretroviral

therapy is available. In all cases, people must retain the right to refuse the test and give informed consent to be tested, and confidentiality must be ensured."[200] "Unless testing protocols adequately address the need to protect women's rights to informed consent and confidentiality, women will face dangers in their homes and communities."[201]

"There is widespread agreement in Canada and in most other jurisdictions that HIV testing should generally only be undertaken with the voluntary, informed and specific consent of the person being tested... Nevertheless, research studies and anecdotal evidence show that HIV testing without obtaining *specific* informed consent is widespread. Physicians and hospitals have performed HIV tests without obtaining such consent, relying instead on the implied consent to treatment and blood tests that hospital patients typically provide."[202] This is particularly frequent for pregnant women during prenatal care, due to so-called "routine" tests.[203] "There is widespread agreement that quality pre- and post-test counselling are essential components of HIV testing… [However, b]oth anecdotal evidence and research studies reveal serious inadequacies in current counselling practices." A Toronto study revealed that 43% of women received no counselling at all and only 7% received both pre- and post-test counselling.[204]

"Voluntary counselling and testing (VCT) is the entry point for treatment of HIV/AIDS as well as for prevention… The goal of VCT…is to ensure that those who test positive receive counselling about stigma and the impact of HIV as well as about antiretroviral treatment (ART). In order to achieve this, ART must be made…available and counselling services must…be improved and increased. Women should be able to discuss their fear of violence if they disclose a positive status and receive referrals for help. Adolescent girls particularly need access to confidential counselling and care. Currently, many cannot be tested or receive treatment unless a family member gives permission. Counselling also helps clients adhere to treatment regimens."[205]

"Anonymous HIV testing sites should be made available at sites where African and Caribbean women [living in Toronto] feel comfortable accessing services. In addition to providing diagnostic services, providers need to ensure that women are prepared to deal with a positive HIV diagnosis…[and] that they understand how HIV can be prevented... [Further, the] development of mechanisms to support and facilitate effective disclosure of HIV status in ways that ensure women's safety and well-being [is needed.] Mechanisms should include supportive counselling for family members of the affected women.[206] Language barriers must also be overcome. "Research participants indicated they also knew of incidents where a male partner who was acting as a translator would not relay information about the woman's HIV positive status in order to prevent her from being suspicious about his own status."[207]

"Federal, provincial, territorial, and Aboriginal government health providers, and Aboriginal AIDS organisations and others in the Aboriginal community should work together to develop accessible options for HIV testing… Mobile HIV testing units [and other programmes to reach isolated communities and individuals] should be examined for their potential to help overcome some of the barriers to accessing testing."[208] These would also need to take into consideration concerns regarding confidentiality.

<u>WE DEMAND</u>:

- ***Implementation, maintenance and enforcement of laws and policies that prohibit mandatory testing of all women and girls, including pregnant women.***

"Initially, in the face of a rapidly growing HIV/AIDS epidemic in Canada, [there were] calls for mandatory testing... People…searched for concrete solutions, and the notion of mandatory testing – coupled perhaps with forced segregation of people with HIV – had…appeal. Calls for mandatory testing became a fairly common political response to HIV/AIDS, partly because they create the appearance of taking a strong stand against the threat of AIDS. Early in the epidemic, some recommended testing all members of so-called "high risk" groups... However, the proposals were rejected because it was recognized that:

- it is a high-risk activity, not identification with a group that has a high seroprevalence rate, that causes HIV transmission;

- a mandatory testing programme would face obvious problems in identifying members of the targeted groups; and
- mandatory testing of these groups would have increased discrimination toward them, and given everybody else a false and potentially dangerous sense of security…

"[T]he World Health Organisation (WHO) has stated "mandatory testing and other testing without informed consent has no place in an AIDS prevention and control programme… There are no benefits either to the individual or for public health arising from testing without informed consent that cannot be achieved by less intrusive means, such as voluntary testing and counseling." The WHO continued by saying that "public health experience demonstrates that programmes that do not respect the rights and dignity of individuals are not effective" and that it is therefore "essential…to promote the voluntary cooperation of individuals rather than impose coercive measures upon them.

Testing programmes that do not require and secure an individual's informed consent can be damaging to efforts to prevent HIV transmission – and are therefore not in the interest of public health – for the following reasons:

- Because of the stigmatization of and discrimination directed at people with HIV, individuals who believe they might be infected tend to go "underground" to escape mandatory testing. As a result, people at highest risk for HIV infection may not hear or heed educational messages about prevention.
- Testing without informed consent damages the credibility of health services and may discourage people needing services from obtaining them.
- In any testing programme, there will be people who falsely test negative, so mandatory testing can never identify all people with HIV.
- Mandatory testing can create a false sense of security, especially among people who are outside its scope and who use it as an excuse for not following more effective measures for protecting themselves and others from infection.
- Mandatory testing programmes are expensive, and divert resources from effective prevention measures."[209]

On April 5, 2006, the Indian state of Goa announced plans for mandatory premarital HIV tests on couples. Dormant provisions of law in Goa still permit the forced testing and isolation of people suspected of being HIV positive. The introduction of mandatory testing in Goa would run counter to national HIV/AIDS policy, which encourages voluntary testing based on informed consent.[210]

Despite Canada's past decisions against mandatory testing, calls for targeted mandatory testing programmes…continu[e]. They most frequently involve pregnant women, newborns, prisoners, persons accused or convicted of sexual assault, sex trade workers, health-care workers, patients, and immigrants.[211]

Immigrants and refugees are subject to mandatory HIV testing to apply and qualify for permanent status in Canada. As a result, Toronto-based women from countries in Africa and the Caribbean, over-represented in the Ontario epidemic, avoid HIV testing. Furthermore, the health-care institutions in their countries of origin were often considered corrupt, and the women continue to question the trustworthiness of Canadian health-care:

> Even if you've got an illness, you're going to try to hide it… you don't want to jeopardize you're your [immigration] status. You have a suspicion of institutions because back home institutions are really corrupt. You don't want to go into an agency because you are afraid that if you admit that you have health concerns that there is going to be an immigration car outside waiting for you.[212]

"[A] law mandating HIV testing of pregnant women would…violat[e] [her] equality and her "security of person"… Voluntary testing programmes that have been well designed and implemented have been

effective. Voluntary testing maintains a woman's relationship of confidence in her physician… [C]ompulsory HIV testing…heighten[s] the existing mistrust of the public health system in communities disproportionately affected by HIV, driving some women away from care. Finally, in contrast to a policy of compulsory testing, a policy of voluntary testing is respectful of the autonomy of the woman, treating her as a person in her own right, rather than as a means to an end…"[213]

"Compulsory testing of sex workers…is detrimental to health outcomes as it creates a false sense of security in clients and workers. Clients believe that a sex worker is free of STIs because she/he has been tested and are more likely to request sexual services without the use of prophylactics. Mandatory testing of sex workers does not assist them in avoiding sexually transmitted infections, as client's sexual health status is unknown. In addition, test results are unreliable due to the 'window period'… Further, by promoting the use of compulsory testing as a legislative tool to allay community fears only perpetuates stereotypes of sex workers as diseased."[214]

<u>WE DEMAND</u>:

- ***Compulsory education of all health-care providers about women and girls and HIV/AIDS as part of their professional training.***

"Education and training directed at increasing doctors' awareness of the potential vulnerability of women to HIV should be undertaken. Many women will not be reached by public education. For these women, a doctor's office may be the only place where they have the opportunity to receive appropriate information about HIV and testing options."[215]

"College and universities providing professional education to health-care professionals should include, as mandatory components of their curricula, training in counselling principles and techniques, and on HIV/AIDS (including psychosocial issues related to HIV/AIDS)."[216]

Women's Health in Women's Hands recommends that " service providers need to have an understanding of the various social and individual factors discussed in [their] report that interact simultaneously to prevent or increase the rates of HIV infection. These factors also influence the medical and non-medical care for those infected or affected by the disease… [C]urrently funded service…[must] ensure language specificity and cultural appropriateness… There should be cognizance of the various social factors that create unique challenges for African and Caribbean women living with HIV/AIDS."[217]

"[To better address Aboriginal peoples, including women and girls, g]reater physician training and support is needed to ensure physicians are providing appropriate care to patients… Mentoring programmes should be encouraged. Increased access to [expertise] and evaluation of the barriers to implementing training and care guidelines [are] required."[218] Further, relevant associations should develop "cultural sensitivity training for health professionals to equip [healthcare providers] with appropriate skills to communicate about HIV[/AIDS] with Aboriginal women…"[219]

"In India, the Society for the Protection of Youth and the Masses reported a reduction in stigmatizing behaviour after a pilot project began training a core group of health professionals to provide care as well as education about HIV[/AIDS]." [220]

Women and girls are denied access to treatment, which leads to rapid disease progression and death. Women and girls are denied access to available treatment information and available treatment information is rarely women and girls-specific. Access is compounded by factors including geography, geographic and social isolation, racism, sexism, poverty and classism. Treatments have been mainly developed for men and are often inappropriate for women and girls.

"A recent study in Zambia showed that, even when they are receiving antiretroviral therapy, many women experience formidable barriers to adherence, including fear of disclosure, domestic violence and being required to share treatment with a non-tested husband."[221] "In one rural town [in Zambia], of the 40 people on ART, only three were women."[222] "In some families, men determine whether women and girls

will be allowed to leave the home and take time away from household duties to visit health centres. When male and female family members are HIV positive and resources are scarce, evidence in some countries shows that men are the first to receive treatment… In Kenya and Uganda, women told Human Rights Watch (HRW) that they could not reach HIV testing and treatment centres because they had no money to travel or pay for care, were too afraid to ask abusive husbands for funds, or were not allowed to leave the home… Many widows told [HRW] that after they had been denied inheritance and lost everything to property-grabbing in-laws, they had no money to survive, much less pay for antiretroviral therapy and other health care."[223]

"A short course of ARVs, known as post-exposure prophylaxis (PEP), has been shown to be an affordable and feasible intervention to reduce the risk of HIV transmission in cases of rape where the perpetrator is or could be HIV positive (and is also used for occupational exposure to HIV…). However, widespread lack of information about, and availability of, PEP in most severely affected countries means that rape continues to pose the threat of HIV infection and ultimately death."[224]

"Researchers are only beginning to examine utilization patterns related to socioeconomic status, urban versus rural location and barriers to uptake for vulnerable groups. However, overwhelming evidence shows that urban residents have higher levels of access than rural residents…as most facilities providing treatment are located in urban areas, a situation that will only change if concerted efforts are made to decentralize treatment sites."[225]

"We now have a great deal of evidence demonstrating that lower income populations, women, ethnic minorities and [IDU] are at risk of poor access to antiretroviral therapy and higher rates of treatment discontinuation. Although the majority of these studies have been conducted among living cohorts, data is emerging to suggest that limited access is contributing to the ongoing HIV/AIDS mortality rates in the developed world."[226]

"In 1994, research in the US showed that giving AZT to HIV positive pregnant women and to their infants after birth could reduce the rate of HIV transmission from mother to child from 25.5 to 8.3 percent."[227] "In most low- and middle-income countries…access to services for preventing mother-to-child transmission [PMTCT] remains inadequate, with less than 10% of pregnant women living with HIV/AIDS estimated to be receiving antiretroviral prophylaxis. As a result, 1800 infants are infected with HIV every day..."[228] "[D]ue to lack of resources, many PMTCT programmes often only focus on the child. In much of the developing world, women's only access to ART is a single dose of antiretroviral medication at the onset of labour to protect the infant during delivery. Without ongoing treatment, HIV positive women give birth only to die a few years later."[229] Yet, "[i]t is clear that care, treatment and support of the mother contributes to the protection and well being of the child, and that the survival of the child is compromised if the mother dies."[230]

"[D]rug metabolism has been shown to differ in women versus men, potentially resulting in differential responses to antiretroviral therapy and an increased incidence of drug toxicities in women."[231] Yet, "[w]omen living with HIV/AIDS [in Canada]…deal with physicians and other 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."[232]

"[W]omen 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.'"[233]

<u>WE DEMAND</u>:

- ***Implemented and sustained treatment programmes offered by governments and healthcare institutions and providers that address the barriers to women and girls accessing confidential, culturally and linguistically relevant HIV/AIDS treatment and treatment information.***

"To counteract these problems, health services can use a variety of measures to reach women, such as providing mobile health centres, reducing or eliminating fees, providing child care at health centres and offering care to everyone in a family so no one member is being treated at the expense of others."[234] "Providing treatment for girls and women requires focusing on the constraints that make it difficult for them to adhere to drug regimens. They will often need counselling to help them stay on treatment in the face of opposition and stigma. Many families will also need social services to ensure that sheer destitution does not interfere with women taking the drugs, which require a certain amount of food in order to be effective. In situations where poverty limits the amount of food available and where women are the last to eat, it is nearly impossible for them to follow antiretroviral therapy without support."[235]

The International Community of Women Living with HIV/AIDS (ICW) states that the following need to be addressed in order to reduce barriers to treatment access for women and girls: food, costs of child care/lost income, free blood tests/drugs, permission from partner/in-laws, access to STI/opportunistic infections control and family planning, good staff training and attitudes, confidentiality/privacy/community support, peer information/advice/support, travel time and costs, and guilt if other family members are sick.[236] According to "Breaking the Cycle: Ensuring Equitable Access to HIV Treatment for Women and Girls", treatment programmes must address "cost of treatment, transportation and child care…appropriate appointment schedules, reduction in waiting times, sufficient women health workers, and guarantees of privacy and confidentiality. Treatment…programmes should provide counselling, referrals, and follow-up about the risk of abandonment or violence after disclosure, including links to safe shelters for women."[237]

"Monitoring and evaluating equity in access to services need to be given higher priority as programmes are scaled up. User charges for treatment and related health services, such as laboratory monitoring, remain a significant barrier to access, and funding mechanisms need to be reformed in many countries to enable the elimination of user fees for HIV treatment and care at the point of service delivery. Policies and interventions that empower women and girls and reduce domestic violence are also needed to ensure equitable access for women and girls. Implementation of a public health approach, including decentralization of services, is also a key strategy to enhance equity."[238]

"As they work to eliminate user fees, several countries are also exploring alternative funding mechanisms to cover some of the costs of antiretroviral therapy… Tax-funded health care funding draws on general tax revenue to support the costs of antiretroviral therapy. Social health insurance taps into contributions collected from workers, self-employed people, enterprises and the government that are pooled into one or several social health insurance funds."[239]

To summarize the WHO/UNAIDS policy statement on "Ensuring equitable access to antiretroviral treatment for women":

1. Develop a supportive policy environment by advocating for gender equity, ensuring equity within the health system, expanding eligibility criteria and promoting the active participation of people living with HIV;
2. Strengthen health systems to make them more responsive to the specific needs of women and men by integrating HIV related services, financing ART programmes, strengthening home and community based programmes and building capacity for health care workers and other care givers;
3. Promote programmes that overcome obstacles to equitable access by addressing gender-related barriers to access, reaching marginalized groups, ensuring that women and men have access to reliable HIV/AIDS information, addressing gender issues in HIV testing and counselling, creating multiple entry points for ART, providing gender sensitive adherence support and offering reproductive health services for women and girls on ART; and
4. Develop benchmarks and indicators to measure progress by setting targets for women and men, monitoring and evaluating, examining the impact of ART financing on women, commissioning new research and sharing promising practices.[240]

"Additionally, increased access for pregnant women for PMTCT *must* be coupled with sustained treatment for the individual women themselves, and not solely to prevent transmission to an infant."[241]

In order to better serve various Aboriginal communities, home-based care services in British Columbia must reduce "the complexity of funding [that] discourages professional service providers from setting-up programmes for Status Indian populations. At same time, provincial funding programmes for home-based care will not pay family members to provide such care… Changes to the funding, training and service structure are required to ensure that equitable access to qualified home based care is available to those with AIDS."[242]

"Harm reduction programmes…provide valuable entry points for HIV testing and counselling, referral to HIV/AIDS treatment and care services and the direct delivery and monitoring of antiretroviral therapy, including antiretroviral therapy adherence support from peer networks of drug users."[243]

"Improve access to treatment and other health-related services for women [in Canada] without residency status and/or health coverage. This can be done through advocacy efforts and through development of linkages with others that are already working on similar initiatives…"[244]

Correctional Services Canada (CSC) must provide Canadian women prisoners "adequate financial and human resources to enable medical staff to provide a standard of care comparable to that available in the community. Female physicians must be available in all women's institutions. Accessibility of pain management medications…must be increased and provided in a non-discriminatory fashion."[245]

<u>WE DEMAND</u>:

- ***Government regulations that require pharmaceutical companies and researchers to demonstrate whether and how treatments differentially affect women and men both as a condition for approval for market and for listing on government treatment reimbursement plans.***

In the Research section of this Backgrounder, the lack of and urgent need for clinical trials that address whether and how HIV treatments differentially affect women and men was discussed. Government regulations that require pharmaceutical companies and researchers to provide such data as a condition for treatments' market approval and listing on government treatment reimbursement plans provides a strong, practical motivation to act. Ethical guidelines are insufficient motivation for action.

Women and girls are underrepresented in the number of people with HIV/AIDS reported to be accessing treatments relative to their representation in this epidemic.

In some countries in the developing world, such as Ethiopia and Ghana, "the percentage of women among those receiving treatment is well below 50%, whereas at least half of those needing treatment are expected to be women." Venezuela reports about 25% of adults receiving ART being women as opposed to just over 30% expected. Panama reports just under 30% with 40% expected. Guyana reports about 45% with about 55% expected.[246]

A study from 2003 that evaluated all HIV-related deaths from January 1 1995 – December 31 2001 in a Canadian province in which all HIV care and antiretroviral therapy are provided free of charge found that "aboriginal ethnicity, female sex, and lower meridian income were negatively associated with receiving HIV treatment before death."[247]

According to the Center for Disease Control and Prevention in the United States, in 2004, African Americans made up 12.3% of the US population, yet they accounted for 50% of the new HIV/AIDS diagnoses in the United States. "It was the number one cause of death for African American women aged 25-34 years old."[248] "Moreover, African Americans are about half as likely to be receiving antiretroviral treatment compared with other population groups."[249]

In eastern Europe and central Asia, injection drug users account for more than 70% of the people living with HIV/AIDS, but represent only about 24% of the people receiving antiretroviral therapy.[250]

A 1998 study showed that "[y]oung IDUs [in Canada] were less likely to receive ART. They may be less aware of ART benefits, and less likely to seek care. Alternatively, clinicians may be less likely to prescribe ART for them if they perceive that young IDUs are less able to adhere to complex regimens. Female IDUs were twice less likely to receive ART than males…"[251]

<u>WE DEMAND</u>:

- ***Development of plans involving all stakeholders, including governments, pharmaceutical companies, women and girls with HIV/AIDS, and health care providers to ensure that women access treatment at rates that reflect their representation in the epidemic.***

"Recent guidelines produced by NGO's and international organisations on how to distribute medication equitably all start from the perspective that access to ART is a human right that should be available to anyone who needs it… [WHO's] '3 by 5' campaign has noted that "special attention will be given to protecting and serving vulnerable groups" and that "the Initiative will make special efforts to ensure access to antiretroviral therapy for people who risk exclusion because of economic, social, geographical or other barriers." The Global Coalition on Women and AIDS has called for half the recipients of ART through the '3 by 5' campaign to be women."[252]

Through literature review and field research, the Center for Health and Gender Equity has identified the following essential elements of a gender-sensitive approach to treatment access:

1. Expand eligibility criteria to ensure that eligibility criteria reflect both biomedical and socio-economic vulnerabilities; ensure that eligibility criteria do not discriminate against women depending on their pregnancy status nor focus on women only in relation to their pregnancy; ensure that criteria and processes for expanding access to treatment are transparent and accountable to communities in question; develop equitable pricing for drugs; and ensure drug adherence programmes are gender-sensitive.
2. Ensure that ART programmes enhance the capacity of health systems so that capacity and infrastructure of primary health systems are developed and improved; invest in quality of care and efforts to eliminate bias within the health care system; expand safe and gender-sensitive counselling services as part of treatment and prevention programmes; ensure equity in access to ARV therapy through more sensitive health-financing mechanisms; and address gender inequities in health staffing and personnel policies.
3. Make ART part of a continuum of prevention, treatment and care to ensure ART services are provided within the context of integrated comprehensive health care; ensure all women and adolescent girls and boys have access to comprehensive reproductive and sexual services and education, including efforts to address gender-based violence; and ensure access to female controlled prevention technologies.[253]

To strengthen programmes focused on women and girls and ensure their treatment access is equal to their representation in the epidemic, "establish gender advisory groups in the target countries [that] include representatives from civil society, including women's groups, networks of women living with HIV/AIDS, service providers and other organisations with gender expertise."[254]

"Develop mechanisms and benchmarks to ensure gender equity…and…proactively seek out women for treatment programmes. Benchmarks should include gender specific information on: the percentage of individuals infected; the number of infected people with access to ARVs; and the percentage of adherence, including the social support and continuous provision of drug access. Establish targets to ensure that at least 50% of those on treatment are women and girls and develop strategies to reach non-pregnant women, including adolescent girls and sex workers."[255]

"Every morning and evening a group of women and a few men, many of them HIV positive, fan out over the villages of the central region of Haiti bringing ART to more than 650 [HIV/]AIDS patients. These '*accompagnateurs*' distribute twice-daily dosages of antiretroviral drugs and provide other medications as needed, some food and a shoulder to lean on… Based on the DOTS (directly observed therapy, short-

course) method first developed for TB patients, the *accompagnateur* system brings health care to the patient rather than the other way around... [T]he Initiative [also] provides treatment for opportunistic diseases to the overwhelming majority of its 6,500 HIV patients and ART to the 10% with AIDS... The *accompagnateurs* factor women's caring responsibilities into their treatment in various ways, including by providing money to help pay school fees when possible. They also try to be aware of the circumstances under which the women became infected."[256]

"Although in urgent need of further study, strategies that may improve access and adherence to antiretrovirals among HIV-infected IDUs include improved access to illicit drug treatment, directly observed therapy programmes, and onsite pharmacists at medical clinics."[257] "In addition, no patient should be denied the opportunity to initiate high active antiretroviral therapy (HAART) regardless of perceived or real barriers to optimal adherence including continued illicit drug use."[258]

For female sex workers (in Vancouver's Downtown Eastside), "[d]espite low reported uptake of HAART as well as high rates of barriers to accessing treatment, there was a high acceptability among this group to accessing HAART through community-driven approaches, such as home-delivery or an urban drop-in centre."[259] "[E]fforts…need to focus on educating women regarding the benefits of HAART treatment and management of treatment side effects… Innovative strategies tailored to women's specific lifestyle patterns and incorporating a high degree of follow-up and outreach are urgently needed to enhance access to HAART. Increasing evidence suggests that directly observed therapy can be highly effective in promoting HAART adherence among even the hardest-to-reach populations. Directly observed therapy programmes have been particularly successful when paired with existing service providers in the community such as needle-exchange programmes or peer outreach workers, as this provides the opportunity to engage active users in entry into treatment, ensures non-judgmental and continuous contact with clients, and ultimately facilitates access to comprehensive medical care."[260]

PREVENTION AND EDUCATION

Prevention and education strategies do not receive sufficient attention and funding, are poorly implemented, and do not respond to women and girls' realities.

"It has long been recognized that gaining the upper hand against AIDS epidemics around the world will require rapid and sustained expansion in HIV prevention."[261] "The need for prevention strategies that reach girls and women is urgent. This is especially the case for adolescent girls, who face infection rates in some countries that are five to six times higher than those of boys the same age. Even though girls and women are highly vulnerable to HIV infection, they [often] know less than males about HIV/AIDS and how it is transmitted."[262]

The Canadian Youth, Sexual Health and HIV/AIDS Study (CYSHHAS) in 2002 showed that "[o]ver two thirds of grade 9 students and just under half of grade 11 students think that there is a vaccine available to prevent HIV/AIDS... Approximately two thirds of grade 7 students, one half of grade 9 students and one third of grade 11 students do not know that there is no cure for HIV/AIDS."[263] A 2003 study in Nova Scotia interviewed young men (15 to 24), sexual health care providers and young women (15 to 24). General findings showed that:

1) young men were less likely to talk openly about sex and seek information/resources for fear of looking unknowledgeable;
2) most youths reported not using condoms consistently;
3) pregnancy prevention was the major concern of youth;
4) most youth did not feel they were personally at risk of acquiring HIV; and
5) young women interviewed generally reported taking on the responsibility for birth control and safer sex.[264]

Canadian statistics reveal that this lack of information about HIV/AIDS among youth is leading to rising infection rates, particularly among young women. "When compared to other age groups, the proportion of

positive HIV test reports attributed to females is highest among youth. In 2005, women aged 15-29 years accounted for 35% of tests, which is an increase from 14.1% for the 1985 to 1995 time period."[265] "Women in other age groups (i.e. 30-39, 40-49 and over 50) accounted for approximately 20 to 25% of positive HIV tests."[266]

The Ontario Women and HIV/AIDS Working Group's *Literature Review: HIV Prevention and Women* found the following general gaps: "lack of theoretical underpinning, lack of consistent evaluation, lack of gender consideration, lack of continuity between policy and practice, under-funding, lack of resources/capacity, underutilization of potential partnerships and research dissemination, [lack of] ethnicity reporting and cultural competency of programming…, and relatively little information on the prevention issues of certain groups of women, including women from endemic countries, transgendered women, lesbian women, Asian women, South American women, Middle Eastern and Arab women, immigrant women, non-status women and refugee women."[267]

Four years ago, Health Canada stopped funding the Centre for AIDS Services Montreal (Women)'s education/prevention service, an in-school testimonial by an HIV positive young woman. Despite this, the Centre continues to offer the service when resources are available. The testimonial is still in high demand at schools. The programme lasts about 90 minutes and is done in three parts: a basic HIV/AIDS presentation, the speaker's sharing of experiences and dreams, and a question and answer period. Literature is provided for reference. All this is done despite the lack of funding for the project. The testimonial has a direct impact on the teens and is a powerful tool.[268]

"Many girls and women know very little about their bodies, their sexual and reproductive health or HIV/AIDS. In many societies, both the discussion of and education about sexual matters is frowned upon. As a result, millions of people, especially girls and women, remain ignorant about HIV/AIDS… Although many adults in both the industrialized and developing world disapprove of sexual and reproductive health education for young people because they believe it encourages promiscuity, research and long experience show that just the opposite is true. A review of 50 sexual health education programmes in different parts of the world found that young people were more likely to delay sexual activity when they had the correct information to make informed decisions."[269]

In Zimbabwe, "research…reveals that public health care providers rigorously enforce parental consent requirements. Health workers will not provide adolescents under 18 with services and information on contraception and STI prevention without parental consent… [I]nvestigation also reveals that service providers routinely inform parents and obtain their consent before providing adolescents with such services and information… [As a result, a]dolescents are forced to seek services and information from unreliable sources outside of public health care institutions and often use methods that are ineffective at preventing pregnancy or transmission of HIV/AIDS or other STIs… Cultural attitudes and expectations of girls create additional impediments for them accessing dual protection methods and information, and they also suffer disproportionately from lack of access… Rural adolescents also encounter more barriers to access than urban populations. Finally, low income adolescents, primarily female sex workers, are routinely denied access to dual protection methods and information…"[270]

<u>WE DEMAND</u>:

- ***Education and prevention programmes that are designed to meet the unique cultural and linguistic needs of women and girls, including sexual and reproductive health and prevention programming. These programmes must be developed by governments across the globe in wide consultation with women and girls affected by HIV/AIDS and all other relevant stakeholders.***

"The rising rates of HIV infection among girls and women require approaches to prevention that address their specific needs and realities and that are linked with other reinforcing elements along a broad continuum of prevention, treatment and care. Effective prevention is composed of many facets – including education, health services, media campaigns, behaviour change, life skills-building and job training. All these components must address the critical role that gender plays in sexual and reproductive life, and how it affects HIV prevention."[271]

"Education enters in a fundamental way into every communication on prevention. Education is intrinsic to every programme of treatment and care. Education is necessary for galvanizing the political momentum and community mobilization that are central to success against HIV/AIDS. Formal school education and non-formal programmes for youth reach into communities and families in ways that no other services do. Formal and non-formal education programmes are largely the province of the young, the category at greatest risk of becoming infected with HIV."[272]

The Ontario Women and HIV/AIDS Working Group's *Literature Review: HIV Prevention and Women* found the following general recommendations in the literature:

- Both macro (general) and micro (tailored/community-specific) level interventions should be used.
- Interventions should be based on a theoretical model with an evaluation component.
- Gender must be seen as a crucial factor influencing women's HIV risk and HIV-prevention needs.
- The determinants of health should be considered in any analysis of HIV risk.
- Policy, research and programming should complement one another.
- Women, including marginalized women, should be included in all stages of intervention development and delivery.
- Condom use and sexual negotiation/communication should be encouraged.
- The design of interventions should take into consideration behavioural, social and structural factors.
- Peer-led skills training and community leader programmes have been found to be beneficial.
- Men, particularly, heterosexual men, have been too often overlooked and should be targeted for HIV prevention education interventions.
- Social norms/issues around sexuality, stigma/discrimination, violence/coercion and addiction should be challenged.
- Resources must be put into the creation of women-controlled HIV prevention technologies, such as microbicides and vaccines.
- Prevention resources must be made accessible to all women.[273]

"Females [IDU in Vancouver] had a greater than twofold risk of requiring help with injecting…"[274] There is a "strong association between requiring help injecting and HIV seroconversion…"[275] Traditional interventions such as needle exchange programmes may not be amenable to addressing this situation for women. "[A]n intervention that has been successfully implemented…and may have substantial potential to mitigate this risk behaviour is safer infection facilities (SIFs), where IDU can inject pre-obtained…drugs under the supervision of trained staff to prevent syringe sharing. SIFs have been credited with improving the health and social functioning of their clients, while reducing overdose deaths, HIV risk behaviour, improperly discarded syringes and public drug use. In addition, improved knowledge of safer injecting practices, as well as improved access to medical care and drug treatment, have been attributed to SIF attendance."[276] HIV prevention initiatives for IDU must be non-stigmatizing and community-tailored, and whenever possible should involve IDU in the design, implementation and evaluation. Women in both urban and rural communities must be addressed. Access to anonymous HIV testing sites must be linked to these efforts.[277]

Specific prevention recommendations for street-involved youth, including young women and girls, include:

1. Promote studies that explore antecedents to street-involvement, such as abuse, unemployment, poverty, drug use, lack of housing options, mental illness, sex trade work.
2. Measure attitudes toward and knowledge of HIV among street-involved youth/women.
3. Ensure access to condoms and harm reduction programmes.
4. Determine effective communication strategies for reaching a transient population.
5. Explore the impact of racism and homophobia on street-involved women.
6. Study the coping mechanisms and social units formed by street youth/women and generate HIV prevention programming that is culturally competent.

7. Create partnerships between AIDS service organisations, reproductive health centres, mental health services, social services, drug treatment organisations and community groups (harm reduction and detox).[278]

For Canadian women prisoners, Correctional Service Canada (CSC), Health Canada and community-based organisations must ensure that "access to women-specific HIV and Hepatitis C (HCV) prevention education programmes…be expanded and made consistent throughout the system. Both correctional and community-based programmes must be offered on an ongoing basis. HIV and HCV information materials must be made widely available in various forms. Information should be up-to-date, presented in plain language, and discreetly packaged." [279] Correctional Service Canada must ensure that "access to peer health programmes be increased and made consistent across the system. CSC staff should work in cooperation with prisoners to ensure that each programme is developed and implemented to meet the specific needs of women in each institution. Condoms, dental dams and water-based lubricants must be made equally and consistently accessible across the system… Access to safer sex measures must...not necessitate making a request to staff. Full strength bleach, as well as information on its proper use for harm reduction, must be made generally and discreetly available to prisoners… Access to bleach should not necessitate making a request to staff. CSC should monitor the implementation of Phase II of its methadone policy to ensure equitable access to the programme for women across the system. Efforts should be made to educate women on the selection criteria and the process for accessing the programme. CSC should…pilot test needle exchange projects in all five regions of Canada, one of which must be in a women's institution. Harm reduction measurers, as well as appropriate materials to practice tattooing and body piercing safely, should be made available. Information on safer slashing/cutting, as well as safer alternatives to slashing, should be developed and made available. Non-punitive responses to women who slash must be implemented in practice, not simply in policy."[280]

Transsexual and transgendered persons require:

1. Accessible, non-discriminatory health care and social services…
2. Safe and consistent access to resources and supervision for hormone injecting.
3. Health service and social service provider training on transsexual and transgender health issues, including HIV prevention needs.
4. Partnerships and collaborations for non-discriminatory policies for AIDS service organisations and community organisations that provide HIV prevention services.[281]

"Governments [must] ensure that funding levels and allocations for targeted, culturally specific HIV/AIDS education and prevention programmes are commensurate with rates of HIV prevalence and incidence… [they must] provide sustained funding for self-governing organisations and networks of people vulnerable to HIV, in order to increase their involvement in designing, planning, implementing and evaluating HIV/AIDS education and prevention programmes."[282]

"Between September 2004 and May 2005, Action Canada for Population and Development (ACPD) facilitated a policy dialogue process on the issue of greater integration of HIV/AIDS and sexual and reproductive health and rights… One of the strongest recommendations that emerged was the need to expand access to integrated health services that provide women and men [including youth] with a full complement of HIV/AIDS, STI and sexual and reproductive health information and services. Another key recommendation was the need for greater integration of HIV/AIDS prevention activities into existing family planning and maternal health programmes."[283]

"The female condom is the first woman-initiated barrier method that protects against HIV and STIs as well as pregnancy… In addition to benefiting women's sexual and reproductive health, the female condom contributes to women's sense of empowerment, especially if supported by education and informational activities. Unfortunately, access to the female condom has been somewhat limited and its uptake has been negatively affected by a number of factors including cost, which remains the major barrier to access. The public sector must play a role in making female condoms widely available and affordable, as well as generating awareness of their benefits. Guaranteeing accessibility requires a sustained commitment to

providing ongoing support for users and providers, through informational materials, promotional messages and training."[284]

WE DEMAND:

- ***Development of a microbicide provision plan that will ensure affordable, free, unlimited access to microbicides once they are proven safe and effective.***

"If effective microbicides are to have an impact on the HIV/AIDS epidemic, they must be made accessible to women at highest risk in the poorest regions of the world as soon as possible… In order for a woman or girl to use a microbicide, it must be acceptable to her and she must know how to use it properly. The product must be available in locations that users can easily access at a price they can afford. A woman's ability to access and use microbicides will be facilitated if there is a political and social environment that supports women's use of these products by actively promoting and incorporating them into policies and programmes. For all this to be possible, microbicide products will need to be approved by regulatory authorities and promoted as an essential component of a comprehensive HIV prevention package."[285]

"Introduction strategies take time to develop and need to be considered concurrently with product development and clinical trials. Operational research is needed to identify characteristics of goods and delivery channels which would better lead to more widespread acceptance of a microbicide product.

While expanding the role of the private sector has been a means of easing financiing constrains, experience with contraceptives suggests that the initial introduction by public sector distribution channels [including free commodities] has been critical in opening the market and reaching the poor and more vulnerable." Introduction strategies that emphasise a mix of methods (including free-of-charge public sector distribution, social marketing, and commercial provision to middle-to-high income populations) are likely to have more success. Different distribution strategies are required in different countries and settings, and product development should be tailored to potential markets. Delivery channels should broaden to reach new people. Promotion is critical in both the initial introduction as well as developing and sustaining demand.[286]

Women and girls with HIV/AIDS often experience violence because they are HIV positive.

As previously discussed, violence against women is a global health crisis of epidemic proportions and often a…consequence of HIV. Numerous studies globally show the links between violence against women and HIV. These studies demonstrate…that HIV infected women are more likely to have experienced violence. Violence is…a barrier for women in accessing HIV prevention, care and treatment services.

A multi-country WHO review found that fear of violence was a barrier to HIV disclosure for an average of 25% of participating women, with rates reaching as high as 51% in Kenya. A study in Uganda found that women were often powerless to access AIDS services because their husbands physically attacked, threatened and intimidated them.[287]

The threat of violence is a deterrent to women in developed countries like Canada and not just in developing countries. "The broader problems of abuse and economic dependence of women need to be addressed to create a climate in which women will be less fearful of the potential consequences of testing HIV positive."[288]

WE DEMAND:

- ***Creation and implementation of sustainable and culturally and linguistically sensitive services for women and girls who experience violence and their families.***

See pages 13 to 15 and 28 to review actions to be undertaken by all relevant stakeholders to create, implement and sustain culturally and linguistically sensitive services for women and girls who experience violence and their families.

The long and brutal legacy of colonization of Aboriginal people [in Canada and] globally has created an HIV epidemic in urban, rural and isolated Aboriginal communities that impedes access to prevention and education in these communities. Susceptibility of Aboriginal peoples to HIV and barriers to access to treatment are compounded for women and girls through the living legacy of the colonization process.

See pages 8 to 9 for more on the legacy of colonization and assimilation and its links to HIV infection among Aboriginal people, particularly women and girls, in Canada and around the world.

"In order to fully participate in society, indigenous peoples and members of ethnic minority groups must learn to negotiate social, economic, political and educational barriers that the dominant society places in their path. A prime example of this systemic discrimination is the lack of targeted, culturally appropriate, HIV prevention messages for the majority of the world's indigenous people[s], and particularly, indigenous youth."[289]

In Canada, "there are a limited number of First Nations, Métis and Inuit prevention messages being offered to Aboriginal youth. Of the messages that are available, a pan-Aboriginal approach is sometimes being taken that is often ineffective. In particular, Inuit youth are being lost in this approach. Aboriginal youth under the age of 15 and injection drug users are the groups most in need of HIV prevention messages but they are among the least likely to be receiving them. Prevention education must begin before youth become sexually active, and it must address injection drug use. Peer education is thought to be the most effective approach to HIV prevention but it is among the least common approaches being used by organisations… Aboriginal and non-Aboriginal organisations lack the funding and human resources needed to design and develop culturally appropriate prevention messages for Aboriginal youth."[290]

The fact that there is only one Aboriginal AIDS service organisation in the entire Atlantic Region of Canada[291] is an example of the lack of financial or other support by Canadian governments.

<u>WE DEMAND</u>:

- ***Full support by the Canadian government for culturally and linguistically appropriate prevention and education strategies and programmes for First Nations, Métis and Inuit, developed by Aboriginal peoples with resources provided by all levels of governments.***

Approaches such as the following can be adapted for First Nations, Métis, Inuit (and other Indigenous peoples): anti-fear, stigma and discrimination campaigns, education and awareness campaigns, life-skills education, youth-friendly services, voluntary testing and counselling, peer-education, engagement of people, including young people, who are living with HIV/AIDS, creation of safe and supportive environments, reaching out to those most at risk, and strengthening partnerships.[292]

In Canada, more Aboriginal, youth-specific services and prevention programmes need to be developed and maintained. Rural areas, isolated areas and on-reserve need special attention. Prevention messages should be targeted and recognize unique cultures. When developing a prevention message for Aboriginal youth, the entire context of the target population must be considered. Those younger than 15 need prevention initiatives. IDU prevention messages and education is needed. A national conference would allow networking and discussion. A national strategy would provide direction. More money [from all levels of government] would allow organisations to design, deliver and maintain prevention messages.[293]

The Ontario Women and HIV/AIDS Working Group recommends:

1. The sexual and drug HIV-related risk behaviours of Aboriginals are different from non-Aboriginal Canadians and different across gender and must be further studied.

2. There is a disproportionate level of addiction…among Aboriginal Canadians. Additional research must look at this phenomenon and further explore gender differences.
3. Recognize the intersection of race, gender, class and HIV risk and advocate against stigma and discrimination.
4. Aboriginal organisations/persons should direct HIV prevention interventions tailored for Aboriginal populations. If not directing the interventions, Aboriginal persons [minimally] should make up community-advisory boards and steering committees to inform the interventions of appropriate cultural competence. This will maintain community control over programmes, improve quality, longevity and…ownership.
5. …Aboriginal values and customs should be incorporated into interventions.[294]

CARE AND SUPPORT

Women and girls with HIV/AIDS face multiple demanding family roles that erode their health and limit the time and attention they can spend on necessary self-care.

"When [HIV/]AIDS enters the household, women and girls [often] provide the care. Globally, up to 90% of the care due to illness is provided in the home by women and girls. This is in addition to the many tasks they already perform, such as taking care of children and the elderly, cooking, cleaning[, working at a job or jobs] and, in subsistence areas, fetching water and fire wood. Women are also deeply involved in work at the community level, often as volunteers. The value of the time, energy and resources required to perform this unpaid work is rarely recognized by governments and communities, despite its critical contribution to the overall national economy and society in general. The devastating effect of HIV/AIDS on women's work is even less recognized. Poverty reduction strategies and national AIDS plans seldom take women's caregiving into account…"[295]

"Caring for an [HIV/]AIDS patient can increase the workload of a family caretaker by one third. This is a burden in any family but particularly onerous for the poor, who already spend much of their day earning a subsistence living… As the crisis deepens in Africa, girls are being taken out of school to provide home-based care… [W]omen in rural villages caring for [HIV/]AIDS patients have little moral or material support. Women's role in the care economy intensifies their poverty and insecurity since a large proportion of an already meagre income is used to support their caregiving… The increased workload, loss of family income and deepening poverty make women more dependent on others and exacerbate gender inequalities.

Ironically, even when community support programmes are developed to serve people living with HIV[/AIDS], they tend to rely on women as unpaid volunteers who – despite the fact that they are often as poor or poorer than the people they are assisting – receive neither stipends nor incentives."[296]

"Canadian women interviewed for this project [*Vectors, Vessels and Victims*] 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… [R]esearchers have noted that…[some women] neglect their own health in favour of focusing on that of their partner or children. 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."[297]

"[In Canada, n]ot 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 care-giving roles, the duties they face in keeping households going, and stigma and discrimination that may come from seeking treatment."[298]

During a community-based study of treatment access conducted by Casey House in Toronto in 2001, one service 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 was alone here, an immigrant with no family. There are many women out there in that position."[299]

<u>WE DEMAND</u>:

- ***Development by appropriate stakeholders, including governments, healthcare institutions, healthcare providers and HIV+ women and girls, of responsive models for health care and support delivery that acknowledge and affirm the multiple roles that women and girls play and the importance of including these in care and support plans.***

"The Millennium Declaration adopted by UN Member States in 2000 declared that all people have the right to live free from fear and want. The eight Millennium Development Goals set up by the international community include eliminating poverty and hunger, reducing the spread of HIV/AIDS and achieving gender equality and empowering women. These goals will be impossible to achieve if women's care-giving work is not shared and given appropriate support…

The most successful community-based mobilization efforts provide counselling and support for volunteers, try to provide incentives such as food or job training when possible and encourage men and boys to share the burden of care…

There are community-based programmes already operating that show how much can be done with relatively few resources. In Haiti, the HIV Equity Initiative (HEI) model, using paid *accompagnateurs* to provide in-home health services, has been successful at comparatively low cost."[300]

"Ghana has been experimenting with distance learning courses through the University of Ghana to train women and men in local communities as 'change agents' in the fight against HIV[/AIDS]. Nationwide, 366 participants have taken part so far and are working in their communities to identify caregivers who need support and to provide information on HIV[/AIDS]. The programmes in Ghana and Kenya have shown that communities are most receptive to new information about HIV when they learn from colleagues and neighbours whom they already know and trust.

One training programme that has been very effective is known as Stepping Stones. It involves a series of meetings where various peer groups such as young women or older men meet separately at first and then come together for larger discussions about issues that are important to them. It has been used in many parts of Africa to help communities decide for themselves how to respond to HIV[/AIDS] and determine where the need is greatest. By also focusing on behaviour change, it allows community members to see how certain attitudes and actions may have contributed to the rise of HIV."[301]

"Training and support programmes need to focus on the needs of young girls who are nursing family members and supporting siblings. Many of these girls are invisible to service providers because they rarely enter the public health system… In Rwanda, NGOs and international agencies are providing vocational training and skill-building classes to youths—mainly girls—who are heads of household and helping to create support groups for them…

Men are also playing an increasing role in taking on tasks and responsibilities within the household that are culturally perceived to be 'women's work'. As part of its strategy for addressing violence against women and its effects on HIV/AIDS, the Men as Partners (MaP) programme in South Africa also focuses on the need to transform gender relations within the household."[302]

In "HIV/AIDS and Aboriginal Women, Children and Families", the Canadian Aboriginal AIDS Network recommends that stakeholders "provide childcare, respite, and domestic assistance for Aboriginal HIV positive women, and Aboriginal women who are caregivers of infected family members."[303]

In a recent Canadian study entitled "Women's Unpaid Caregiving and Stress", an analysis of coping mechanisms used to offset caregiving-related stress indicated that "unstressed" women…drew on strong personal and community support networks and knowledge of programmes and services available to care

recipients. Women in the focus groups who did not experience caregiving as stressful also mentioned that they believed they had had a right to support and services.[304]

Women and girls are adversely impacted by the social determinants of health including inadequate housing, limited education, un-employment and under-employment, a lack of training and other social factors that greatly reduce the health and quality of life for women and girls with HIV/AIDS.

"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."[305]

"[HIV/]AIDS tends to affect the poor more heavily than other population groups."[306] "Worldwide, of the 1.2 billion people living on less than $1 a day, 70% are women. Women own a minority of the world's land, and yet produce two-thirds of the food in the developing world, and are the primary caretakers for children, orphans, and the sick."[307]

"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. Of single-parent families, 56% of those headed by women were living in poverty compared with 24% of those headed by men… Unfortunately, there are no recent data from large-sample studies in Canada on the links among gender, poverty and HIV/AIDS… 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."[308] "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."[309]

A British Columbia-based study published in 2005 sought to determine "the level of food insecurity and hunger among HIV positive persons accessing antiretroviral therapy in British Columbia… Overall, 1213 responding men and women were classified as food secure (52%), food insecure without hunger (27%) or food insecure with hunger (21%). In both categories of food insecurity, individuals were significantly more likely to be women, aboriginals, living with children, and to have less education, a history of recreational injection drug and/or alcohol abuse, and an unstable housing situation… In HIV positive individuals, the occurrence of food insecurity was nearly 5 times higher than in the general Canadian population."[310]

In Canada, "Aboriginal women are twice as likely to be poor than their non-Aboriginal counterparts..."[311] "Low income has many consequences, including (but not limited to) crowded or inadequate housing, reduced availability of nutritious food, less access to health care, and limited ability to cope with prolonged illness in oneself or in a family member."[312] These are direct results of the colonial legacy.

"Generally, [African and Caribbean women in Toronto] struggle with obtaining gainful employment (even after many years in Canada)… Both the women and men in these communities experience significant levels of unemployment, underemployment, and many people often have (one or more) low-salaried jobs. To support their families, women have often taken any available jobs, including those that pay low wages."[313] "Many women were forced to accept jobs below their skill level and salary expectations because they could not get their academic and/or professional credentials recognized in Canada and/or they didn't have Canadian experience. This generated feelings of frustration and skepticism about the Canadian system, which affected their trust of the health care system."[314]

"The continuing denial of education to an estimated 60 million girls is a global emergency, even though the international community is refusing to acknowledge it as such. This year alone, failure to reach the 2005 UN girls' education goal will result in over 1 million unnecessary child and maternal deaths; 10 million over a decade. HIV/AIDS infection rates are doubled among young people who do not finish

primary school. If every girl and boy received a complete primary education, at least 7 million new cases of HIV could be prevented in a decade."[315]

"In a survey of 83 developing countries for which there are data, only 50% achieved gender parity in education at the primary school level, and less than 20% have done so at the secondary level… In AIDS-affected households and communities, the economic and social burden of AIDS often forces children, especially girls, to drop out of school, or to never attend. Many children leave school in order to provide care for members of their families who are sick and dying – and, if their parents die, for themselves and their siblings left behind."[316]

"Overwhelmingly, girls are not in school because of poverty. The more expensive education is, the less likely families are to invest in education for girls… [C]hildren's labour, paid or unpaid, is often an important part of household survival, and sending girls to school may mean less food on the table..."[317]

"Using an indivisibility of human rights approach, the Special Rapporteur presents an analysis of several identified obstacles to the effective realization of housing rights for women including homelessness among women,…violence against women, discriminatory cultural and social norms and family or personal laws, multiple discrimination, privatization and unaffordability of housing for women, and the impacts of natural disasters, forced evictions and HIV/AIDS on women… As indicated by testimonies and other information received, there is a culture of silence regarding the prevalence of violations across the world of women's right to adequate housing and land."[318]

<u>WE DEMAND</u>:

- ***Leadership from all levels of government and the private sector to develop a comprehensive, culturally and linguistically appropriate plan to redress the inequalities that women and girls face in relation to the social determinants of health.***

"[W]omen who own property or otherwise control economic assets have higher incomes, a secure place to live, greater bargaining power within their households, and can better protect themselves against domestic violence and having to exchange sex to meet their essential economic needs. With greater ownership and control over economic assets, women are more empowered to negotiate abstinence, fidelity, and safer sex, and can avoid exchanging sex for money, food, or shelter."[319]

To summarize the Global Coalition on Women and AIDS's recommendations to national governments and international partners, national and international HIV/AIDS prevention and mitigation strategies must include strategies and programmes that promote economic and educational opportunities for women and protect their property and inheritance rights. They must increasingly fund the governments and community organisations that promote these strategies and programmes. They must collect sex-disaggregated data to document and monitor women's access to these options and services and better tailor programmes to their needs. They must ensure those with gender expertise and community organisations that promote economic opportunities for women are represented on all relevant local, national and international decision-making and consultative fora. Governments must train all relevant stakeholders about women's property, inheritance and legal rights and their duty to enforce these rights. Women must be educated about their rights and ways to protect themselves and their families. Safe shelters with legal and social support for women who are at risk of losing or have lost their land or other assets must be established.[320]

"In Zimbabwe, one project works with 200 women to reduce poverty and economic dependence on men, increasing their bargaining power for safer sexual relations. The women…receiv[e] grants and training to start income-generating projects such as grinding mills, horticulture, poultry farming, soap making, juice making, butchery and tailoring. The interest repaid on the loans goes into a revolving fund that is used to make loans to other women. During the entire process, women…receive technical support and education on their human rights, reproductive and sexual health and how to deal with domestic violence. They are given personal empowerment lessons on assertiveness, communications and negotiation. The project also involves men and the community at large, including traditional leaders, to encourage sensitivity to

women's concerns and responsibility for preventing both domestic violence and HIV/AIDS. The campaign is led by women and other trained community resource persons."[321]

For Canadian Aboriginal women, the Canadian Aboriginal AIDS Network recommends integrating "HIV/AIDS prevention and education into job training programmes, life skills education, nutrition workshops, and healthy lifestyles training. Since poverty is directly related to HIV vulnerability, increasing meaningful job opportunities and job training for Aboriginal women will, over time, decrease their vulnerability to HIV infection… Aboriginal women who are familiar with street life and can relate to the experiences of Aboriginal women who are vulnerable to HIV infection [should be trained] to deliver this training."[322]

"By itself, merely attending primary school makes young people significantly less likely to contract HIV. When young people stay in school through the secondary level, education's protective effect against HIV is even more pronounced. This is especially true for girls who, with each additional year of education, gain greater independence, are better equipped to make decisions affecting their sexual lives, and have higher income earning potential – all of which help them stay safe from HIV. Higher education levels are also clearly correlated with delayed sexual debut, greater HIV awareness and knowledge about HIV testing sites, fewer sexual partners, higher rates of condom use, and greater communication about HIV prevention between partners – all factors that substantially lower HIV risk. By providing young women with greater economic options and autonomy, education also affords them the knowledge, skills and opportunities they need to make informed choices about how to delay marriage and childbearing; have healthier babies;…and gain awareness of their rights."[323]

"Rapid progress on girls' education, on the scale needed to achieve gender parity worldwide within the next few years, is eminently possible. Many of the poorest countries have made remarkable progress in a short period of time. Mauritania, which made a commitment to free and compulsory primary education, increased the ratio of girls to boys from 67% to 93% between 1990 and 1996…After Uganda abolished fees, girls' enrolment increased by 20 percentage points almost overnight; among the poorest fifth of girls, it went from 46% to 82%… What made these countries different? They were not satisfied with a string of small-scale projects and pilot-programmes. They embarked on massive expansion and upgrading of the public school system, while also investing in measures to help poor girls and other excluded groups get an education… Among the pro-girl steps taken by 'success story' countries, some of the most effective have been abolishing fees and charges; making primary education compulsory as well as free; prohibiting the worst forms of child work; and providing extra incentives to help compensate poor families for girls' labour."[324]

"[Girls in school] need to be freed from the threat of sexual harassment and abuse, and from gender-biased assumptions of what and how children should learn. They need equitable opportunities to advance up the educational ladder, to secondary and even tertiary level. Schools need to support girls to acquire knowledge and skills that society generally denies to women: whether this means maths and science[s], or sexual and reproductive health instruction and life skills programmes to build self-confidence and negotiating skills."[325]

In "Girls can't wait", the Global Campaign for Education, makes the following recommendations: "cancel the unpayable debt of poor countries, and increase donor aid to basic education to US $7bn per year… [T]ake immediate and effective measures to eradicate the worst forms of child labour, as governments promised when they ratified ILO Convention 182 in 1999… [I]ncrease government spending on basic education to at least 3% of GDP… [A]bolish fees and charges for primary education, and make education free and compulsory for at least 6 years… [I]ntroduce comprehensive national programmes to provide extra support…to the poorest families… [G]uarantee adult learning opportunities for every illiterate woman, since mothers' literacy helps support girls' enrolment and achievements in school… [E]nsure that every girl has access to a safe and welcoming place to learn… [I]ntroduce gender-disaggregated monitoring of learning achievements and outcomes. Promote respect for a range of learning styles. Integrate life skills education and sexual and reproductive health information into the curriculum. Improve women's participation in education decision-making, and ensure female teachers enjoy equal conditions of service and career development opportunities."[326] "Provide teachers with the

curricula, materials and training opportunities they need to effectively teach HIV/AIDS education in schools."[327]

"The Special Rapporteur [on adequate housing] concludes that there continues to be a need for States to strengthen national legal and policy frameworks for protecting women's rights to adequate housing, land and inheritance, and provide avenues for redress where violations occur. He addresses the need to bridge the gap between legal and policy recognition of women's right to adequate housing and implementation by States of national programmes to execute the legal and policy framework, including supporting initiatives by civil society groups to the same end."[328]

OVERARCHING DEMAND

WE DEMAND:

- ***All demands must be met with adequate and sustained resources, including financial and human resources; must be culturally and linguistically appropriate and must include women and girls with HIV as an integral part of the solution making and decision making process.***

"Studies show that HIV…efforts work best when they are intensive, i.e. comprehensive and long term."[329] This requires adequate and sustained resources, including financial and human resources.

"[R]epresentatives from national and community organisations…stressed that sufficient and stable funding is necessary for them to provide the services or programmes needed to address stigma and discrimination. Stigmatizing attitudes and discriminatory behaviour are not changed overnight. Efforts to change them need long-term funding."[330]

"*If* the funding requirements for 2006-2008 can be met, *if* adequate funding can be sustained beyond 2003 and *if* the national and international partners can meet the challenges outlined [in Chapter 10 of UNAIDS' 2006 *Report on the Global AIDS Epidemic*], the following could be achieve by 2010:

- Comprehensive HIV prevention, based on the characteristics of the epidemic in each country, including programmes to reduce risk behaviours by those at greatest risk of exposure to HIV, as well as all adults and youth; to prevent mother-to-child transmission; and to ensure safe blood supplies and injections.
- Treatment and care for 9.8 million people, including 80% of those in urgent need.
- Adequate support for all orphans and vulnerable children, including home support, schooling, health care and community support.
- Sufficient programme capacity (planning, administration, staff, etc.) and infrastructure (hospitals, health centres, laboratories etc.) to support the interventions shown.
- Sufficient numbers of appropriately trained nurses, doctors and other personnel to support the above."[331]

"As donor countries continue to increase their financial commitments for health and development, contradictions remain between the higher levels of public spending required to meet the Millennium Development Goals and the amount of spending possible under the macroeconomic framework model favoured by the International Monetary Fund. This policy bottleneck needs to be urgently resolved so that countries have greater confidence in making the public-sector investment they need to scale up national HIV/AIDS efforts."[332] Specifically, "[t]he [World] Bank and the [International Monetary] Fund…offer loans in return for which the recipient countries…have to live with certain conditions. The conditions [in the 1980s and 1990s] ranged from the sale of public sector corporations, to the imposition of 'cost-sharing' (the euphemism for user fees imposed on health and education), to…cut-backs in employment levels in the public service, mostly in the social sectors. To this day…International Financial Institutions continue to impose 'macroeconomic' limits on the numbers of people ([such as] nurses and teachers) who can be hired, and…there are financial limits placed on the amount of money that can be spent on the social sectors as a percentage of a country's gross national product."[333]

The Global Coalition for Women and AIDS points out that "[w]hile a majority of National AIDS Strategies have language which recognizes and addresses the vulnerability of women and girls, there is often no clear operational plan on how to programme specific interventions, and consequently no budget attached to activities."[334]

The situation is no different in Canada, despite the commitments made in *Leading Together: An HIV/AIDS Action Plan for All Canada, 2004-2008*. According to Peg Frank, a Blueprint for Action on Women and Girls and HIV/AIDS National Steering Committee member, the Blueprint started when a handful of women involved in the Canadian fight against HIV/AIDS decided that women's and girls' issues could only be addressed through their own work, since there is no other coordinated, funded, long-term strategy. They put together enough money to meet in-person twice, with a smaller National Steering Committee meeting more regularly by teleconference. The Manifesto, launched on World AIDS Day in 2005, the Canadian Report Card, launched at the XVI International AIDS Conference, and the other initiatives they have undertaken have been done without the support of a national body charged with addressing women, with very limited funding, and only as a result of tireless volunteer hours from women, many HIV positive, who are already tasked with significant responsibilities.

"Populations vulnerable to HIV…come from many different cultures and social settings. They have different and specific needs with regard to HIV/AIDS education and prevention, as well as, more broadly, health promotion. The means, language, locations and partners needed to effectively reach a particular population will…be specific to that population."[335] "'[C]ultural competence' refers to programming that incorporates the active involvement of individuals from differing cultural contexts in the design, implementation, and evaluation of HIV[/AIDS]…interventions so as to ensure that community-based values, traditions and norms are not overlooked or assumed in the planning phases of HIV[/AIDS]…activities."[336] "Community involvement and mobilization, including that of people living with HIV/AIDS[,] has proven to be an essential element in an effective and sustainable response to HIV/AIDS."[337]

Including those with HIV as an integral part of the decision-making processes in the fight against HIV/AIDS has been called the Greater Involvement of People living with HIV/AIDS, or GIPA, principle. As Peg Frank further points out, actively involving women who are HIV positive means giving women the tools to become meaningfully involved. They need to have literature available, in the language they read and at a literacy level they comprehend. It means addressing the fact that HIV positive women have medical costs that drastically reduce their expendable income, so they may require financial assistance in order to travel to meetings or take courses to improve communications or negotiation skills. In order for them to be on a level playing field with financially backed stakeholders like government employees and pharmaceutical company representatives, their needs must be considered and addressed.

The International Community of Women Living with HIV/AIDS states "that when HIV positive people are involved at all levels of decision-making of an organisation, it is better able to respond to the concerns of people living with HIV/AIDS. Moreover, exposure to women, men and children living with HIV has a profound impact on attitudes to people living with HIV... To promote rights and to tackle the HIV/AIDS epidemic effectively, HIV positive women need to be taken seriously by policy-makers. The best way to challenge stigma and discrimination is to promote solidarity with and involvement of HIV positive people in all levels of decision-making, and to ensure this includes women."[338]

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