



The Community-Based Response to HIV/AIDS in British Columbia

A Discussion Paper

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About the Pacific AIDS Network

The Pacific AIDS Network (PAN) is a provincial network of 41 community-based organizations that are HIV/AIDS mission stated or run programs devoted to addressing the care, treatment, support or prevention-education needs of persons living with HIV/AIDS (PHAs) or those “at risk”. With a large geographically dispersed province like British Columbia, with unique challenges that often vary from region to region, the network fulfills a critical role.

PAN is a pro-active member-based coalition that provides a network to support the abilities and efforts of member organizations to respond to the epidemic in British Columbia. PAN provides education and skills development integrated with face-to-face networking opportunities; inter-agency mutual support; and undertakes collective action to inform public perceptions and policies affecting people living with HIV (PHAs). PAN’s vision is to create a future where member organizations are making demonstrable and consistent progress in ending the HIV epidemic in British Columbia and PHAs have improved health outcomes, choices and freedoms to equally participate in society.

By providing skills-building and workforce development opportunities to staff and key volunteers, member organizations are provided with the opportunity to explore, learn best practices and network with their peers from around the province. Content specific to those living with HIV has also been developed to provide PHAs with similar opportunities for skills development and networking. PAN therefore works to increase the local, regional and provincial capacity of HIV/AIDS service providers to develop and implement culturally appropriate and sustainable skills/strategies that enhance programming and the quality of life of PHAs. By providing PHAs and service providers with the opportunity to explore best and promising practices, the network strives to ensure that those living with HIV, as well as those most at risk, can receive the best care, treatment, support and prevention/educational information possible.

PAN is also working in active partnership with the Ontario AIDS Network (OAN) to deliver leadership development training to PHAs in BC. This is a peer-driven and delivered professional development opportunity dedicated to assisting PHAs in realizing their individual leadership potential, in order that they might make a greater contribution in their communities either as volunteers or as members of the work force.

HIV/AIDS represents a significant public health risk to the province

More than 20 years after its emergence, HIV/AIDS continues to be a serious public health threat globally and locally and despite the advent of successful treatment regimes, there is no “cure” for HIV. The face of the epidemic in BC is complex and ever changing. With the increase and in some cases a marked resurgence of HIV incidence rates among certain segments of the population, the epidemiological evidence suggests permanent vulnerability.

Gay men, men who have sex with men and injection drug users continue to carry a large share of HIV/AIDS cases in BC, while the disease is increasingly affecting individuals outside these groups. Of particular concern, HIV rates are growing at an alarming rate among Aboriginal people, the poor, and the homeless among others.

Medications for the treatment of HIV, such as anti-retroviral therapies, are not only expensive but come with a myriad of side-effects. Many people who are living with HIV in BC are not accessing the treatments that are available.

Prevalence:

In 2005, there were 8,600 to 12,200 people in BC living with HIV/AIDS, for an estimated median prevalence of 10,420 people. This represented approximately 18 per cent of the estimated 58,000 Canadians living with HIV and AIDS in 2005. Given that BC represents approximately 13 per cent of the overall population in Canada; **this province has a disproportionate share of HIV burden.** (Public Health Agency of Canada Epi-Updates 2007)

It is estimated that there are 3321 people in BC who are HIV+ but unaware of their status. These undiagnosed infections represent a significant “hidden epidemic”. (BC Centre for Disease Control HIV/AIDS Annual Report 2007)

In 2007, the total number of persons living in the province who had been diagnosed with AIDS was 4,169 (cumulative from 1983 to December 2007). The total number of people known to have died from AIDS in BC was 3117. A total of 61 persons were diagnosed with AIDS in 2007. (BC Centre for Disease Control HIV/AIDS Annual Report 2007)

Incidence:

The provincial rate of new infections also speaks to the disproportionate impact of the epidemic in BC. In 2006, there were 357 new HIV+ tests in BC. In 2007, there were 395 new tests, representing a 10.6 % increase. The rate of new infections for BC was 9.1 NI/100,000 people versus 7.5 NI/100,000 people in Canada. **Our province therefore continues to have one of the highest rates of new infections in the country.** (Ministry of Healthy Living and Sport Priorities for Action: Managing the Epidemics HIV/AIDS in BC 2003-2007, 2007 Annual Progress Report)

Multiple Vulnerabilities:

HIV and AIDS can affect anyone of any age, gender, ethnicity or social status. Any person who engages in a risk behavior can become infected with HIV. However, a number of other social and personal factors contribute both to HIV infection rates and the obstacles experienced by British Columbians when trying to access appropriate care, treatment and support – factors such as gender inequality, racism, and other forms of stigma and discrimination, higher-risk sexual activity, mental health issues, unsafe drug and alcohol use. Poverty, homelessness or substandard housing, lack of social support networks, lack of access to health care services...when combined with HIV, the result is a toxic mix. Populations and persons who exist more at the margins of society are particularly vulnerable to and disproportionately affected by the epidemic in BC.

For example, there is a serious and growing HIV/AIDS epidemic in the Aboriginal population in BC. In 2007 Aboriginal British Columbians comprised 13.4 percent of all persons testing newly positive, despite comprising only 5 percent of the overall provincial population. Aboriginal women are particularly being impacted, accounting for 35.7 per cent of all newly tested women in BC. (BC Centre for Disease Control HIV/AIDS Annual Report 2007) Within Vancouver's Downtown Eastside, a recent study reports that Aboriginal intravenous drug users are contracting HIV/AIDS at twice the rate of non-Aboriginal users. (Wood et al., 2008) Furthermore, Aboriginal people living with HIV are more likely to die from AIDS without ever accessing antiretroviral therapy despite the distribution of these medications free-of-charge. (Wood, Montaner, Yip, Schechter, & Os, 2003)

The legacy of racism, cultural denigration and colonialism of Aboriginal people in Canada is sadly obvious. 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. All of these issues contribute in some way to an increased risk for contracting HIV.

Looking at other populations that have particular vulnerabilities, HIV/AIDS continues to be a real threat within the gay community, and in fact is demonstrating a concerning resurgence. In 2007 gay men and MSM accounted for 43.3 percent of new infections acquired in BC, a demonstrable increase since 2001 when that figure was 34.5 percent. (BC Centre for Disease Control HIV/AIDS Annual Report 2007)

PHAs in BC are also more susceptible to other health problems, especially where poverty, homelessness, unemployment or other variables are a factor. For example, four out of five persons living with HIV/AIDS/HCV in BC experience a mental health disorder (including substance use/misuse). Yet, despite the high prevalence of rates of mental health conditions among PHAs in BC, only 10.7 percent have been able to access formal mental health supports. Thus mental health conditions affect people living with HIV/AIDS/HCV in BC at four times the rate of the Canadian adult population and yet they access mental health support services at 1/4 of the rate of the "average Canadian". (Source: Dingwall, 2008).

Hepatitis C and co-infection with Hepatitis C (HCV) is also a grave concern. As at 2007, the BCCDC estimated that there are between 1050 and 2625 persons in BC that are co-infected with HIV and HCV. The rate of new infections for BC was 67.6 NI/100,000 people versus 36.8 NI/100,000 people in Canada. **Our province therefore ranks #2 of all Canadian provinces and territories for both incidence and prevalence of HCV**, with between 37 percent and 90 percent of persons with HCV co-infected with HIV. (BC Centre for Disease Control HIV/AIDS Annual Report 2007)

Every infection represents significant social & economic costs to the province

Preventing the transmission of HIV not only saves lives and alleviates suffering, but also potentially mitigates the immense economic and social costs inherent in each new infection. Hence, beyond the ethical and moral considerations, clear economic justifications exist for maintaining the investment in combating the epidemic, shoring up prevention efforts, and ensuring the necessary treatment and support to persons living with HIV.

Extensive research has been conducted in the United States (Holtgrave), Canada (Spigelman) and in other jurisdictions around the economic case for HIV prevention. In cost of illness (COI) studies, “direct costs” represent the value of resources used to treat the illness. “Indirect costs” represent the productivity losses (future income) of mortality and time away due to disability. The direct costs of HIV disease are a “moving target” because of the steady development of new, often expensive, HIV medications and the costs of treating the side effects of such medications.

Applying the economic evaluation technique of threshold analysis to a BC context, in 2003, it was estimated that the direct lifetime medical care and treatment costs were \$180,000 per person. Indirect social costs relating to a loss of productivity and premature death were estimated to be as high as \$1 million per person (Martin Spigelman Research Associates Organizing for Effective Action: Health Care Restructuring and HIV/AIDS in British Columbia 2003). Applying those figures to the year for which the most recent surveillance data is available for BC, the 395 new positive tests in 2007 represent:

- **an estimated \$71.1 million in direct lifetime medical care and treatment costs; and**
- an additional \$395 million in indirect social costs.

These are 2003 figures, and it may be safely presumed that in 2009, some increase would be attributed due to inflation – hence the combined figure of \$466 million is highly conservative.

Community Based AIDS Organizations (CBAOs) play a cost-saving and cost-effective role in addressing the HIV/AIDS epidemic in BC

Since the HIV/AIDS epidemic first began, in response to emerging and urgent needs, community-Based AIDS Organizations (CBAOs) have provided services and programs that have been flexible, timely, innovative and creative, often with minimal financial resources. In many BC communities and for many people infected and affected by HIV/AIDS, grassroots, community-based organizations continue to be the primary providers of HIV-related prevention and support services as well as non-medical care. CBAOs have also brought the lived experiences of persons living with HIV/AIDS (PHAs) and those most at risk “to the table”, calling attention to the prevention, care, treatment and support needs of some of the most marginalized people in our society.

The province of BC has one of the most sophisticated and effective networks of CBAOs in Canada, the importance of which was recognized by the Ministry of Healthy Living and Sport when it stated in its most recent annual report:

According to 2007 data available from health authorities, community organizations across the province continued to deliver support services to an increasing number of people living with HIV. **These services are an important component of a comprehensive and integrated continuum of care for people with HIV/AIDS.** Further efforts to strengthen the links between community support programs and clinical services are needed to increase uptake of care and treatment by underserved populations....

... The Ministry of Healthy Living and Sport recognizes the commitment and dedication of local community agencies and partners in providing care, treatment and support to those most affected or most vulnerable to the HIV epidemic. These include marginalized and hard-to-reach populations in communities and regions throughout the province. **The knowledge and trust developed by these organizations in their work with clients – often those most vulnerable to disease and least able to access treatment – are essential for a comprehensive and effective community-based response to HIV.**(Priorities for Action: Managing the Epidemics HIV/AIDS in BC 2003-2007 – 2007 Annual Progress Report)

Recently we have witnessed increasing attention and in some cases allocation of significant resources to important biomedical approaches such as microbicides, antiretroviral prophylaxis, reduction of population or ‘community’ viral load through antiretroviral therapy i.e. “expanded HAART”, and vaccines. For example, in 2007, the Government of Canada announced it would commit up to \$111 million to the Canadian HIV Vaccine Initiative.

We were also intrigued by Premier Gordon Campbell’s announcement in April of this year in Vancouver during the national Canadian Association for HIV/AIDS Research (CAHR) conference that \$20 million a year would be dedicated for a pilot project dedicated to increasing

access to HAART for persons living in Prince George and the Downtown Eastside. We applaud the Premier's stated interest in expanded HAART, as so vigorously advocated for by Dr. Julio Montaner, Director of the BC Centre for Excellence in HIV/AIDS of the BC Centre for Excellence, and the stated desire to drastically increase access to HAART among vulnerable communities in BC.

At the same time, we maintain that treatment and bio-medical approaches are not enough. In the words of Dr. Montaner himself, expanded HAART must take place "as part of a comprehensive care and support package". This is consistent with extensive research that demonstrates that biomedical approaches and interventions delivered by health professionals, absent a community base, are less successful (M. W. Ross & Williams, 2002; Kourtis et al., 2006). CBAOs in BC have and will continue to play a key role, especially among the growing population of persons with HIV who are substance abusing, homeless, or suffer from mental illness.

In addition to being essential, the prevention, care and support interventions provided by CBAOs can be both cost-saving (the medical and other costs averted by a community program outweigh the cost of service-delivery: a high standard) as well as cost-effective (where the community program does not actually save public money but the cost-per-quality-adjust-life-year saved is considered reasonable relative to other readily accepted medical and public health interventions: a lower standard). (US Centers for Disease Control, Compendium of HIV Prevention Interventions with Evidence of Effectiveness, Collins, et. al., 2007, Eke, et. al., 2006)

Cost-saving and cost-effectiveness happen in a number of ways. CBAOs in BC significantly rely on volunteers to deliver services and programs to PHAs and those most at risk, which represents millions of dollars in value to society. Furthermore, the prevention and education efforts, that help to prevent new infections; and the support and care services, that help improve the quality of life, health prognosis and wellness of PHAs - delivered by CBAOs - save the province significant amounts by averting acute health care costs.

Conclusion

HIV/AIDS issues in BC need to be addressed in a comprehensive, coordinated and holistic fashion, with a view to broader socio-economic, health and cultural issues. CBAOs are in a unique position to address the social determinants of health that place people at risk of infection; those same determinants also shape the experience of PHAs including their quality of life and long-term prognosis.

Stemming the epidemic will continue to require a multi-sectoral approach and continued and strengthened partnerships between PHAs, the regional health authorities, the Ministry of Health, the MOHLS, other ministers and community organizations including CBAOs.

We applaud your government's commitment to innovative harm-reduction initiatives such as INSITE, your long-standing support of the BC Centre for Excellence in HIV/AIDS, and your interest in expanded HAART. However, we also look to you for support of community-based organizations, the agencies who are working "on the ground" in battling this epidemic. The member agencies of the Pacific AIDS Network call on you to ensure that past efforts are not lost and that we continue to move forward in partnership in addressing this epidemic.

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