

A Proposed HIV/AIDS Strategy for Ontario to 2008

**Prepared by the Ontario Advisory Committee
on HIV/AIDS (OACHA)**

June 2002

Preface

Over the past five to eight years, there have been significant changes in: our ability to treat HIV, the course of the disease, the public and media attention given to HIV, and the spread of the virus. Because of these changes, the Ontario Advisory Committee on HIV/AIDS (OACHA) believes it is time to reinvigorate Ontario's response to HIV and develop a new provincial strategy.

Since 1985, when the government first began funding HIV initiatives, the HIV community has played a lead role in planning and implementing strategies, programs and services. This strategy is no exception. The OACHA strategy development process involved:

- analyzing the data on HIV infection in Ontario and Canada
- reviewing strategies developed in other jurisdictions
- surveying organizations in Ontario that provide HIV/AIDS prevention education, care, treatment and support
- surveying people living with HIV
- conducting Delphi groups with HIV stakeholders to identify key issues and possible strategies
- establishing an expert group to identify process and outcome indicators and develop a monitoring/evaluation plan for the strategy
- conducting focus groups across the province to review and refine the draft strategy.

For more information on methodology, see Appendix I.

Two other distinct strategic initiatives contributed to the OACHA strategy process: the Ontario Aboriginal HIV/AIDS Strategy and the Strategy to Address Issues Related to HIV Faced by People in Ontario from HIV Endemic Countries. Representatives of those two strategies were members of the OACHA HIV/AIDS Strategy Subcommittee. OACHA endorses both these strategies. These strategies are included as Appendices IV and V.

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In particular, OACHA would like to thank the many HIV stakeholders who participated in the two Delphi Groups and eight focus groups to develop and refine the strategy.

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The Aboriginal Strategy

OACHA gratefully acknowledges the work of the Reference Group in the development of *A Strategic Plan for the Years 2001 - 2006* for Aboriginal Canadians. The Reference Group was comprised of representatives from:

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Off-reserve organizations
Aboriginal PHAs
Elders
The Ministry of Health and Long-Term Care.

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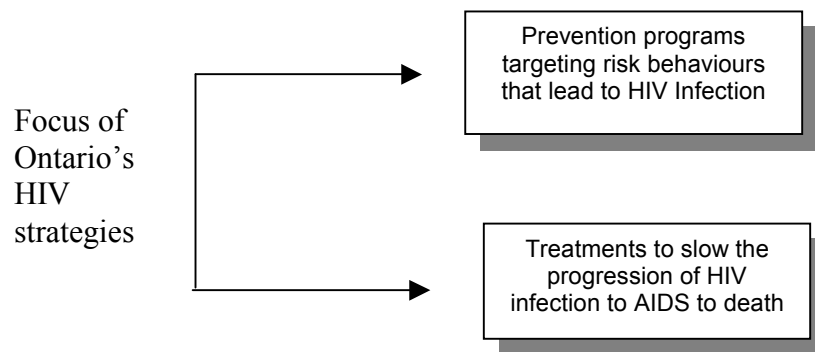
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Executive Summary

Ontario's Current Response to HIV

In the mid 1980s, when little was known about HIV and people died within months of diagnosis, Ontario's response to HIV focused on stopping the spread of HIV and caring for those who were infected. Its strategy was to:

- target the behaviours that put people at risk of acquiring HIV (i.e., unprotected sex and needle sharing)
- identify and provide treatments that would slow the progress from HIV infection to AIDS and keep people alive (i.e., treating opportunistic infections, developing anti-retroviral therapies).



For a time that strategy was effective. Between 1990 and 1997, the number of new cases of HIV infection diagnosed each year in Ontario dropped by more than 50%, from a high of more than 2,091 to 961¹.

Over the same period, our ability to treat HIV infection also improved dramatically. The number of deaths from AIDS dropped significantly during the mid to late 1990s, and the number of people living with HIV has grown. By the end of 2000, a total of 21,272 people in Ontario had been diagnosed with HIV, and about 14,612 – or about 69% – were still alive².

Yet, despite the progress that has been made, **HIV continues to be a serious, unstable, infectious, life-threatening illness.** While there has been a decrease in new infections, the incidence of HIV in Ontario each year is still unacceptably high.

¹ Remis et al. Report on HIV/AIDS in Ontario 2000. Ontario Ministry of Health and Long-Term Care. December 2001.

² Ibid.

Emerging Trends

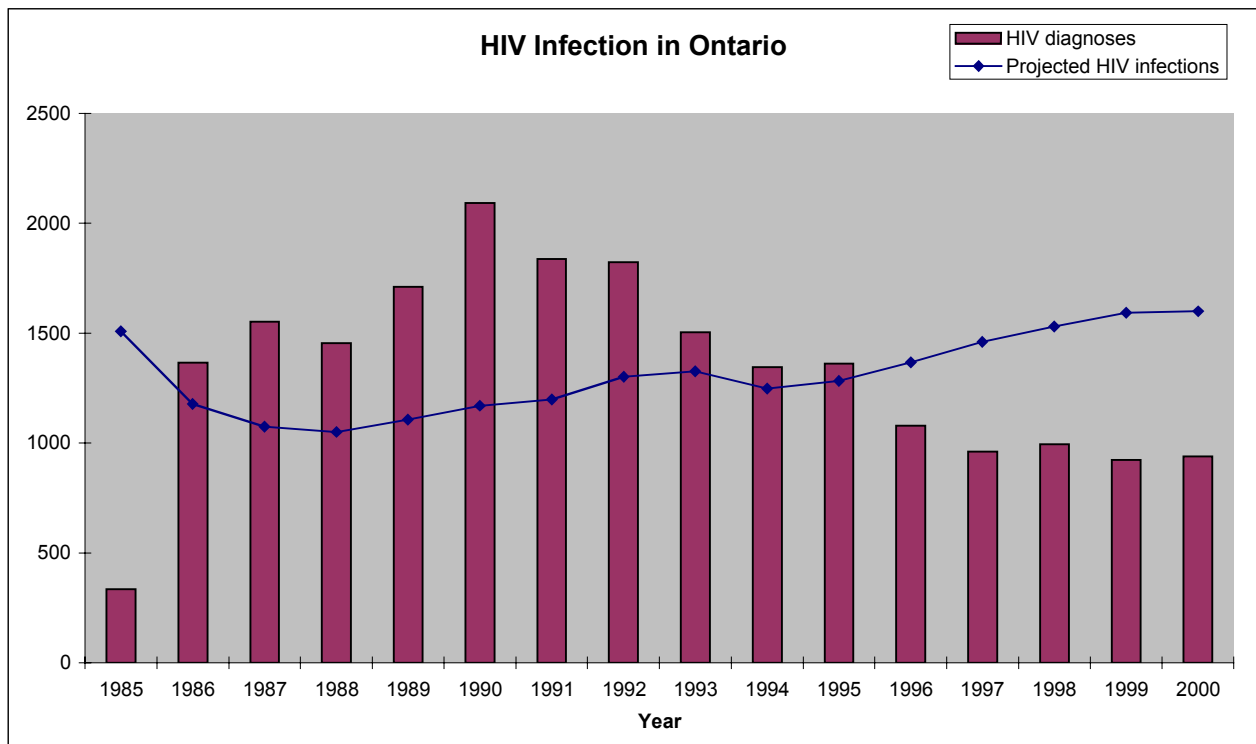
New Infections

Over the past three years, there are disturbing signs that the gains Ontario made in the 1980s and 1990s in preventing HIV have stalled. The epidemic continues and may be getting worse:

- Between 1997 and 2000 – for the first time since the mid 1980s – the number of new infections diagnosed each year stopped declining and remained steady between 900 and 1000.
- In 2000, there were indications that the rate of new infections may be increasing in certain populations, in certain parts of the province.

Undiagnosed Infections

What we know about new infections is cause for concern, but what we do not know may be more alarming. The number of new diagnosed cases of HIV understates the actual number of new infections occurring in Ontario. While we know that 21,272 people have been diagnosed with HIV in the province since the beginning of the epidemic, modeling and prevalence studies suggest that as many as 27,241 may actually have been infected. That means there may be almost 6,000 people who do not know they are infected, and who are not receiving appropriate treatment or information about preventing transmission. The following chart shows the actual number of diagnosed HIV infections each year since 1985, as well as the total number of projected infections.



Growing, Changing Caseloads

Because of improvements in treatment, more people with HIV are living longer in better health. The number of people who need ongoing care and treatment has increased from about 7,000 in 1990 to more than 14,000 in 2000. This growing caseload is putting pressures on the agencies, physicians and health care providers that provide care, treatment and support. Organizations that used to serve clients for a relatively short period of time (i.e., six months to two years) and focus more on end-of-life services may now provide services for the same client for 10 to 15 years or longer, and be dealing more with issues, such as support for life-long prevention, employment and other health and social needs.

Treatment Issues

Despite the steady progress that has been made in treating HIV, the treatment situation is not stable. There are signs that some treatment regimens may be faltering and losing their efficacy over time. Physicians are reporting more problems with resistance to and side effects from anti-retroviral drugs used to treat HIV. The long-term toxicity associated with anti-retroviral therapy are potentially life-threatening, and researchers predict that a preventive vaccine is still many years away.

Increasing Complexity

HIV is more than a health problem. The needs of people and communities affected by HIV are becoming increasingly complex. Determinants of health, such as poverty, marginalization and homelessness, are contributing to new infections, while a broad range of health and social needs, such as addictions, mental illness, legal problems or income/employment issues, are affecting the ability of people living with HIV to maintain their health.

Pressures on the Health Care System

Over the past 17 years, Ontario has developed an extensive infrastructure of HIV/AIDS programs and services (see Appendix II). While the funding for HIV-related services has remained relatively stable in most areas and increased in others³, the HIV infrastructure – like all parts of the health care system – is under stress. HIV programs are now managing more clients with increasingly complex needs. Like the rest of the health care system, the HIV infrastructure is also under increasing pressure to demonstrate that its resources are being used effectively and having a positive impact. Because most HIV programs and services developed in the 1980s and early 1990s, in response to the AIDS crisis and before the development of anti-retroviral therapy, there is some question whether there are more effective ways to structure,

³ In fact, since 1998, the ministry has provided almost \$13 million more each year in funding for HIV services (not including the drug costs covered by the Trillium program): \$8 million to support the Ontario HIV Treatment Network (OHTN), \$1 million for IDU outreach program, \$1 million for community-linked evaluation of AIDS programs/services, \$1 million to increase the base operating funding for AIDS service organizations, \$.789 million for the HIV prenatal screening program and \$50,000 for the infant formula program.

organize and deliver services to meet the changing needs of people living with HIV and populations at risk.

Changing Attitudes

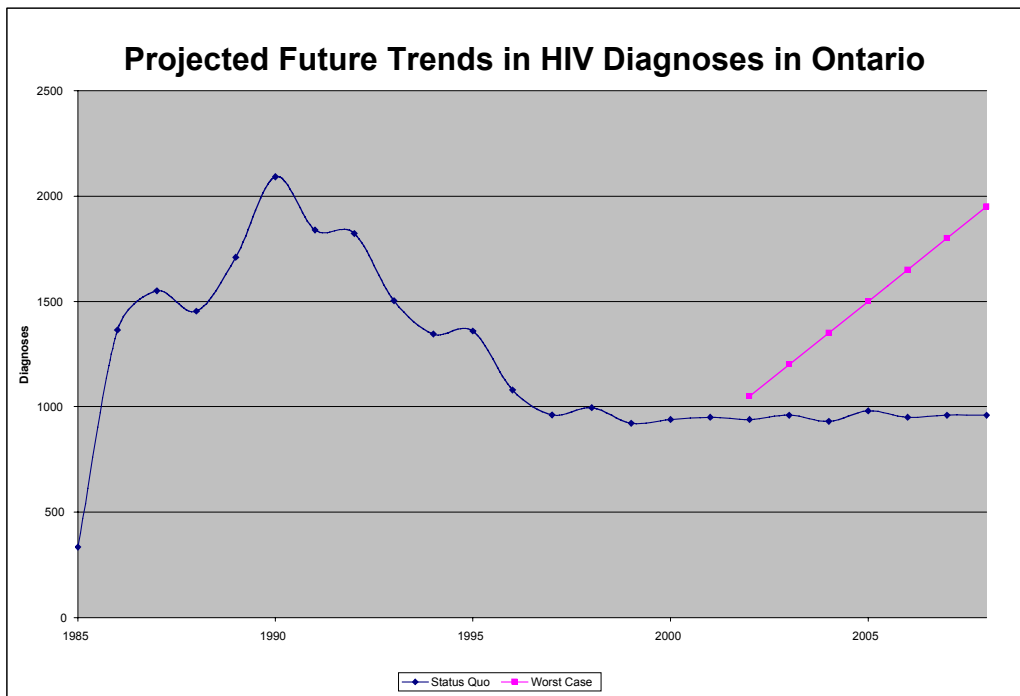
These increasing pressures are occurring at a time when there is little public or media attention being given to HIV, and less community support than existed in the 1980s and 1990s. This makes it significantly more difficult for agencies to deliver prevention messages.

The Challenge in 2002

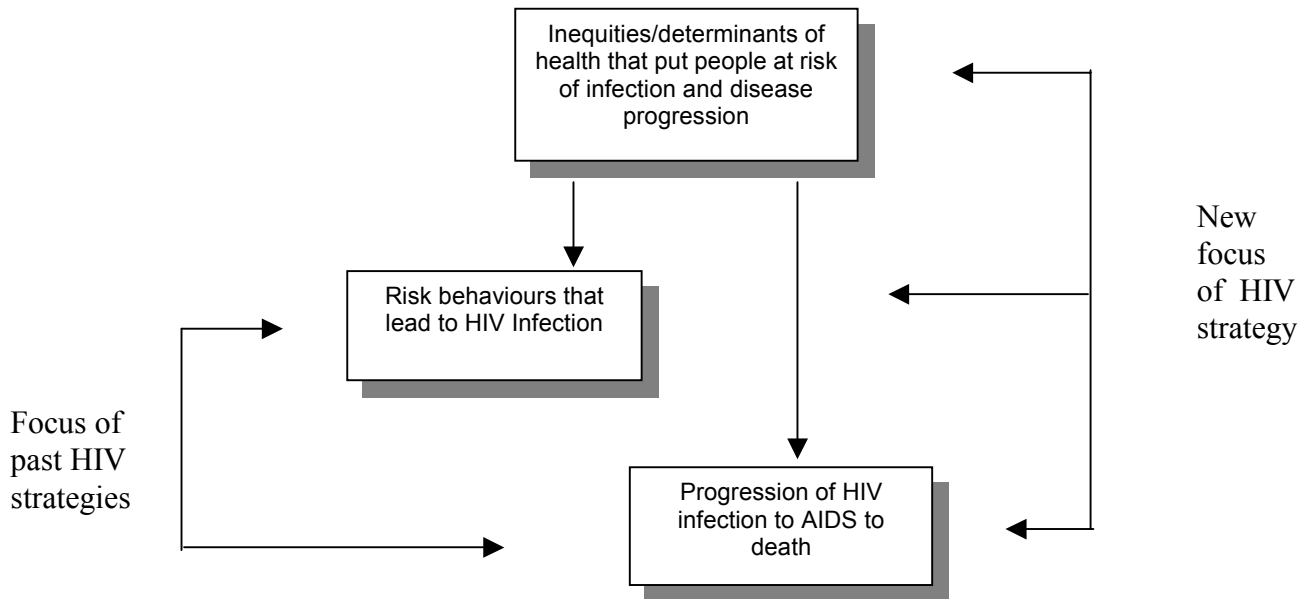
The challenge for Ontario over the next five to 10 years will be to maintain its investment in the treatment and prevention programs that have slowed the transmission and progression of HIV while, at the same time, identify innovative ways to respond to emerging trends and issues.

It appears that Ontario's strategy of targeting the risk behaviours that lead to HIV infection and the epidemiology of the disease itself can only do so much.

If we continue with the same approach and strategy that we have used in the past, the epidemic will either continue at the same level or, in a worst case scenario, it will move aggressively in some populations and we could see a doubling of diagnoses by 2008. With either the status quo or the worst case scenario, the health and social costs associated with HIV will continue to rise.



If we wish to make more progress, to keep reducing the number of new cases and prolonging lives, we must attempt to address the inequities that put people at risk and the broader health and social problems that affect health.



At the same time, we must be able to demonstrate our ability to manage our resources effectively by investing in evidence-based programs and services, and identifying ways to collaborate and share or leverage resources to meet clients' needs.

Goals

The goals of Ontario's new response to HIV/AIDS are:

- to prevent the spread of HIV
- to improve the health and well-being of people living with HIV and their communities.

Targets and Outcome Measures

NOTE: OACHA is in the process of identifying targets for the new strategy, and intermediate and ultimate indicators that can be used to assess progress in achieving those targets. The measures are likely to include:

- *behavioural indicators, which would indicate whether people are taking steps to reduce their risk*

- *surrogate indicators, such as rates of other STDs (e.g., rectal gonorrhoea) which would indicate whether people are continuing to engage in activities that put them at risk*
- *HIV indicators, such as the number of new infections in certain populations (i.e., gay men, IDUs, people from endemic areas).*

OACHA is also developing targets/measures that can be used to assess quality of care, access to care, and the impact of treatment on health and productivity.

The actual targets/timelines will depend on whether the strategy is approved in its entirety and the resources available to support it.

Policy Directions

To achieve these goals and targets, Ontario will pursue four key policy directions over the next five years:

1. Adopt a determinants of health approach; address social justice issues

HIV is more than a health problem. A wide range of social, economic, environmental and health factors contribute to the epidemic. Ontario will work to reduce the inequities that put people at risk of infection or at risk of disease progression, adopting a determinants of health approach and addressing related social justice issues, such as poverty, housing, and marginalization, as well as health issues.

2. Focus on long-term, integrated, sustainable, targeted responses

Over the past 17 years, Ontario has developed an extensive infrastructure of HIV/AIDS programs and services. To ensure that infrastructure continues to respond effectively, Ontario will re-examine its programs and services, looking for opportunities to integrate activities within the infrastructure and with other health and social services. It will ensure that resources are used judiciously and invested in programs and services that are effective. It will also target its efforts to populations most affected and/or at risk, and develop long-term, sustainable services that can respond more quickly and appropriately to changing needs.

Link with the Canadian Strategy on HIV/AIDS (CSHA)

Ontario's strategies are consistent with the Canadian Strategy on HIV/AIDS:

1. Mobilize integrated action on HIV/AIDS
2. Build unique approaches for Aboriginal people
3. Build a broad information strategy
4. Get public commitment, political leadership, and funding
5. Build a strategic approach to prevention
6. Build a strategic approach to care, treatment and support
7. Renew and develop human resources
8. Engage vulnerable Canadians
9. Move to a social justice framework

3. Develop a flexible provincial response to HIV that takes into account local/population needs.

The epidemic – the numbers, the populations most affected, the needs and the services – varies significantly in different parts of the province, in large versus medium-sized centres, and in urban versus rural and remote areas. In each of the populations most affected and most at risk, the cultural drivers of the epidemic and the prevention and care/treatment approaches are also quite distinct. Ontario's HIV strategy must be flexible enough to respond to the different cultural drivers of the epidemic, to recognize the impact of geography on delivering services, and to reflect regional/local needs and services.

4. Improve Ontario's capacity to respond effectively through improved monitoring and accountability.

Over the past 10 years, there has been extreme pressure within the health care system to manage health budgets efficiently and ensure greater accountability. Ontario's HIV programs and services are committed to providing high quality, evidence-based services. Ontario will increase its capacity to respond to HIV, and develop the information and monitoring systems that will ensure accountability, demonstrate the value of HIV programs, and lead to better, more responsive services.

Proposed Strategy

Over the next five to 10 years, the Ontario Advisory Committee on HIV and AIDS (OACHA) proposes a more comprehensive approach to fighting HIV: one that takes into account the factors that put people at risk of infection and disease progression, the dramatic changes that have occurred in the course of HIV infection, the increasing complexity of client needs, the services in place, and the need for new leadership.

That approach has five main strategies:

1. Knowledge

Develop, disseminate and apply the knowledge required to monitor and understand the epidemic, improve prevention programs, improve care and treatment services, and develop effective strategies to influence the determinants of health.

2. Leadership/Integration

Foster leadership for an integrated approach to HIV prevention, support, care and treatment based on the determinants of health.

3. Services

Ensure that everyone in Ontario who could benefit from HIV prevention, support, care and treatment services as well as other related health and social services has access to them.

4. Resources

Ensure adequate resources for HIV and related programs and services.

5. Accountability

Ensure HIV programs and services are accountable for the quality of their services and their use of resources.

OACHA believes that the implementation of this strategy has the potential to dramatically change the course of the epidemic in Ontario, improve the health of people affected, and reduce the long-term health and social costs.

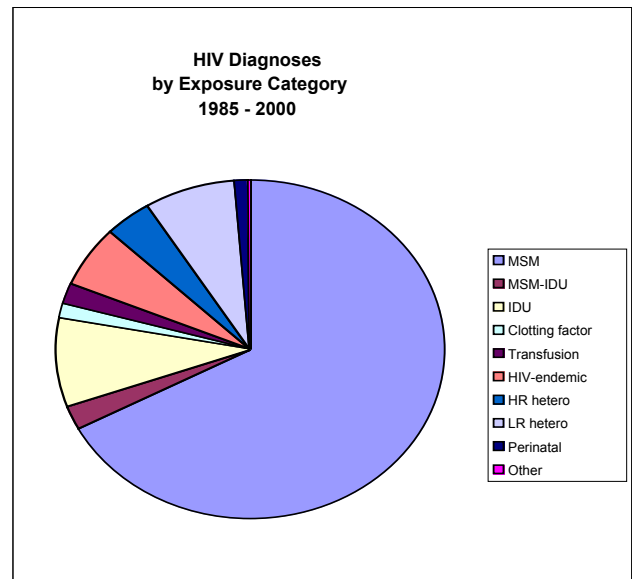
I. HIV in Ontario in 2002

To develop an effective strategy, it is vital to understand the nature of the epidemic: who is infected, what changes have occurred in the disease, what are the emerging trends and issues?⁴

1. Who is Infected?

Between 1985 and 2000, about 67% of HIV diagnoses in Ontario were in gay men.

Over that same period, 11.4% of diagnoses were in heterosexuals, 8.7% were in injection drug users (IDU), 6% were among people from countries where HIV infection is endemic (i.e., parts of Africa and the Caribbean), and 3.1% were in infants, with a disproportionate number of infected infants being born to women from endemic areas⁵. Although information from the Ontario testing system does not tell us much about infection among Aboriginal people, data from other sources indicates that this community has been disproportionately affected by HIV.



Gay Men

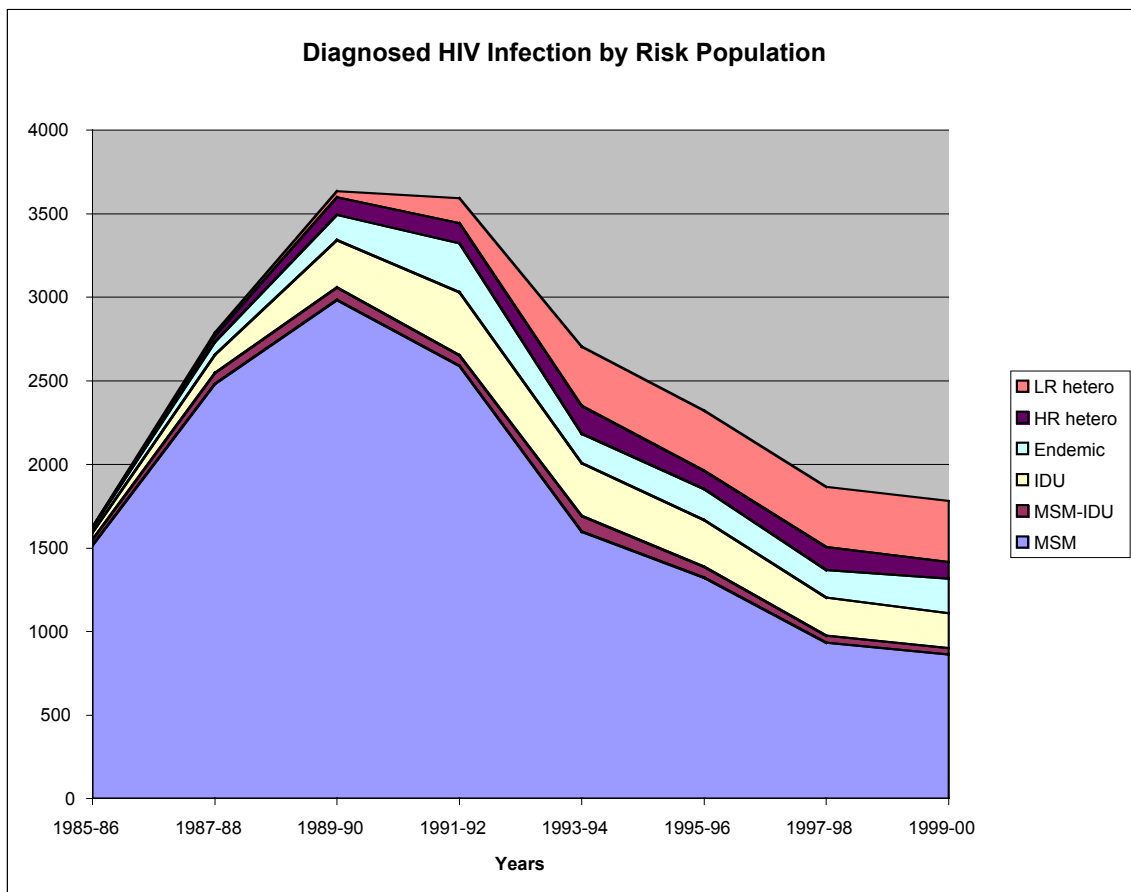
In the early days of the epidemic, HIV primarily affected gay men, and that is still the case today. Although the rate of new infections in gay men dropped significantly during the early 1990s (the result of awareness, prevention and community support initiatives launched in the 1980s), gay men still account for almost half of all new infections each year.

From the beginning of the epidemic until December 2000, 14,277 gay men plus 483 gay men who also inject drugs had been diagnosed with HIV. In 2000 alone, the number of newly diagnosed infections in gay men was two to three times as high as the number in the next largest affected population.

⁴ Most of the data that Ontario has on people infected with HIV comes from the laboratory testing system. When physicians request an HIV test, they are asked to identify any behaviour(s) the person has engaged in – such as men having sex with men, injection drug use, heterosexual intercourse – that may have put the person at risk of acquiring HIV. Most of the check boxes on the requisition form are for specific risk activities, but some – such as perinatal infection and being from an area where HIV is endemic – focus on other factors that put people at risk and help epidemiologists understand the disease.

⁵ Remis et al. Report on HIV/AIDS in Ontario 2000. Ontario Ministry of Health and Long-Term Care. December 2001.

Of particular concern is the increasing rate of infections among gay men who are repeat testers.⁶ For the past few years, epidemiologists have been monitoring people who repeatedly test for HIV. These are people who are believed to be involved in



high-risk activities (e.g., unprotected anal sex) and are using the testing system to monitor their health status.

The continuing and increasing HIV epidemic in gay men must be addressed. According to those who have looked closely at the issues contributing to the epidemic in gay men, this requires a new approach. "Our experience with the successes and limits of HIV prevention in the last two decades points to the increasing importance of seeing health in a holistic manner, taking into account both the whole person and the whole person's relationship to others and to the larger society. Those with the most experience in HIV prevention have come to realize, long before policy makers, that looking at HIV prevention among gay men without addressing the psychological, social, legal, political and economic contexts in which they live ignores major influences on their ability to make good decisions."⁷

⁶ In 1996, the rate of seroconversions in men who have sex with men was about 0.79 per 100 person years. In 1999, it was 1.39 per 100 person years.

⁷ Health Canada National Reference Group. Valuing Gay Men's Lives: Reinvigorating HIV prevention in the context of our health and wellness. 2001.

Injection Drug Users

As of December 2000, a total of 1,843 injection drug users had been diagnosed with HIV. In 1985, only two injection drug users were diagnosed with HIV and they represented only 0.5% of HIV infections. Between 1994 and 1999, the number of IDUs diagnosed each year with HIV numbered between 104 and 191, and accounted for between 11% and 14% of new HIV infections respectively.

However, in 2000, both the number (78) and proportion of new infections (8.3%) in IDUs dropped dramatically. This change is significant and is due, in part, to the new investment in both prevention/harm reduction programs (needle and syringe exchange programs, outreach, counselling) and treatment services for IDUs over the past few years. This indicates that increasing/enhancing these services have the potential to save more lives.

People From Endemic Areas

As of December 2000, approximately 1,274 people from areas where HIV is endemic had been diagnosed with HIV. Although people from areas where HIV is endemic make up less than .5% of Ontario's population, they account for 6% of HIV diagnoses. Based on statistical modeling, epidemiologists believe that the prevalence of HIV in this community is actually much higher. They estimate that over 2,600 people from endemic areas living in Ontario are infected, and over 1,600 are still undiagnosed. They also believe the number of new infections in this population is increasing at a rate of about 240 (10%) per year.

Efforts to provide prevention, support, care and treatment programs to people from countries where HIV is endemic are limited by the stigma associated with HIV in these communities. People who are diagnosed often tell no one, and have little social support within their community. Recent immigrants or those who are undocumented may not seek the care they need for fear that being diagnosed with HIV will affect their legal status in Canada. The ability of this population to respond to HIV is also affected by discrimination and racism.

In 1999, Toronto-area HIV/AIDS groups and programs (e.g., the Black Coalition for AIDS Prevention, Africans in Partnership Against AIDS, African Community Health Services, Youth Clinical Services Inc., Women's Health in Women's Hands, Rexdale Community Health Centre, and the Centre médico-social communautaire) and researchers at the University of Toronto Department of Public Health Sciences came together to form the HIV Endemic Task Force (HETF) and develop a strategy to address HIV/AIDS in communities of African and Caribbean descent.

Aboriginal People

Because Ontario does not collect data on the ethnicity of people who are infected, it is difficult to determine the prevalence of HIV in the Aboriginal community.

Based on data from the provinces that do collect information on ethnicity, Health Canada estimates that Aboriginal people, who make up only 2.8% of Canada's

population, accounted for 19.5% of new HIV infections in 1998, 25.8% in 1999 and 17.7% in 2000.

Health Canada also reports that, compared to other populations with HIV, the majority of Aboriginal people with HIV are younger, a larger proportion are women and a larger proportion are injection drug users. Based on the experience of Aboriginal HIV organizations in Ontario, gay and two-spirited men continue to be the most adversely affected by HIV (which is consistent with overall HIV trends in Ontario). The organizations are also seeing a significant number of women.⁸

In 1993, recognizing the risk of HIV in the Aboriginal population, the province supported the development of the Ontario Aboriginal HIV/AIDS Strategy, which has developed a new strategic plan for the years 2001 to 2006.

Heterosexuals

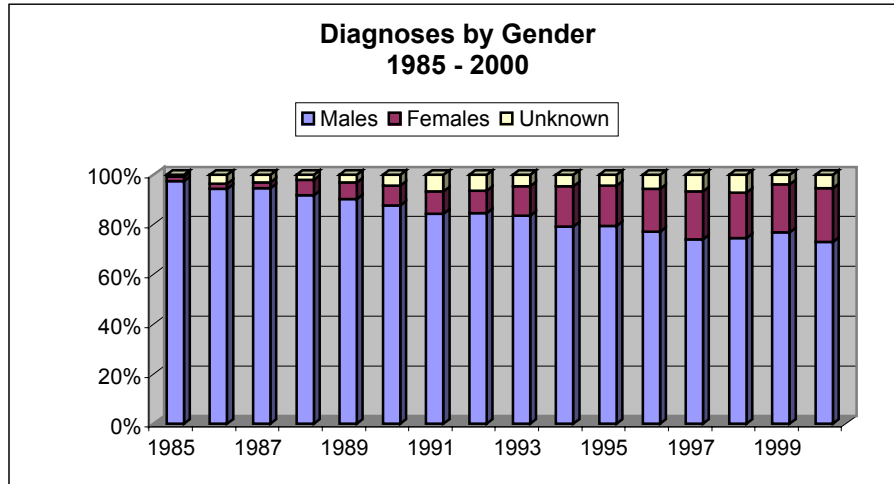
Since 1985, Ontario has recorded a total of 2,434 diagnosed infections in people who report themselves as being heterosexuals who are not IDUs or from areas where HIV is endemic. Of these infections, 792 or 33% are categorized on the HIV reporting form as “high risk” – that is, people who have a history of sexual contact with someone known to have HIV or someone at risk (e.g., a bisexual male, IDU, person from an area where HIV is endemic). The remaining 67% have been reported on the test requisition form as “low risk” – that is, people who have had sex with people of the opposite sex, none of whom were known to have HIV or to be at risk for HIV infection.

The number of new infections each year among “low-risk” heterosexuals has remained steady for the past eight years with no sign of decline. However, of the 1,642 low risk heterosexuals infected, 1,065 or about 65% are male. Given that it is more difficult for males than females to be infected through heterosexual contact, there is some concern that the risk exposure category is not being reported accurately. This requires further study.

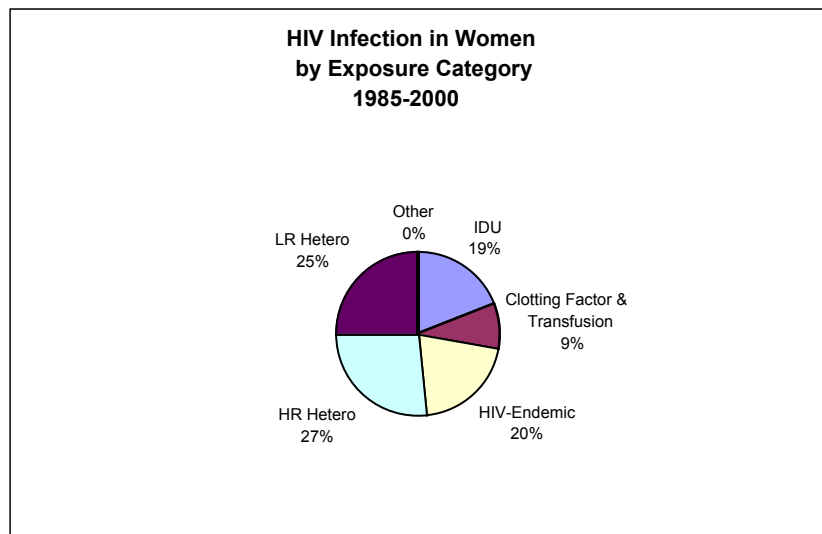
⁸ A Strategic Plan for the Years 2001- 2006. Ontario Aboriginal AIDS Strategy. February 2002.

Women

Since 1990, the number of adult women diagnosed with HIV in Ontario has ranged from 166 to 216 each year. Women account for about 20% of new diagnoses.



Of the 2,339 women in Ontario who have been infected, most are categorized in the testing data as high risk⁹ (630) or low risk¹⁰ (577) heterosexuals. Almost 25% are women who are known to be from countries where HIV is endemic and almost 25% are injection drug users. It is clear from this that women with HIV are not a homogeneous group. Efforts to prevent HIV in women and to provide care and support must take into account a range of factors, including their risks, and the support they may need, within their communities and their relationships, to make healthy decisions.



⁹ Women who had a partner involved in high-risk activities, such as injection drug use or men having sex with men.

¹⁰ No partner known to be involved in high-risk activities.

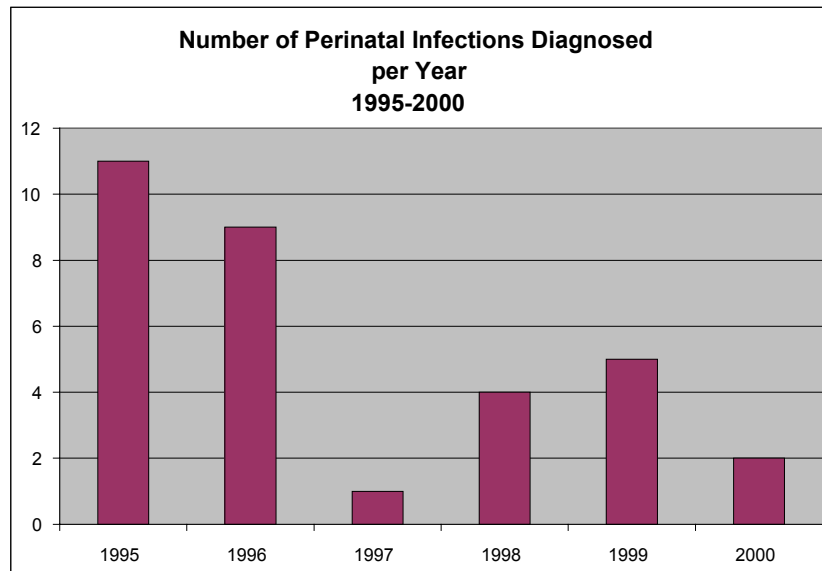
Infants

Of the 352 infants born to HIV-infected women between 1984 and 2000 in Ontario, 130 were infected. Most of these children were born to women from countries where HIV is endemic (79) or to women in the heterosexual exposure category (33). About seven were born to women who were IDUs.

With the development of prophylactic therapy in the mid 1990s, the proportion and number of infected infants each year has dropped significantly, from 11 in 1995 to two¹¹ in 2000.

However, despite the fact that Ontario provides free prenatal HIV screening for all pregnant women, less than 50% of pregnant women are being tested. This means that a number of women giving birth each year do not

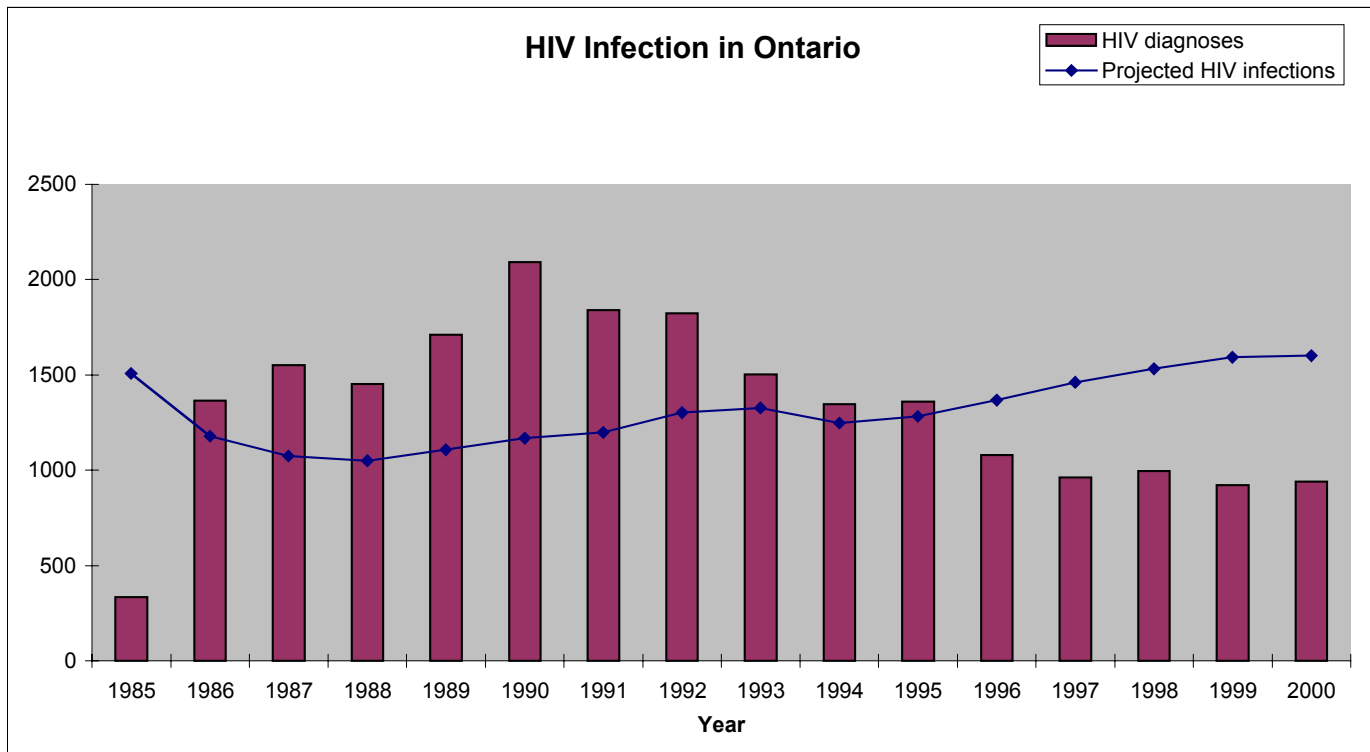
know they have HIV and, therefore, are not given the option of receiving treatment that could prevent perinatal infection.



Undiagnosed Infections

The number of HIV diagnoses provide only part of the picture of new HIV infections in Ontario. Since the beginning of the epidemic, a total of 21,272 people have been diagnosed with HIV in Ontario. However, modeling and prevalence studies suggest that as many as 27,241 may actually have been infected. That means there may be almost 6,000 people who do not know they are infected, and who are not receiving appropriate treatment and HIV prevention information. The following chart shows the actual number of diagnosed HIV infections each year since 1985, as well as the total number of projected infections.

¹¹ All infants born to HIV-infected women will have passive maternal antibodies. It can take up to 18 months for those antibodies to clear and for clinicians to determine whether the infant is positive or negative. At the time this report was written, only two of 29 infants born to HIV-infected women in 2000 were confirmed infected. However, five were still unknown.

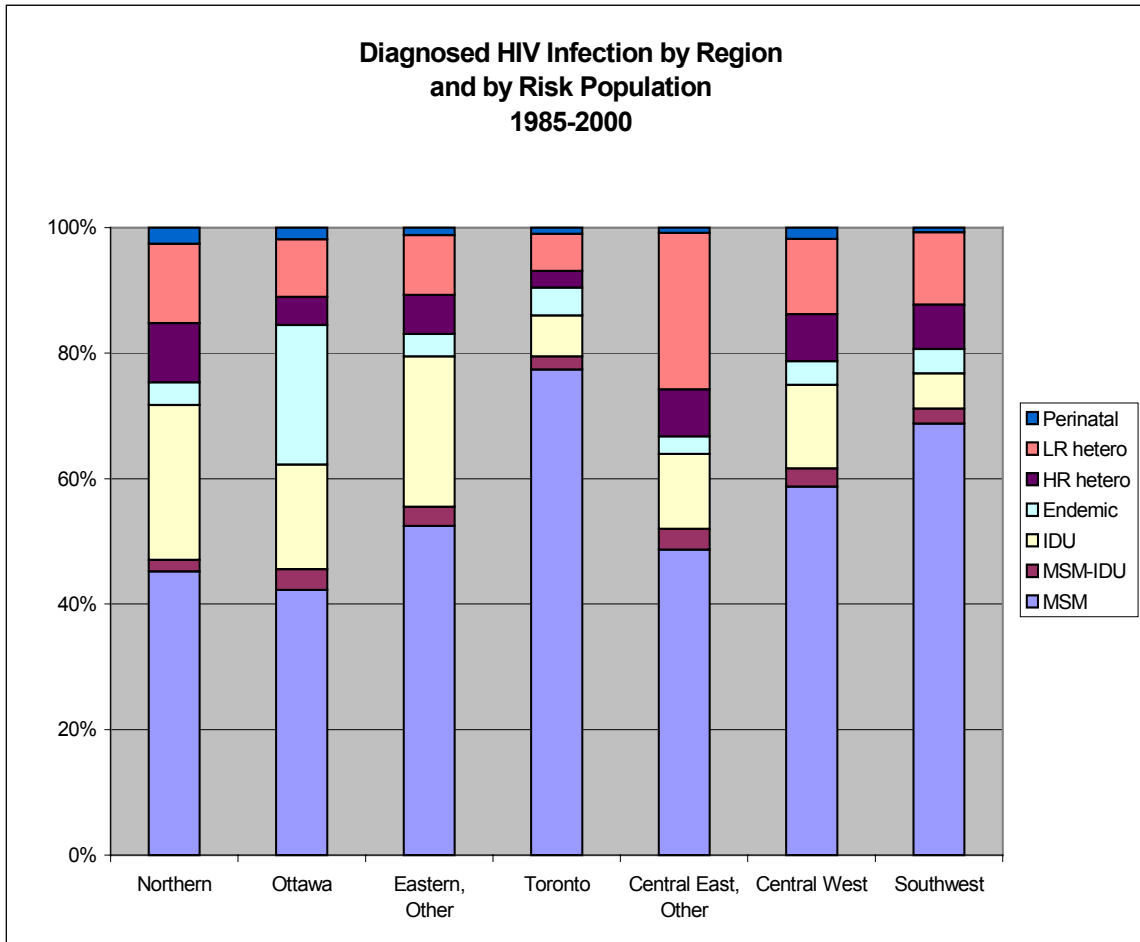


2. Emerging Geographic Patterns of Infection

Different patterns of infection are emerging in different parts of the province. For example, about 24% of HIV infections in Northern Ontario and 15% of HIV infections in Ottawa are in injection drugs users. These rates are significantly higher than the 6.2% of infections in Toronto attributed to injection drug use and the even lower rates in the rest of the province. These two areas of the province continue to show a pattern of IDU-related disease transmission that is not occurring in the rest of Ontario – although the number of new infections in IDUs in eastern Ontario (including Ottawa) dropped considerably in 2000. The north is also seeing a significant increase in the proportion of women infected.

Toronto and Ottawa have 46% and 42% respectively of all cases in people from countries where HIV is endemic. This reflects the large proportion of immigrants from Africa and the Caribbean who have settled in these cities. About 88% of babies diagnosed with HIV are also in Toronto and Ottawa.

Geographical differences or disparities are also emerging in terms of the health of people living with HIV. Those in larger centres tend to have lower viral loads than those in more rural and remote areas. This may mean that more information or services are required in parts of the province to ensure that people have the same opportunities to maintain their health.



The emerging geographic nature of the epidemic reinforces the need for a more local/geographical approach to planning both prevention and treatment/support services.

3. What Does HIV Cost?

Ontario has not completed a detailed analysis of the economic costs associated with HIV. However, according to a 1998 report prepared by the Canadian Policy Research Network and funded by Health Canada¹², the “economic burden [of HIV] is rising significantly because the number of cases is increasing, people infected are living longer, and new therapies are more expensive. The lifetime costs of treating someone living with HIV infection are \$153,000.¹³ The total tab to date amounts to some \$36 billion.” About 45% of Canada’s HIV infection is in Ontario.

¹² Albert T, Williams G. The Economic Burden of HIV/AIDS in Canada. Canadian Policy Research Network. 1998.

¹³ These are treatment costs only. They do not include any of the social or other costs associated with the disease.

The report goes on to note that, in addition to the direct costs of treatment, the indirect costs of HIV (i.e., loss of productivity due to premature death) amount to about \$600,000 per person living with HIV – although, if anti-retroviral therapy increases productivity, the indirect costs will be reduced. In fact, if treatment can increase each individual's productive life by only 15%, the savings in indirect costs will cover the treatment costs.

In 1997, in addition to spending on treatment, Canada invested about \$80 million or \$2,044 per person living with HIV on prevention (compared to \$3,897 in Britain and \$1,300 in the US). The report argues that sustained investment in prevention and epidemic control has the potential to save Canada millions in treatment costs. For example, Britain spends 1.9 times as much per prevalent case on prevention than Canada and has a smaller epidemic (48 people per 100,000 population living with HIV compared to 120 per 100,000 in Canada). In contrast, the United States spends 36% less per prevalent case than Canada, and has over twice the prevalence of HIV.

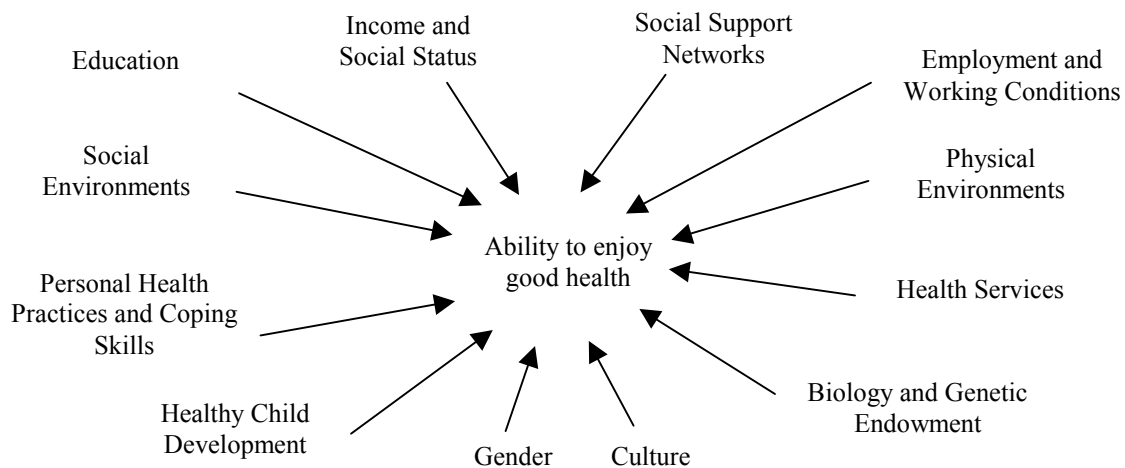
II. Factors that Contribute to the Epidemic

“I discovered then how divided and fragmented our societies are. On the one hand are those who are healthy and well integrated into society; on the other are those who are excluded, on its margins.”

*Jean Vanier
Made for Happiness:
Discovering the Meaning of Life with Aristotle*

The Impact of the Determinants of Health

Health Canada has identified 12 determinants of health¹⁴: factors that affect people’s ability to enjoy good health.



Many of these determinants are at play in the lives of people vulnerable to HIV and in the lives of those who are infected. For example, a study¹⁵ of IDUs’ adherence to anti-retrovirals and other health services identified the following factors that put IDUs at risk for infection and disease progression: unstable housing, lack of social support, their addiction (which makes avoiding withdrawal more important than avoiding exposure to HIV), fears about treatment and possible side effects, their perception of health services as judgmental and disrespectful (marginalization), and their ability to manage their drug treatment programs.

¹⁴ Health Canada Population and Public Health Branch. For a more complete description of the determinants of health and their underlying premises, see Appendix III.

¹⁵ Pelude L, Kristiansen C, Weldon L. *Factors Affecting Injection Drug Users’ Adherence to Antiretrovirals and Other Services: An Exploratory, Descriptive Study*. Centre for Addiction and Mental Health HIV Program. May 2001.

The determinants of health are inter-related, and do not function in isolation from one another. For example, the lack of one determinant, such as education, can have an impact on other determinants, such as employment, income and social status. Discrimination (lack of social status or lack of social support) can also have a direct impact on people's ability to find employment or appropriate housing (physical environment), and on their ability to access health services. The inter-relationship between determinants of health means that any strategies designed to influence them must also be comprehensive and inter-related.

Key Contributing Factors

A survey of the organizations that provide services for people with HIV or those at risk, and of people living with HIV identified the following determinants of health¹⁶ that put people at risk of becoming infected or of disease progression. These same factors also put people at risk of contracting hepatitis and other sexually transmitted diseases or of developing addiction problems.

1. Income (poverty)

A significant proportion of people at risk and those infected have low incomes. Although Ontario does not routinely collect data on socio-economic need among people living with HIV or AIDS (PHAs), there are indicators that poverty is a growing issue:

- A survey conducted for a Canadian AIDS Society project revealed that most people living with HIV/AIDS are poor; almost 60% reported annual personal incomes under \$20,000.¹⁷
- The number of PHAs using the Ontario Drug Benefit (ODB) program and Trillium drug program has increased every year. In 1996/97, 2,232 PHAs were using government drug programs. By 1999/2000, that number had increased by more than 50% to

Factors that contribute to the risk of infection

- addictions/drug use/mental health problems and the lack of treatment services (personal health practices, biology, health services)
- poverty/homelessness (income and social status)
- marginalization (income and social status)
- lack of information (education)
- cultural barriers (culture)
- unsafe environments, such as prisons or the lack of safe houses where IDUs can shoot up (physical environments).

Factors that contribute to the risk of disease progression

- poverty (income and social status)
- lack of affordable housing (income and social status, social environment)
- mental health problems, such as depression and hopelessness (biology, coping skills)
- drug and alcohol use (personal health practices, coping skills)
- isolation (social support networks)
- lack of employment opportunities (employment).

¹⁶ The Health Canada determinant of health is listed first followed by the factor identified in the survey in brackets.

¹⁷ *Force for Change: Labour Force Participation for People Living with HIV/AIDS*. Canadian AIDS Society. 1998.

3,543 – or over half the people on anti-retroviral therapy. This may indicate that a growing number of PHAs do not have adequate financial resources or access to employment opportunities with benefits such as drug coverage.¹⁸

- The Toronto People with AIDS Foundation has noted a significant change in requests for financial assistance. In addition to the ongoing increase in requests from people from endemic areas and families with children, the organization has seen a marked increase in the past year in the number of requests from longer term, formerly middle class clients. These are clients who are living longer and may have used their savings and resources, or are dealing with insurance/benefit plans that have tightened or limited their criteria for funding. The number of requests per day for financial assistance has also increased significantly. In 2001, the organization received in eight months the number of requests they normally receive over a year.
- A recent University of Toronto study on welfare recipients indicated that they do not receive enough in social assistance to be able to feed themselves.¹⁹

The increasing need for financial support may be due to: the larger proportion of already socio-economically disadvantaged people who are becoming infected (i.e., IDUs and recent immigrants from endemic areas) who do not have the resources (savings, drug plans, disability insurance) that can help them during a long illness; the increasing number and cost of HIV drugs; the reduction in inpatient care and shift to outpatient care, where patients bear more of their treatment costs; and/or the fact that many people with HIV are either unable to work or unable to find employment that can accommodate their health needs. It may also be due to the impact of more effective treatments on the trajectory of illness. Living longer with a chronic, life-threatening illness creates a range of financial issues.

2. Personal Health Practices/Biology and Genetic Endowment/Coping Skills (addictions, substance use, mental health problems)

A significant proportion of people at risk and people living with HIV also have an addiction, substance use or mental health problem that affects their ability to make healthy choices, adhere to treatment regimens or maintain their health. Drug and alcohol use is a factor in the culture of both gay men and IDUs. Even among gay men who are not addicted, occasional drug and alcohol use may affect their ability to make healthy choices, and is a co-factor in unsafe sex.

AIDS service organizations report that a larger proportion of their clients now have an addictions problem and/or mental health problems than in the past, and that finding appropriate treatment services is becoming more difficult.

3. Social Status (discrimination/marginalization)

Many people with HIV and populations at risk face the stigma associated with homophobia, racism, sexism, and other forms of discrimination. Four of the

¹⁸ Even those who have private drug plans often incur significant costs (i.e., private plans usually cover only up to a maximum of 80% of drug costs) and may still require access to Trillium.

¹⁹ Tarasuk V, Whiteside J, Vozoris N. Canadian Journal of Public Health. March 12, 2002.

communities most vulnerable to HIV²⁰ – gay men, injection drug users, people from endemic areas and Aboriginal people – are marginalized.

While stigma and discrimination appears to be less of a problem for gay men in major urban centres, they are still direct contributing factors to new infections in gay men in small or rural communities. Discrimination is also a contributing factor to the high rate of HIV infection in people from countries where HIV is endemic. According to anecdotal reports from service providers, people from countries where HIV is endemic often fail to seek out the care they need because the stigma associated with HIV. Fears about the impact of a positive diagnosis on immigration status and/or personal relationships can also keep many recent immigrants from receiving the care they need. For women, the stigma is compounded by issues they face because of their gender, such as being financially dependent on a partner or at risk of violence in their relationships.

4. Physical Environment (Lack of affordable housing/homelessness)

Community-based AIDS organizations report a significant increase in the proportion of clients experiencing housing problems. Survey respondents identified affordable housing as the most urgent unmet need of people living with HIV.

This is part of a larger housing problem in Ontario. According to the Canadian Mortgage and Housing Corporation, rental vacancy rates in Ontario are extremely low: .6% in Toronto, .2% in Ottawa, 1.9% in Windsor, 2.2% in London and .9% in Barrie and Orillia. (A 3% vacancy rate is considered the minimum for a healthy rental market.)²¹

The lack of housing is compounded by the cost of housing for people with low incomes or on social assistance. In most parts of Ontario, rents are high (between \$700 and \$900 a month for a two-bedroom apartment, even in smaller communities) and not in line with welfare rates, disability pensions or the minimum wage, and the costs are increasing. Between 1989 and 1998, the average rent for a two-bedroom apartment in Ontario increased 38% – or about twice the rate of inflation. Waiting lists for social housing now range between three and 10 years, depending on the community, and eviction rates are up significantly. The Canadian Mortgage and Housing Corporation estimates that Ontario has a shortfall of 74,000 affordable housing units.²²

Discrimination is also an issue in housing. Landlords are often reluctant to rent to people on social assistance, those who earn a low wage or people who look unwell.

Housing can also have an impact on the type of care people living with HIV receive. For example, visiting nurses may refuse to visit people living in sub-standard housing (e.g., rooming houses) although this is the only type of accommodation some people can afford.²³

²⁰ Not enough is known about the low-risk heterosexuals becoming infected to determine the contributing factors or whether they are socially, economically or culturally disadvantaged.

²¹ Shapcott M. *Made-in-Ontario Housing Crisis*. Technical Paper #12. Canadian Centre for Policy Alternatives. May 2001.

²² Ibid.

²³ Anecdotal report from the Canadian Mortgage and Housing Corporation in Simcoe County

The Impact of Correctional Facilities on HIV

Closed physical environments, such as prisons, have a direct impact on people's ability to avoid risk or maintain their health. The policies, programs and procedures required to give inmates the best access to HIV prevention and care are often in conflict with the policies and procedures designed to ensure safety and order in the institutions.

For example, prison policies that prohibit any form of drug use or sexual activity within prisons prevent inmates from having access to clean needles or condoms. When prisons do provide bleach or condoms, prisoners cannot obtain them without guards or other prisoners seeing them (lack of confidentiality). Urine testing programs designed to reduce drug use in prisons lead inmates to inject drugs that metabolize quickly (rather than using cannabis) so they can't be traced in urine. This increases their risk of HIV transmission from needle use. Lockdowns that are ordered for security reasons may prevent inmates who are infected from taking their medications on time. Prisoners also report that there is little access to information and often long waits for specialist services.

Although some prisons will ensure that inmates who come in on methadone are able to continue treatment, methadone therapy is not usually well managed in prisons, and it is rarely offered to inmates who could benefit from it. The problems created by the environment are compounded by the fact that inmates are usually poor and often suffer from addiction or mental health problems. Most do not have stable living arrangements outside prison, and are particularly vulnerable to HIV and other illnesses both inside and outside correctional institutions.

5. Social Support Networks (a growing sense of apathy and lack of social support)

In the 1980s and early 1990s, the strong social support and sense of community among gay men was a significant factor in the ability to slow the spread of HIV. Over the past 10 years, that has changed. As one survey respondent noted, "for the gay male community, the AIDS 'crisis' is over!" The normalizing of HIV, the development of effective treatments, the success of early prevention efforts, the lack of public attention, and the mainstreaming of HIV prevention messages have all served to blunt the sense of urgency and the sense of community/social support that characterized the early days of HIV.

According to the Centres for Disease Control, "optimistic attitudes about treatment [of HIV] may be contributing to increased risk behaviour." This is consistent with the findings from a number of qualitative studies which conclude that some people have become less vigilant about safer behaviours, and would help explain the recent trends in infections in gay men in Ontario. However, there has not been any research to determine the cultural factors affecting safer sex practices in the gay community.

Because of the stigma associated with HIV and sexually transmitted diseases, other communities at risk (e.g., IDUs, people from countries where HIV is endemic) also lack the social support that is an important determinant of health.

6. Employment (lack of employment opportunities)

Lack of employment opportunities is an issue in many of the communities vulnerable to HIV (i.e., IDUs, people from endemic areas, Aboriginal people). Even among gay men – who tend to be better educated and more employable – work opportunities are an issue, particularly for people living with HIV. Discrimination in employment practices, and the lack of HIV-friendly workplace policies (e.g., flexible work hours, job accommodation, time for medical appointments, opportunities to work part time without losing disability benefits) inhibit the ability of people with HIV to remain in or return to the workforce²⁴ and still manage their illness.

7. Culture

Some cultures have been more adversely affected by HIV than others, and people in those cultural communities may be more at risk. However, Ontario does not collect data on the race or ethnicity of people infected (beyond identifying whether people are from an area where HIV is endemic) so it is difficult to assess the impact that ethnicity or culture has on risk.

Cultural communities are not defined solely by race or ethnicity. They may also be defined by sexual orientation (i.e., the gay community) or by common activities or circumstances (i.e., IDUs, street culture).

Regardless of the factors that define a cultural community, the community's values and attitudes towards sex, homosexuality, drug use and sexually transmitted diseases appear to be a contributing factor in HIV infection. However, there is little data on cultural factors within defined communities that may contribute to risk and poor health. It is also difficult to determine the impact of factors within a given ethnic culture (e.g., genetic factors, attitudes and values) as opposed to the impact of marginalization or stigmatization by the dominant culture on risk.

The Impact of Public Policy

Over the past few years, the social inequities that contribute to the epidemic have been exacerbated by certain policy decisions. For example, people with HIV and those at risk who are dependent on social assistance have been adversely affected by cuts to those programs. The removal of rent controls in Ontario and government decisions not to invest in affordable or social housing have exacerbated housing problems. The weakening of the social safety net is a trend that could have significant negative implications for HIV in Ontario. As one survey respondent said, "Poverty will become a huge factor [in the epidemic] as the social network continues to erode."

Restrictive policies in place in Ontario prisons make it extremely difficult for people with HIV to receive treatment and those at risk to protect themselves from infection.

²⁴ *Force for Change: Labour Force Participation for People Living with HIV/AIDS*. Canadian AIDS Society. 1998. This report identifies the main barriers to returning to work as: the possible loss of disability benefits and drug coverage, uncertainty about their health status, fear of discrimination in the workplace, managing treatment schedules and side effects, and how to explain their absence from the work force.

The increasing “criminalization” of HIV also contributes to the stigmatization and marginalization of vulnerable populations. For example:

- The 1998 Supreme Court decision (the *Cuerrier* case) that HIV-positive persons have a duty to disclose their status to sexual partners means that HIV positive individuals who do not disclose may be criminally charged. This places additional pressure on people living with HIV to disclose their status, and may discourage people from testing so that they cannot be accused of knowingly infecting others.
- Bill 105, an act to amend the *Health Protection and Promotion Act* (HPPA), which passed in Ontario in 2001, allows mandatory testing of anyone who exposes a police officer, emergency services worker, good Samaritan or victim of crime to a “bodily substance.” Although this legislation has not yet been proclaimed, it reinforces the fear and stigma of HIV. (Similar legislation, the *Blood Samples Act*, has been proposed at the federal level, but has been withdrawn and the issue referred for further study.)
- Changes in immigration policy and law have made it less likely that immigrants – particularly those who are undocumented – will come forward for testing.
- The requirement that people on social assistance be tested for substance use and participate in treatment may drive some people with HIV and an addiction underground, and keep them from seeking the care and financial assistance they need. It may also put more pressure on an already overburdened addiction treatment system, making it more difficult for people with HIV to obtain treatment.
- The requirement that people on social assistance must be actively looking for work or participating in workfare may adversely affect those who are not well enough to participate in these programs but not sick enough to qualify for disability benefits through the Ontario Disability Support Program (ODSP).

Even legislation designed to help people with HIV often does not go far enough. For example, the recently passed *Ontarians with Disabilities Act* does not include the monitoring and enforcement requirements that have made the *Americans with Disabilities Act* so effective in creating meaningful, respectful employment opportunities for people with HIV.

III. Managing Complexity

Ontario has developed an extensive array of HIV services and expertise across the province (see Appendix II). There are public health programs in all parts of the province, community-based AIDS organizations in most areas, and an HIV outpatient clinic in every region except the northwest, where a small number of specialists provide many of the functions of a clinic, but without the support of a clinic structure or funding.

Individuals and organizations across Ontario that deliver HIV prevention, support and treatment programs and services are coping with increasingly complex client problems and needs. This is having an impact on the types of services people need, the way services are delivered, and the skills and information required to provide effective prevention, support and treatment services. There is some question whether the current HIV infrastructure, which was established mainly in the 1980s in response to the crisis, is still the most appropriate, effective way to meet changing HIV needs.

Emerging Issues for Prevention/Support Services

Prevention and support services are facing pressures from a number of sources, including:

Client Demographics and Needs

- a highly **diverse client group**
- **changing service demands** (as a result of treatment advances) – for example, there is less demand for traditional community-based services (i.e., buddy programs) and more demand for “hard” treatment and practical support services, such as addiction treatment, methadone programs, mental health services, physician services, help accessing social services, income support and housing, and services to help people make the transition between prison and community.
- clients’ **need for integrated comprehensive programs** that address a wide range of their health and social needs and the factors that contribute to risk, and make it easier to access efficient care and prevention services.
- the unique needs of **clients who move in and out of the justice system** and have varying access to prevention, harm reduction and support services.
- the increase in number of people with HIV who are living longer in better health and who want to have fulfilling relationships, **the need for long-term prevention and support programs**, and the important lead role that people

Urgent Unmet Needs of Populations at Risk

- accurate, effective prevention information/strategies
- addiction services
- harm reduction services
- social support
- mental health/psychiatric services
- empowerment skills, including supportive socio-economic conditions
- accessible testing services.

From the OACHA survey of people living with HIV and organizations that serve people with HIV and those at risk.

with HIV can and should play in HIV prevention (e.g., the PWA-led San Francisco “HIV Stops With Me” program).

HIV-Related Issues

- **lack of information** to be able to anticipate future trends in the epidemic.
- **conflicting reports** about the risks associated with oral sex, which make it difficult to deliver a clear, consistent prevention message.
- **misperceptions about the risks** associated with unprotected sex with someone with a low viral load – many equate a low viral load with being non-infectious, which is not the case.
- **apathy/lack of public/media attention** on HIV to provide support for prevention programs and safer behaviours – which is occurring at a time when there is more virus in the population and a greater need for effective, long-term prevention programs.
- **lack of targeted prevention strategies** to address the factors that contribute to risk in different populations (e.g., gay men, IDUs, people from endemic countries, youth, women, people in correctional facilities).

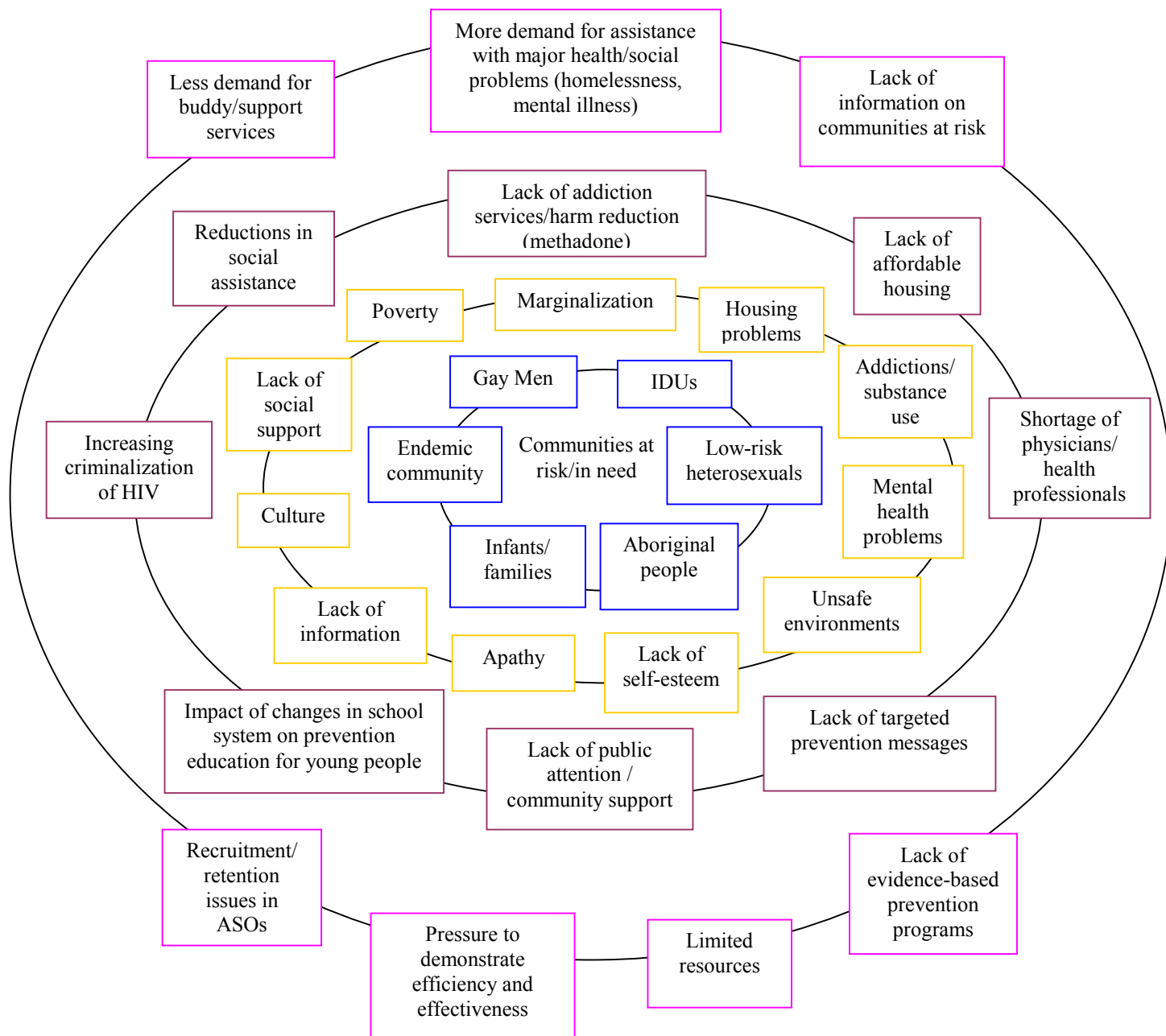
Broader Health and Social Issues

- **waiting lists for and shortages of other health services** – such as addiction treatment, methadone treatment, and mental health services.
- **lack of harm reduction addictions programs** – Despite the ministry’s policy on harm reduction strategies in addiction treatment,²⁵ most treatment programs do not offer a range of harm reduction strategies²⁶ and are unwilling to accept clients who are still using alcohol or drugs.
- **social policies** that have a negative impact on affected communities (e.g., lack of affordable housing, the removal of rent controls, cutbacks in social assistance).
- growing **pressure to evaluate prevention** programs (i.e., do they work?) and demonstrate that limited public funds are being invested efficiently and effectively.
- **changes in the school system** (e.g., the introduction of the new school curriculum, cutbacks in education funding) which are making it more difficult to deliver prevention education targeted to young people.

²⁵ *Setting the Course. A Plan for Ontario’s Addictions Services*. Ministry of Health and Long-Term Care. 1999.

²⁶ Harm reduction is an approach designed to decrease the health, social and economic adverse consequences of drug use without necessarily requiring a cessation in consumption. A harm reduction approach includes abstinence, but also offers clients smaller, more achievable targets, such as reducing substance use or eliminating needle use. In harm reduction, the steps along the way – including building relationships with drug users – are as important as the end result. Excerpted from: *Comprehensive Guide for the Care of Persons with HIV Disease. Module 6. Psychosocial Care*. Health Canada. 1997.

Pressures on Prevention and Support Services



Organizational Issues

- **problems with recruitment and retention** – community-based AIDS service organizations experienced a 42% turnover rate during the 1990s.
- **lack of capacity to integrate information** on effective prevention programs into existing services.²⁷

Emerging Issues for Care and Treatment Services

With the advent of anti-retroviral therapy, the care and treatment needs of people living with HIV have changed dramatically. Pressures on the treatment system include:

HIV Care Issues

Many of the issues relate directly to the change in the course of the disease:

- **the growing number requiring care** – with more people with HIV living longer in better health, the number of people who need ongoing care and treatment has increased from about 7,000 in 1990 to more than 14,000 in 2000.
- **increasing drug resistance** – about 7,000 people in Ontario with HIV are on anti-retroviral therapy and most are doing extremely well (70% have experienced a marked decline in viral load²⁸). Although anti-retroviral treatments have been effective in improving health and reducing viral load, a significant proportion of people involved with HIV identified drug resistance as an urgent emerging issue, and laboratory data reinforce that view (see box below).

Urgent Unmet Needs of People Living with HIV

- affordable housing
- new treatments
- primary care services, particularly in rural and remote areas
- financial assistance
- food
- employment/return to work opportunities
- acceptance/support

From the OACHA survey of people living with HIV and organizations that serve people with HIV and those at risk.

²⁷ Guenter D et al. Ontario ASO HIV Prevention Study. Doing HIV Prevention Work in Ontario's AIDS Service Organizations. Community Linked Evaluation AIDS Resource (CLEAR) Unit. November 2001. According to the report, there is a growing amount of information on effective HIV prevention programs, but the information does not appear to be used to guide Ontario's prevention programs. There seems to be "a reluctance on the part of many [ASOs] to make use of published materials on designing HIV prevention programs, or to be involved with more formal types of learning about HIV prevention. There was seldom mention of referring to specific theories of behaviour change when developing prevention programs. Numerous publications have accumulated information on various prevention programs for different target groups, how to implement these programs, and the evidence for their effectiveness in changing behaviours. However, these types of resources were not discussed in relation to developing HIV prevention ideas."

²⁸ They have a median baseline of 70 copies/ml compared to 13,601 copies/ml for those not on therapy.

Results from Drug Resistance Testing

Between November 1996 and December 1999, viral load tests were performed for 8,642 or about 60% of PHAs in Ontario. Based on the results of that viral load testing, most people with HIV who were on therapy were taking between two and four drugs, and were doing well.

However, genotype testing of the 600 to 700 people (about 10%) for whom therapy was not effective indicated that 87% of those patients had virus resistant to one or more of the drugs in their regimen. According to the genotyping results, resistance is often not limited to one or two drugs. (E.g., of the over 50% of PHAs in the pilot for whom a three-drug regimen was failing, 38% had virus resistant to one drug, 37% had virus resistant to two drugs and 10% had virus resistant to all three drugs.)

The growing extent of drug resistance will make it more difficult for patients to control the virus and maintain their health. The virus mutates completely differently in different people – even in those who are on the same drug regimen. The extent of drug resistance combined with the variations in virus mutation make it extremely difficult to identify effective treatment regimens for patients for whom current therapy is failing.

- **side effects of anti-retroviral treatments** – because anti-retroviral treatments are relatively new, little is known about their long-term side effects. However, a growing number of people with HIV on treatment are experiencing significant side effects and toxicities, such as cancer, lipodystrophy, heart disease and neurocognitive impairments. More data are needed to assess the extent and impact of the side effects and toxicities on health.
- **the timing of treatment** – since the mid 1990s, doctors have tended to treat HIV aggressively, starting people with HIV on anti-retroviral therapy as early as possible in order to increase their chance of surviving the disease. However, a recent study by the B.C. Centre for Excellence indicates that delaying treatment (i.e., monitoring a patient's immune system and beginning treatment before it becomes dangerously impaired) does not reduce longevity and offers other benefits, such as avoiding the side effects associated with anti-retroviral therapy and reducing health care costs.
- **the increasing complexity of HIV care** – HIV treatment has become so complex that physicians must maintain a certain critical mass of patients with HIV (e.g., a minimum of 15 patients²⁹) and have access to ongoing training and support to maintain their competence and provide high quality care. This makes it increasingly difficult for primary care physicians – particularly those in remote or rural communities who see relatively few patients with HIV and may not have access to training or mentors – to play a role, unless they choose to specialize in HIV care or are linked to specialists who will provide information and support.

²⁹ Kitahata M. et al. *Physicians' Experience with the Acquired Immunodeficiency Syndrome as a Factor in Patient Survival*. New England Journal of Medicine. Vol 34, No 11. March 1996.

- **complex health needs of PHAs** – For many people living with HIV or AIDS, HIV is only one of a number of health and social issues they face. A growing proportion of people living with HIV have a dual diagnosis (e.g., HIV and an addiction, HIV and a mental illness, HIV and hepatitis C). A significant number suffer from depression. They require treatment programs that can help them manage all their health and social issues. A proportion move in and out of the correctional system, which can make it difficult for health care providers to maintain continuity of care.
- **patients' complex social needs** – as the earlier list of urgent unmet needs indicates, many people living with HIV have serious non-medical needs, such as housing, food, social support and assistance in finding employment, that have an impact on their health and ability to adhere to therapy.
- **the need for greater integration of primary, secondary and tertiary care and prevention** – for a growing number of people with HIV who are in good health, their only contact with the health care system and HIV services is their physician or clinic. A significant number are not accessing traditional, community-based prevention and support services, and some have drifted away from their primary care physicians. The specialists and clinics are stepping in to fill gaps in their care.

Broader Health System Issues

A number of changes and pressures in the broader health care system are affecting HIV treatment, including:

- **shortages of physicians and other health care professionals** – despite past efforts to recruit physicians to HIV care, there are only about 100 physicians in Ontario who routinely order HIV tests and treat patients with HIV. This is due, in part, to the general shortage of physicians in Ontario and to the increasing complexity of HIV care.
- **lack of services in rural and remote areas**
- **lack of transportation services** and/or transportation programs that do not meet the needs of people living with HIV – the Northern Travel Grant Program will only subsidize the cost of travel to specialized services. It will not assist people living with HIV who have to travel for primary care.
- **long waiting times for addiction services/lack of appropriate services** – between September 2000 and August 2001, waiting times for addiction treatment services in Ontario averaged 18.5 days for day/evening services, 23.5 days for outpatient services, 35 days for long-term residential services, and 56 days for short-term residential services. Even when services are available, they are often not appropriate for people living with HIV. Most of the province's addiction treatment services are abstinence-based and will not accept people on methadone or medicinal marijuana.
- **lack of methadone maintenance program** – Ontario continues to have problems recruiting physicians to prescribe methadone and providing the comprehensive counselling and support essential to effective methadone maintenance.

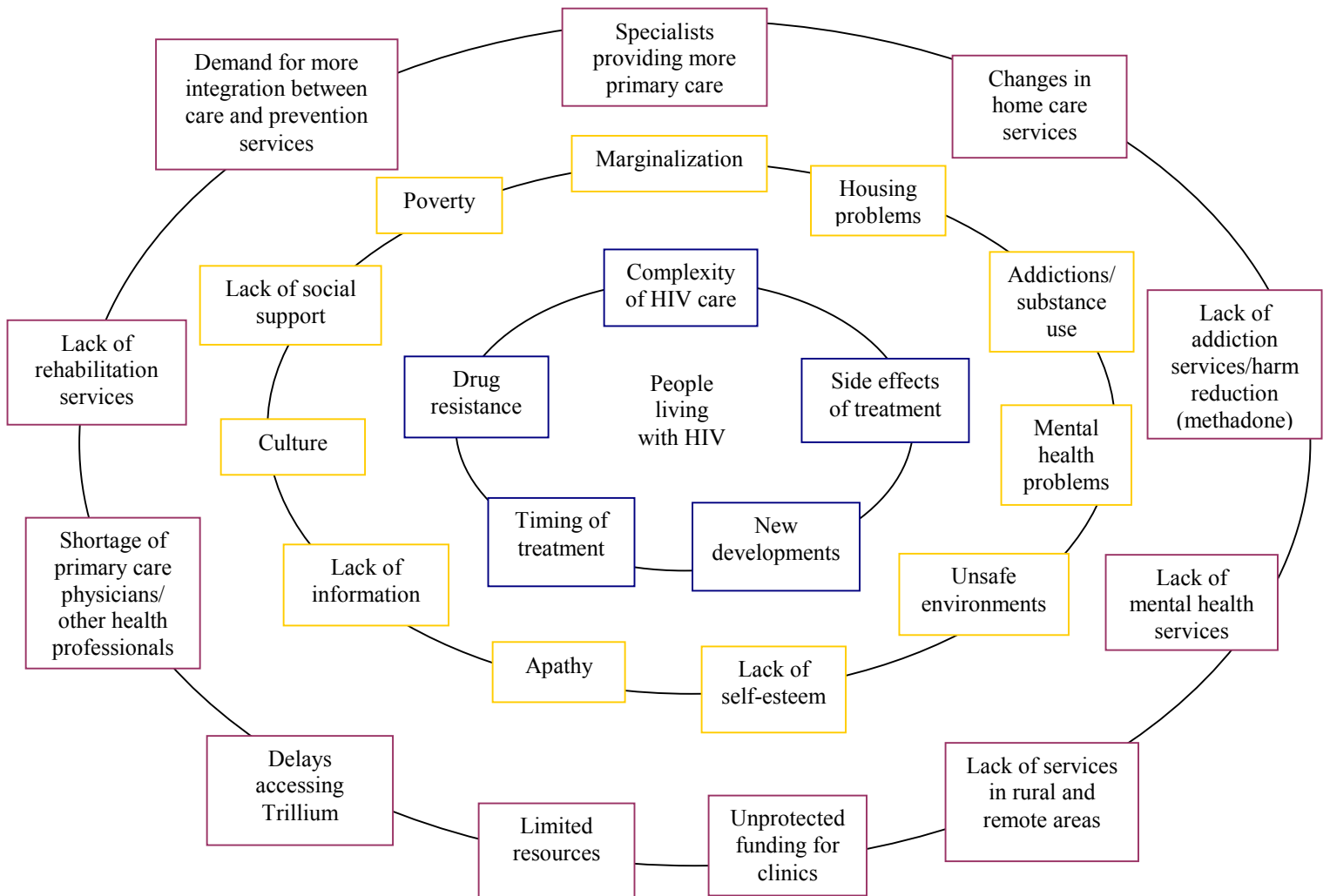
- **delays accessing the Trillium Drug Program** – Although the Trillium drug program is a valuable service, patients often experience delays being approved for the program and being reimbursed for prescription drug costs. This has a direct impact on treatment adherence.
- **the limited resources available for locally managed home care services** – which has resulted in inconsistencies in the level and type of home care services available across the province and reduced the total number of hours of home care available for each client.
- **funding uncertainties** – the funding the ministry provides for HIV outpatient clinics is no longer “dedicated” to HIV, but part of hospitals’ global budgets. This means that hospitals can, if they choose, move some of that funding or staffing complement to other program areas in the hospital.

Emerging Issues for Research

With the development of the Ontario HIV Treatment Network (OHTN), there is now a consistent source of funding for certain types of HIV research in Ontario. However, there are still pressures on HIV researchers including:

- **lack of funding for epidemiological research** – there is no set fund to support epidemiological studies or to strengthen Ontario’s ability to monitor the epidemic.
- **lack of co-ordination between research centres** – Ontario has several different centres involved in HIV research, with no clear definition of responsibilities (as in the United States). A committee has been established, the Canadian Association of HIV Research Ontario (CARO), to improve co-ordination and collaboration among researchers but it may be possible to take other steps to ensure that research resources are used efficiently and to avoid duplication.
- **lack of access to clinical trials** – for people living with HIV, access to clinical trials often depends on where you live or receive care.
- **shortage of new researchers** – few young researchers are entering HIV research, and this could have a negative effect on Ontario’s ability to maintain its HIV research capacity and develop new knowledge.

Pressures on Treatment Services



Innovative Responses

Faced with these pressures, many individuals and organizations across Ontario have developed innovative responses designed to make effective use of available resources and provide more comprehensive, integrated services. For example:

Comprehensive Community-Based Care for Gay Men: the Maple Leaf Clinic

Five primary care physicians and one internal medicine specialist recently came together to establish the Maple Leaf Clinic, a community-based clinic for gay men with HIV in Toronto. Located across the street from the AIDS Committee of Toronto, the clinic is the first of its kind in Ontario to provide comprehensive care outside a hospital setting. It offers primary care, specialist care, an in-house lab, an in-house pharmacy, and the services of a dietician. Because the physicians are part of a research consortium linked to the University of Toronto and the National Institutes of Health in the United States, patients also have access to clinical trials. In addition to treating HIV and managing the side effects of anti-retroviral therapy, the clinic is playing an active role in treating hepatitis C, and in handling other health issues, such as chest pain, cholesterol, smoking and diet. In the future, the clinic plans to add a naturopath, a chiropractor and a massage therapist.

To help people living with HIV manage their illness, the specialist runs two regular education courses: a six-hour program for people recently diagnosed about getting started on therapy (e.g., why you need medications, the side effects) and a more advanced, interactive program for people who have been on therapy for a while, where they share their experiences and teach one another. He also offers an education program for people working in AIDS service organizations about HIV treatment issues, and a two-day program for physicians,³⁰ which is sponsored by the Ontario College of Family Physicians as part of its efforts to encourage more primary care physicians to care for people living with HIV.

For gay men, the benefits of the clinic's one-stop shopping are quality and convenience. If a patient needs specialist care, he can be referred and seen within a week. For the physicians, the benefits are peer support, the opportunity to collaborate on difficult cases, better communication and coverage when they are away.

One-Stop Prevention and Care for IDUs: Street Health Centre

The Street Health Centre, an inner-city, store-front partnership in Kingston, provides prevention, treatment, health counselling and primary care services to high risk and marginalized people, including injection drug users. By combining on one site programs and services funded by various parts of the Ministry of Health and Long-

³⁰ The physician training program is part of a five-day traineeship. Physicians who complete the traineeship receive all the continuing medical education credits they need for five years in the one course.

Term Care (e.g., Public Health Branch, AIDS Bureau, Ontario Health Insurance Plan, Drug Programs Branch, Community Health Programs Branch), the Street Health Centre is able to provide one-stop prevention and care services for IDUs.

The Centre's success is based on persuading its partners to be flexible in interpreting their mandates and allocating resources. Services are developed by asking four key questions: What are we trying to achieve? What are proven ways to achieve that goal? Who should be responsible? How can we make it happen?

Because a large proportion of the Centre's clients are opiate users, the clinic began to provide methadone therapy – a highly effective, proven way to reduce or eliminate the risks associated with injection drug use. The Centre attracts physicians who are interested in taking a harm reduction approach to care and prevention. By providing the support and counselling services for clients, the Centre makes the physicians' job much easier. As a result, Street Health Centre now has five physicians who give a certain amount of time to prescribing methadone and providing some primary care. Two years ago, the ministry's Community Health Programs Branch approved funding for a nurse practitioner, which has significantly strengthened the Centre's ability to provide effective, consistent primary care and to promote screening for HIV, hepatitis and other STDs.

A public health program, the Street Health Centre tries to involve as many people as possible in its services in order to reduce the risk of infection in the population. Its approach demonstrates the benefits of integrating services and resources to provide comprehensive care for clients. While rates of HIV and hepatitis C infections in IDUs in other communities rose over the past few years, this was not the case in Kingston. In the past six years, the Street Health Centre has had only one client diagnosed with HIV, and the annual prevalence rate of hepatitis C dropped from 37% in 1998 to 11% in 2001 (prevalence is higher among clients on methadone maintenance treatment).³¹ The number of positive hepatitis C tests in the Kingston, Frontenac, Lennox and Addington health unit dropped from a high of 790 in 1998 to 386 in 2000, despite a significant increase in the number of people tested.

Developing Services to Meet Complex Needs: HIV Care Program – Windsor HIV Outpatient Clinic

When clients of the outpatient clinic operated out of the Windsor Regional Hospital were having problems obtaining their medications at local pharmacies,³² the clinic persuaded the hospital to open a pharmacy on site. The pharmacy ensures patients receive the right medications, and makes special arrangements that allow patients to wait to pay until they have been reimbursed by the Trillium Drug Program, thereby relieving some of the financial pressure of HIV. Because the pharmacy is linked with the clinic, it helps monitor any problems that patients may be having adhering to their medications. For example, if a patient fails to come in for his or her medication or is not using the recommended dosage, the pharmacy will alert the clinic so nurses can contact the patient and discuss any problems or side effects they may be having.

³¹ Health for all?: A primary care profile of the Street Health Centre" April 4, 2002.

³² Pharmacies didn't always have the medications in stock and sometimes provided the wrong drugs because of lack of familiarity with HIV treatments.

Aware that a growing number of clients were not using community-based prevention and support programs, the clinic has made prevention counselling a standard of care, and clinicians discuss these issues at every appointment. Recently, the clinic realized that many patients had drifted away from their primary care physicians and were no longer receiving routine preventive care. As many clients are now 40 years of age and older, and at risk of developing cardiac problems or cancer, the clinic now provides an annual health review that assesses patients for all their health needs.

The clinic recently completed an assessment of its use of diagnostic tests and identified ways to decrease lab costs while still obtaining the information clinicians need to monitor patient's health and treatment.

Lessons Learned

Ontario's innovative responses to the complexity of HIV share some common features. They look beyond the virus itself to other factors that affect people's health and well-being. They attempt to bring together and integrate the different services that clients need into workable programs. They are based on social justice, and use strategies that are client-focused and have been proven to be effective. They also help guide the approach for Ontario's reinvigorated HIV strategy.

IV. The Strategy

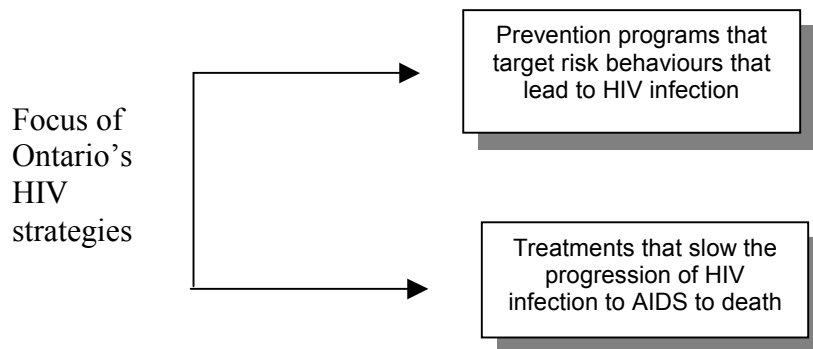
Rationale for a New Strategic Approach

“[T]he task of any government is to organize society in such a way that the largest possible number of people can live well within it.”

*Jean Vanier
Made for Happiness
Discovering the Meaning of Life with Aristotle*

Between 1985 and 2000, Ontario’s response to HIV focused on stopping the spread of HIV and caring for those who were infected. Its strategy was to:

- target the behaviours that put people at risk of acquiring HIV (i.e., unprotected sex and needle sharing)
- identify and provide treatments that would slow the progress from HIV infection to AIDS and keep people alive (i.e., treating opportunistic infections, developing anti-retroviral therapies).



Given the influence that the determinants of health have on the HIV epidemic, and the impact of public policies on the determinants of health, Ontario now needs a broader, more comprehensive HIV strategy – one based on social justice.

Social justice is the notion that society should be organized in a way that allows equal opportunity for all its members.³³ In a society committed to social justice, all those involved in HIV programs and services would pursue a variety of strategies – social, economic, environmental and public policy – to ensure that everyone has access to the same opportunities for health.

Programs and services that are based on social justice would:

- recognize individual and cultural differences and diversity
- recognize the dignity and worth of each person, encourage self-esteem

³³ The Canadian Oxford Dictionary. 1998.

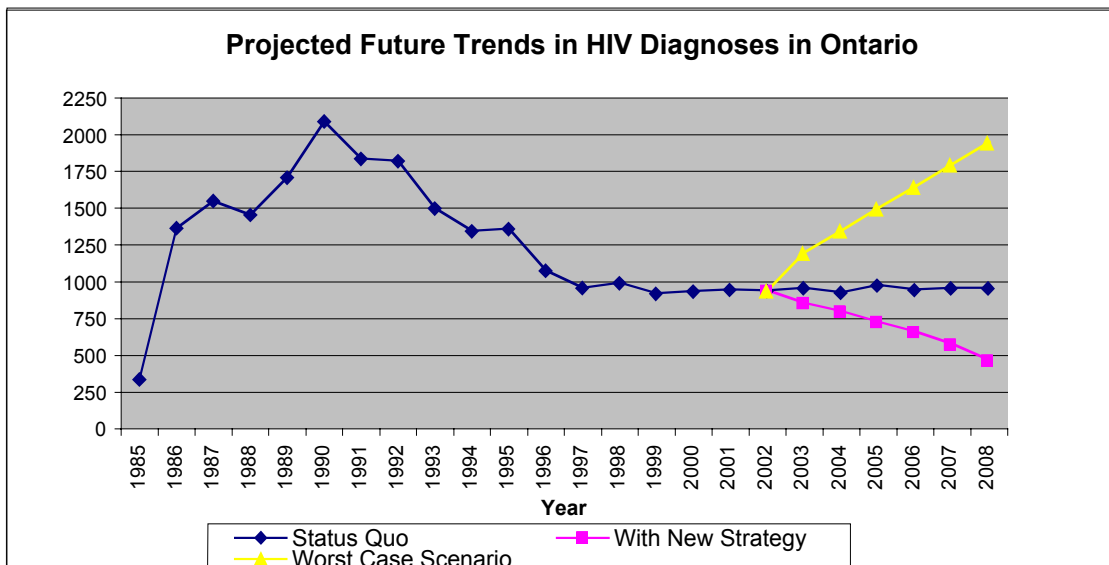
- strive to ensure that all clients are treated fairly and have access to the same treatments and health outcomes
- meet basic needs
- reduce inequities in wealth, income and life chances
- encourage participation by all, including the most disadvantaged.³⁴

The challenge for Ontario over the next five to 10 years will be to maintain its investment in the treatment and prevention programs that have slowed the transmission and progression of HIV while, at the same time, identify innovative ways to respond to emerging trends and issues.

If Ontario continues with the same strategic approach used in the past, the epidemic will continue and likely increase in certain populations, and the health and social costs associated with HIV will continue to rise. If Ontario wants to reduce the number of new cases and prolong lives, it must attempt to address the inequities that put people at risk and the broader health and social problems that affect health.

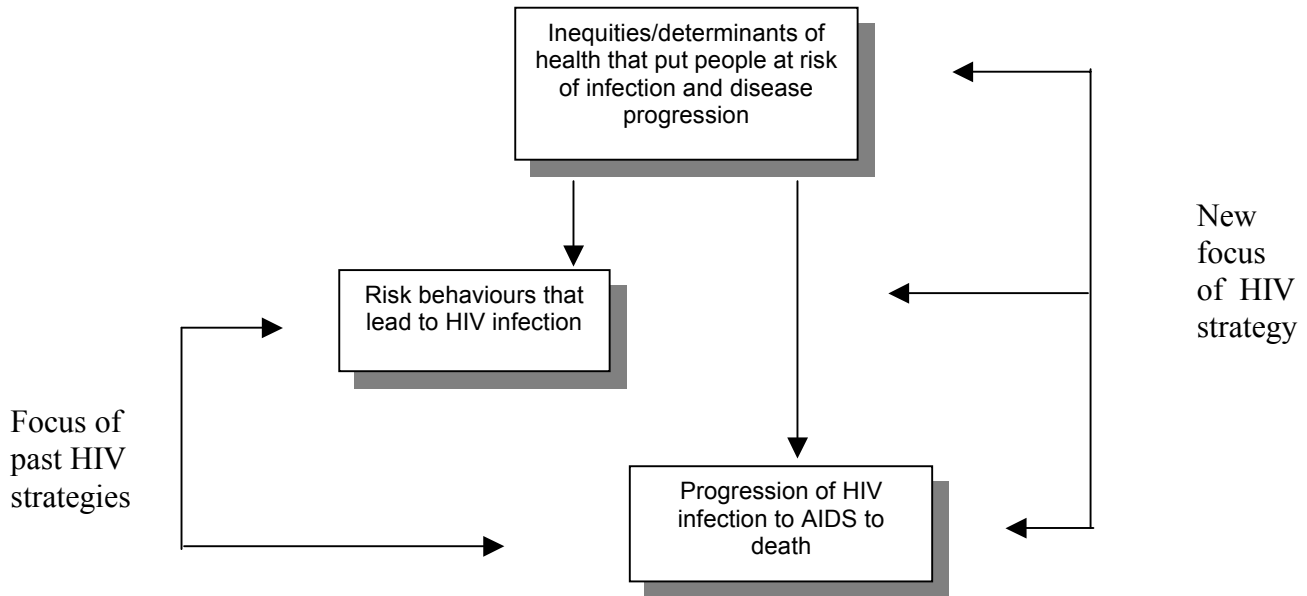
The following graph illustrates three possible scenarios for HIV in Ontario:

- the status quo – using the same strategic approach as in the past, with no increase in incidence in populations at risk
- the worst case scenario – using the same strategic approach as in the past, but experiencing an increase in HIV infections in IDUs (consistent with what has occurred in Montreal and Vancouver), in gay men, and in people from endemic areas
- the best case scenario – implementation of a new strategic approach that addresses the inequities that put people at risk.



³⁴ Craig G. Professor of Social Justice, the University of Hull, U.K. 2001

Over the next five to 10 years, the Ontario Advisory Committee on HIV and AIDS (OACHA) proposes a more comprehensive approach to fighting HIV: one that takes into account the factors that put people at risk of infection and disease progression, the dramatic changes that have occurred in the course of HIV infection, the increasing complexity of client needs, the services in place and the need for new leadership.



This approach is consistent with the Declaration of Commitment on HIV/AIDS adopted at the United Nations General Assembly Special Session on June 27, 2001, which acknowledges that respect for the rights of people living with HIV/AIDS drives an effective response to the epidemic, and makes a commitment to:

- eliminate all forms of discrimination against people living with HIV and “in particular to ensure their access to... social and health services, prevention, support and treatment”
- develop strategies “to combat stigma and social exclusion connected with the epidemic”
- ensure, by 2003, that national strategies, supported by regional strategies and international strategies, “in an urgent manner, make every effort to provide... the highest attainable standard of treatment for HIV/AIDS.”

Goals

The goals of Ontario’s new response to HIV/AIDS are:

- to prevent the spread of HIV
- to improve the health and well-being of people living with HIV and their communities.

Targets and Outcome Measures

NOTE: OACHA is in the process of identifying targets for the new strategy, and intermediate and ultimate indicators that can be used to assess progress in achieving those targets. The measures are likely to include:

- *behavioural indicators, which would indicate whether people are taking steps to reduce their risk*
- *surrogate indicators, such as rates of other STDs (e.g., rectal gonorrhoea) which would indicate whether people are continuing to engage in activities that put them at risk*
- *HIV indicators, such as the number of new infections in certain populations (i.e., gay men, IDUs, people from endemic areas).*

OACHA is also developing targets/measures that can be used to assess quality of care, access to care, and the impact of treatment on health and productivity.

The actual targets/timelines will depend on whether the strategy is approved in its entirety and the resources available to support it.

Policy Directions

To achieve these goals and targets, Ontario will pursue four key policy directions over the next five years:

1. Adopt a determinants of health approach; address social justice issues

HIV is more than a health problem. A wide range of social, economic, environmental and health factors contribute to the epidemic. Ontario will work to reduce the inequities that put people at risk of infection or at risk of disease progression, adopting a determinants of health approach and addressing related social justice issues, such as poverty, housing, and marginalization, as well as health issues.

2. Focus on long-term, integrated, sustainable, targeted responses

Link with the Canadian Strategy on HIV/AIDS (CSHA)

Ontario's strategies are consistent with the Canadian Strategy on HIV/AIDS:

1. Mobilize integrated action on HIV/AIDS
2. Build unique approaches for Aboriginal people
3. Build a broad information strategy
4. Get public commitment, political leadership, and funding
5. Build a strategic approach to prevention
6. Build a strategic approach to care, treatment and support
7. Renew and develop human resources
8. Engage vulnerable Canadians
9. Move to a social justice framework
10. Develop a five-year operational/strategic plan.

Over the past 17 years, Ontario has developed an extensive infrastructure of HIV/AIDS programs and services. To ensure that infrastructure continues to respond effectively, Ontario will re-examine its programs and services, looking for opportunities to integrate activities within the infrastructure and with other health and social services. It will ensure that resources are used judiciously and invested in programs and services that are effective. It will also target its efforts to populations most affected and/or at risk, and develop long-term, sustainable services that can respond more quickly and appropriately to changing needs.

3. Develop a flexible provincial response to HIV that takes into account local/population needs.

The epidemic – the numbers, the populations most affected, the needs and the services – varies significantly in different parts of the province, in large versus medium-sized centres, and in urban versus rural and remote areas. In each of the populations most affected and most at risk, the cultural drivers of the epidemic and the prevention and care/treatment approaches are also quite distinct. Ontario’s HIV strategy must be flexible enough to respond to the different cultural drivers of the epidemic, to recognize the impact of geography on delivering services, and to reflect regional/local needs and services.

4. Improve Ontario’s capacity to respond effectively through improved monitoring and accountability.

Over the past 10 years, there has been extreme pressure within the health care system to manage health budgets efficiently and ensure greater accountability. Ontario’s HIV programs and services are committed to providing high quality, evidence-based services. Ontario will increase its capacity to respond to HIV, and develop the information and monitoring systems that will ensure accountability, demonstrate the value of HIV programs, and lead to better, more responsive services.

Strategies

Ontario HIV programs and services must have the flexibility to respond to the changing demands of communities at risk and those infected. Given the changing course of HIV disease and the desire for more co-ordinated services, Ontario’s HIV infrastructure must develop a more integrated, sustainable response that will meet needs over the long term.

The following strategies are designed to ensure that Ontario has the knowledge, leadership, innovation, relationships, services, resources and accountability required to achieve its goals.

Knowledge

- 1. Develop, disseminate and apply the knowledge required to monitor and understand the epidemic, improve prevention programs, improve care and treatment services, and develop effective strategies to influence the determinants of health.**

Knowledge must be the basis for all HIV programs and services, and for decisions about how to allocate resources. Ontario is more likely to achieve its goals and objectives if its policies, programs and decisions are based on current, accurate information.

Knowledge Development

Monitoring

- 1.1 Use a range of epidemiological research (e.g., disease surveillance, seroprevalence studies, comparisons with rates of other STDs and hepatitis C, behavioural surveillance) to improve the province's and the regions' capacity to monitor, understand and predict the course of the epidemic.*
- 1.2 Conduct systematic studies in populations and regions of the province with a high incidence of HIV to identify the social and cultural factors that drive the epidemic (e.g., determinants of health, social justice issues and cultural issues, such as understandings, organization, attitudes towards sex, sexuality and STDs, and the meaning of sexuality and drug use), and use that information to design prevention programs.*
- 1.3 Develop a more detailed understanding of the people who are infected or at risk, their needs, and how to meet them by identifying effective ways to gather information on:*
 - their full range of health and social needs (e.g., income, education, housing/living arrangements, addictions and mental health issues, legal/correctional issues) and how these needs change over time*
 - demographic characteristics, such as race/ethnicity.*

Prevention

- 1.4 Strengthen Ontario's ability to provide effective prevention and support programs in all its diverse communities by:*
 - studying different prevention strategies, including harm reduction strategies, to determine which are most effective in different settings (e.g., large urban centres, mid-sized communities [250,000 people], rural and remote communities) and with different populations/social cultures*

- *identifying strategies that can be used to influence the determinants of health*
- *analyzing over time the impact of public policies on people living with HIV and populations at risk, promoting those that have a positive impact, and advocating for changes to those that have a negative effect.*

Care and Treatment

- 1.5 Improve Ontario's ability to contribute to global efforts to develop treatments for HIV by identifying basic, clinical and community-based research priorities that take into account research being done in other jurisdictions and build on the strengths of Ontario's HIV research infrastructure.*
- 1.6 Improve access to clinical trials for people living with HIV in all parts of the province.*
- 1.7 Increase the efficiency of Ontario's research efforts by promoting/establishing criteria for co-ordination and collaboration among HIV researchers.*

Knowledge Dissemination

- 1.8 Improve Ontario's ability to share and disseminate useful information/research findings by:*
- *consulting with local HIV programs and services to determine the type and level of information they need to plan and deliver programs, and providing that information in a timely way and user-friendly form*
 - *ensuring Ontario data is shared in a timely way with those responsible for HIV monitoring at the federal level, and that the province's data is collected in a form that is comparable to other provinces*
 - *developing a proactive dissemination/research transfer strategy that would ensure information reaches the people who can use it, and include training on how to use/adapt research information to develop more evidence-based programs/services*
 - *requiring all research funded by the Ministry of Health and Long-Term Care to include a dissemination strategy*
 - *developing an efficient way to provide easy access to research/best practice information/knowledge (to be determined through collaboration among the OHTN, the Community-Linked Evaluation of AIDS Resources Unit, Canadian AIDS Treatment Information Exchange and the University of Toronto HIV Social, Behavioural and Epidemiological Studies Unit)*

- *advocating for greater focus on HIV, addictions, hepatitis C, mental health and other associated health needs in all health and social service professional education.*

Knowledge Application

- 1.9 Ensure all HIV prevention, support, care and treatment programs have the capacity to apply and deliver evidence-based services.*
- 1.10 Continually assess the system's capacity to provide evidence-based services, and address any gaps or weaknesses.*

Leadership/Integration

- 2. Foster leadership for an integrated approach to HIV prevention, support, care and treatment based on the determinants of health.**

With the change in the course of HIV disease, the lessening sense of crisis, and the lower public profile of HIV, Ontario's HIV efforts require a new kind of leadership and its infrastructure may need to change. Over the next five to eight years, Ontario's HIV leaders must work to develop a long-term, sustainable response that reflects the complex, diverse needs of people living with HIV and of populations at risk. Ontario must develop effective partnerships and identify opportunities to integrate services to provide more comprehensive, effective care and support. When identifying opportunities for partnerships and service integration, HIV programs and services should use a social justice approach designed to reduce inequities and influence the determinants of health.

At the Provincial Level

- 2.1 Reaffirm the AIDS Bureau role in providing leadership within government on HIV-related issues, and ensure it is responsive to an integrated approach to planning and delivering HIV programs and services.*
- 2.2 Identify key individuals in other ministries and levels of government who are responsible for programs and services that affect people living with HIV and those at risk (i.e., housing, social services, justice/corrections, labour, citizenship, education), develop effective working relationships with them, and advocate for more effective, appropriate policies and services.*
- 2.3 Engage all Ministry of Health and Long-Term Care programs that have responsibility for HIV and related services (i.e., addictions, mental health, public health, supportive housing, home care, hospital services, palliative care, drug programs) in the strategy and ensure they fulfill their responsibilities to provide appropriate services.*

2.4 Pursue collaborative initiatives with other health services and disease groups facing common challenges and issues (e.g., public health, addiction treatment services, hepatitis C) to achieve common goals.

2.5 Develop the capacity to respond quickly to any emerging trends in HIV.

2.6 Identify high profile spokespeople (e.g., community leaders, PHAs, experts) who will raise media/public awareness of HIV and related issues.

At the Local/Population Level

2.7 Identify and mentor individuals who, through particular social or professional networks, can provide leadership in all aspects of HIV and related services (i.e., in prevention, support, care and treatment, and research; in populations with high rates of HIV, gay men, people who come from countries where the disease is endemic, IDUs, women who are infected).

2.8 Identify people living with HIV who will provide leadership in developing life-long approaches to HIV prevention, and provide the ongoing support that will help them fulfill that role.

2.9 Bring together all organizations/individuals that provide prevention, care and treatment services for people living with HIV within each service catchment area of the province to:

- *identify the various “players” in the service area, assess local needs, and assess the capacity of the current programs and services to meet those needs*
- *develop a local strategy that responds to local/regional needs and reflects provincial goals and directions*
- *increase access to appropriate health and social services for people living with HIV and populations at risk (e.g., gay men’s health services, addictions agencies, mental health services, crisis management services, housing services, social services, organizations that serve ethnic populations at risk)*
- *integrate programs and services to provide more comprehensive, co-ordinated care (i.e., one-stop shopping) and develop innovative service delivery models (e.g., locating HIV services on one site, developing a gay men’s health centre; using a case management approach; establishing clinics for street people that provide outreach, testing, primary care, harm reduction programs, treatment services, access to social services, assistance with housing and other needs; integrating HIV treatment into settings that already provide culturally sensitive services for people from countries with high rates of HIV infection)*
- *develop mechanisms (e.g., service agreements) to formalize partnerships between agencies and organizations, define roles, and clarify*

responsibilities for providing services and activities, including maintaining client confidentiality

- *identify unmet needs and ways to address them.*

2.10 *Bring together key people/organizations to develop supportive communities for people who are homeless or underhoused, and to help them develop the life skills to find and maintain housing.*

Services

3. Ensure that everyone in Ontario who could benefit from HIV and other related health and social services has access to them.

Although Ontario has developed a strong infrastructure of HIV programs and services, there are still some unmet needs and gaps that must be addressed. Every effort must be made to ensure that appropriate services are available in all parts of the province, and that services are targeted to those at risk and/or with high rates of infection.

Prevention

3.1 *Work with people living with HIV to develop the life-long prevention support services that will enable them to be leaders in HIV prevention.*

3.2 *Develop a comprehensive, provincial prevention strategy for gay men, which addresses their health and the psychological, social, legal, political and economic contexts in which they live, and which can be adapted for use in local communities.*

3.3 *Continue to endorse and fund the Ontario Aboriginal HIV/AIDS Strategy and its goal of providing “culturally appropriate, inclusive education and prevention programs, and support and care strategies, consistent with harm reduction principles, to Aboriginal people living with and affected by HIV/AIDS.”*

3.4 *Endorse and provide funding for the Strategy to Address Issues Related to HIV Faced by People in Ontario From HIV Endemic Countries and its goal of reducing “the incidence of HIV among people in Ontario from HIV endemic countries (i.e., communities of African and Caribbean descent) and to improve the quality of life for those infected and affected by HIV/AIDS.”*

Objectives of Strategy to Address Issues Related to HIV Faced by People in Ontario from HIV Endemic Countries

- to co-ordinate the work of agencies, institutions and policy makers working with and for endemic communities (EC) regarding prevention, education, health promotion, care and support
- to facilitate community development in response to HIV/AIDS challenges
- to identify research needs, priorities and opportunities.

3.5 Identify and implement strategies to ensure that young people in Ontario receive education about HIV and other STDs, including:

- *engaging the Ministry of Education to ensure that the mandatory HIV/STD curriculum is delivered consistently in all school boards across the province*
- *at the local level, working with school boards to identify community resources that can be used to augment HIV/STD/sexuality education and to identify other places in the curriculum to incorporate messages about risk, decision making, STDs, harm reduction, discrimination and marginalization*
- *identifying non-school settings/media to deliver STD prevention and decision-making information (e.g., sports organizations, street youth programs, community clubs, youth media, young offenders' facilities)*
- *developing a multi-risk approach to adolescent education, which recognizes that youth often engage in more than one risk behaviour*
- *developing a strategy targeted to gay/bisexual youth.*

3.6 Develop and implement an innovative province-wide public education initiative designed to raise awareness of:

- *sexual health, and the risks associated with HIV and other STDs*
- *the information, skills and supports people need to maintain/improve sexual health*
- *how discrimination (i.e., racism, homophobia, sexism), stigmatization and marginalization contribute to the risk of HIV and STDs, and other health/social problems.*

Prevention, Care and Treatment

3.7 Increase the proportion of people who are infected who know their status (i.e., are diagnosed) to enable them to seek appropriate treatment and prevention services by:

- *launching a high profile, province-wide public education campaign to promote HIV testing and informed decision making and reinforce sexual health/STD prevention messages, focusing particularly on populations at risk*

- *making it a standard of care to offer an HIV test to everyone diagnosed with a disease associated with HIV (e.g., a sexually transmitted disease, hepatitis B or C, tuberculosis, an addiction)*
- *integrating HIV counselling in all sexual and reproductive health services*
- *providing a mobile HIV testing service, linked with IDU outreach and needle-syringe exchange programs*
- *reviewing the current use of partner contact/counselling services, and developing strategies to enhance their role as a prevention/care tool*
- *addressing the barriers that prevent people from being tested (e.g., lack of culturally sensitive testing services)*
- *addressing the physician's role in promoting testing as well as the assumptions or administrative barriers that keep physicians from offering HIV testing*
- *developing an education campaign for primary care physicians and obstetricians/gynecologists designed to ensure that all pregnant women are offered prenatal HIV testing, with appropriate counselling*
- *educating physicians about the value of testing data and how it is used, and encouraging them to complete test requisition forms.*

3.8 Collaborate with the addictions treatment system, provincially and locally, and other stakeholders to develop comprehensive addiction management programs that will meet the needs of people with HIV and those at risk, including:

- *increasing the availability of comprehensive methadone programs that provide counselling and social support, consistent with Ontario's draft methadone strategy*
- *increasing the number of physicians willing to prescribe methadone by providing appropriate incentives (e.g., bursaries to cover training costs, providing a site away from the physician's regular practice, providing administrative support, providing all counselling/case management services)*
- *providing access to a range of other harm reduction strategies (e.g., needle and syringe exchange services, low threshold programs)*
- *ensuring that every part of the province has non-abstinence based addiction treatment services that will provide services for people with HIV who are on medications (e.g., methadone, anti-retroviral therapy, medicinal marijuana)*
- *establishing and supporting clinics that provide a full range of services for IDUs, including outreach, needle and syringe exchange, primary care, methadone, counselling and support services.*

- 3.9 Collaborate with mental health services, provincially and locally, to develop mental health services that meet the unique needs of people living with HIV, focusing on outreach services for people with mental health problems and HIV or addictions.**
- 3.10 Ensure all health and social services professionals (e.g., physicians, nurses, social workers) receive education about HIV as part of their professional training and have access to continuing education in HIV.**
- 3.11 Develop a comprehensive strategy to ensure more consistent access to primary and specialized care services for people with HIV that addresses the current physician shortage, the complex demands that HIV care places on physicians, and the fact that many primary care physicians will not have the critical mass of patients to maintain competence in this field. The strategy should include:**
- **establishing minimum expectations for all primary care physicians in HIV care (e.g., the ability to conduct risk assessments, providing pre- and post-test counselling, diagnosing HIV infection, linking patients to specialized services)**
 - **providing supports for the small number of primary care physicians who choose to provide HIV care (e.g., recognizing HIV care as a primary care subspecialty, providing access to training, linking primary care physicians with the appropriate HIV outpatient clinic)**
 - **analyzing the impact of primary care reform on primary care physicians with a large HIV practice and, if the effect will be negative, identifying a more effective way to fund HIV primary care**
 - **continuing to support HIV outpatient clinics to provide specialized care, and ensuring all clinics have adequate resources to deal with a growing, aging caseload with complex health needs**
 - **establishing new HIV clinics in parts of the province not currently served by one**
 - **working with the clinics and local primary care physicians to identify strategies to ensure people living with HIV have access to primary care (e.g., having a primary care physician or nurse practitioner working out of the clinic).**
- 3.12 Improve access to services in rural and remote areas by:**
- **identifying innovative ways for providers to use technology, such as Telehealth, Telepsychiatry and web-based services, to deliver care**
 - **identifying effective, innovative ways to use local services and resources (e.g., nurse practitioners) to provide care in areas where there are physician and other shortages**

- *advocating for changes to the Northern Health Travel Grant program to ensure that it recognizes HIV primary care as a specialty primary care service and will subsidize transportation to primary care for people living with HIV when these services are not available locally*
- *identifying new funds to cover the cost of transportation to treatment for clients who live in rural and remote areas, and establishing criteria for administering these funds.*

3.13 *Work with correctional services to ensure that people living with HIV and those at risk have consistent access to care and prevention services while in prison (i.e., condoms and clean needles/bleach, information, counselling, culturally sensitive services, methadone maintenance, specialist services, anti-retroviral therapy, addictions treatment, mental health services) and are linked with community services when released.*

Resources

4. Ensure adequate resources for HIV and related programs and services.

In 2001-2002, the Ontario government provided approximately \$50 million to support HIV-related programs and services, *not* including physician costs, drug programs, inpatient hospital services, home care services, and palliative care services. Since 1998, the government has increased its annual investment in HIV programs and services by \$13 million a year. However, the existing resources may not be adequate to meet changing HIV needs, and there may be more effective ways to fund/resource HIV programs and services. Because HIV must compete with other health needs for its share of health care resources, it is also vital to document the positive impact of investments in HIV programs and services.

Recognizing the current pressures on the health care system and the competition for health care funding, Ontario will work to ensure that adequate funding is allocated to provide the full range of services to meet the needs of people living with HIV, and to support effective prevention initiatives.

4.1 *Determine the costs associated with this strategy and whether it can be implemented with existing resources; if not, identify the new resources required and develop the business case for increased funding.*

- 4.2 *Have the AIDS Bureau negotiate with the Canadian Strategy on HIV and AIDS to develop a new approach to funding community-based programs and services in Ontario, which would include:***
- *shifting from short-term (i.e., two-year) special project grants to more long-term investments in/enhancements to existing effective programs and services*
 - *harmonizing the application, monitoring and reporting requirements among all funders.*
- 4.3 *Identify opportunities to work with the ministry's hepatitis C strategy to increase the resources available for people who have both HIV and hepatitis C.***
- 4.4 *Assess different existing models for funding/managing HIV programs (e.g., B.C., Quebec, Ontario, Australia and the United States) for their cost effectiveness, quality of care and integration of prevention, treatment and research; develop an approach that builds on the strengths of all.***
- 4.5 *Develop a stronger capacity to document the province's HIV resources, how they are used and their impact by:***
- *developing effective ways to track the number of people served, the services they use and how often they use them (i.e., service frequency)*
 - *identifying the health and social service utilization/costs avoided because of the availability of HIV services*
 - *developing a model to estimate the number of infections prevented or avoided because of the investment in HIV programs and services.*
- 4.6 *Work with community-based AIDS organizations and the HIV research community to address recruitment, retention and succession issues.***

Accountability

5. Ensure HIV programs and services are accountable for the quality of their services and their use of resources.

Everyone involved in HIV programs and services in Ontario is committed to providing the best possible programs and care, and to accounting to their clients, communities, funders and the public for their use of resources. Monitoring and evaluation are an essential management tool for individual organizations and the entire program, and the way in which organizations are able to identify strengths and weaknesses, and improve services. HIV service providers see evaluation and accountability as a means to demonstrate the benefits of HIV services, and ensure they are achieving their goals and objectives.

- 5.1 Establish clear provincial standards/criteria for all provincially funded HIV-related programs and services which reflect the goals and policy directions in this strategy and promote the use of service agreements.***
- 5.2 The Ministry of Health and Long-Term Care will work with HIV programs and services to enhance their capacity to continually monitor, evaluate and improve their programs by:***
- *developing appropriate common evaluation tools*
 - *establishing performance indicators*
 - *providing training in program evaluation/outcome measurement*
 - *ensuring the evaluation process does not require a disproportionate amount of time, which could detract from front line service delivery*
 - *funding third-party evaluations when useful and appropriate*
 - *organizing opportunities for similar organizations to share lessons learned.*
- 5.3 Develop a consistent approach to evaluation (i.e., quality management) in all HIV prevention, care and research programs, and encourage organizations to use evaluation results to determine whether programs are achieving goals and objectives, and to refine their services.***
- 5.4 Based on evaluation results and local needs, identify opportunities to make more effective use of existing resources.***
- 5.5 Develop a monitoring/evaluation system to track the implementation of the strategy and the progress in achieving its goals by:***
- *establishing measurable objectives and outcome measures*
 - *establishing a system to track and analyze the measures*
 - *providing periodic, public reports on the strategy implementation*
 - *refining the strategy based on evaluation results.*

Conclusion

According to the Centres for Disease Control in Atlanta, the “most effective prevention works at multiple levels simultaneously – at individual, social network and community levels as well as at the structural level – addressing the sometimes hidden social barriers to effective prevention.”³⁵ OACHA believes this same kind of strategic approach is required to address all aspects of HIV.

This strategy proposes an integrated approach, based on social justice and the determinants of health which – when implemented – has the potential to dramatically change the course of the epidemic in Ontario, prevent new infections, improve the health of people affected, and reduce long-term health and social costs.

³⁵ Centres for Disease Control and Prevention. HIV Prevention Strategic Plan Through 2005. 2001.

Appendix I: Methodology

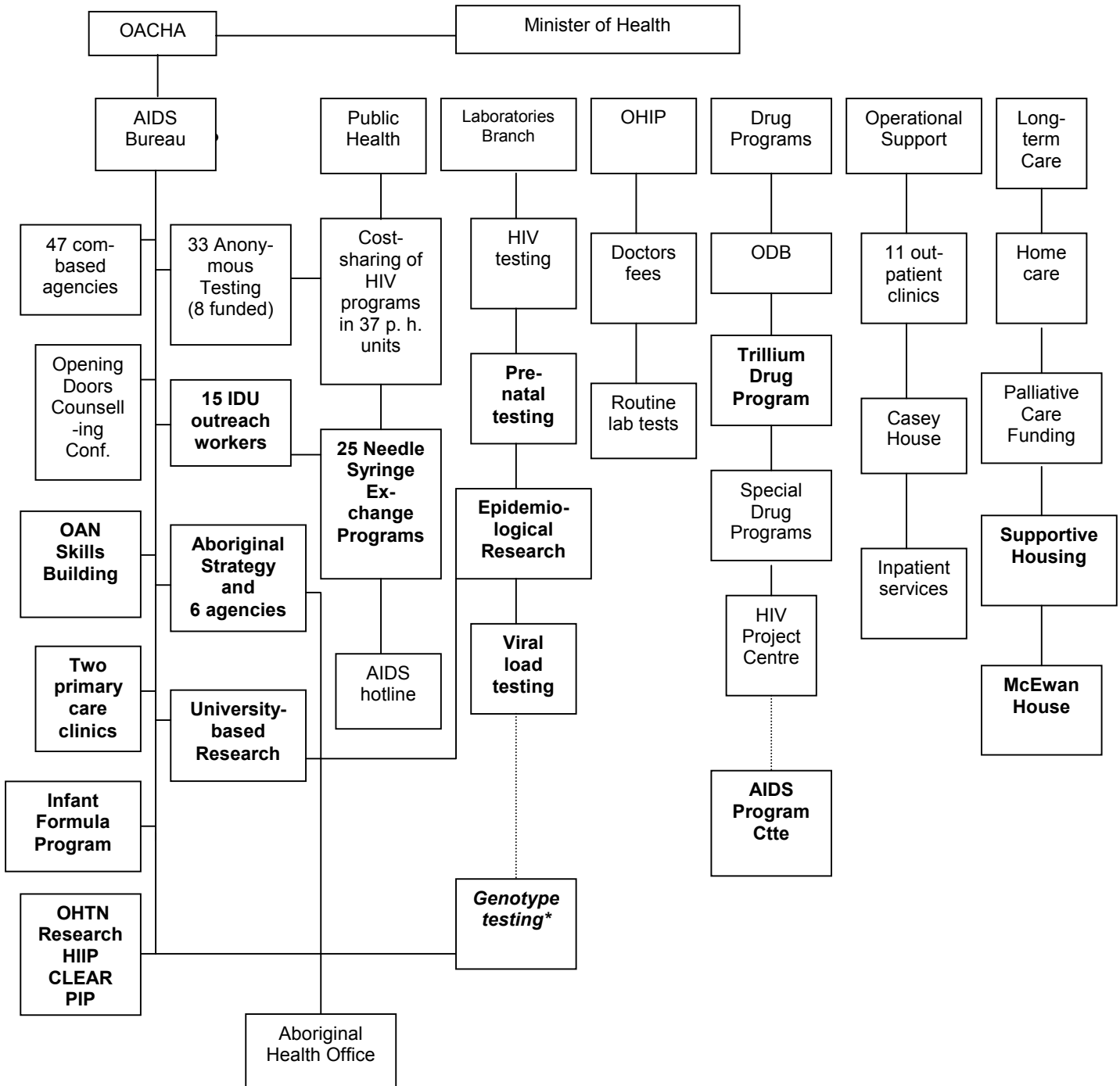
In 2001, the Minister of Health and Long-Term Care asked the Ontario Advisory Committee on HIV/AIDS (OACHA) to revisit the provincial AIDS strategy, and to make recommendations for a new strategy for Ontario. The process of developing the strategy was led by an OACHA subcommittee, chaired by David Hoe, former co-chair of OACHA and a person living with HIV.

As with all previous HIV/AIDS strategies and, in fact, most of Ontario's HIV programs and services, the strategy was developed through consultation with people living with HIV and individuals/organizations that provide HIV services, including: community-based AIDS organizations, public health units, HIV outpatient clinics, physicians, and researchers. The process included:

- surveying all organizations/individuals involved in HIV prevention, care and research
- developing a background discussion paper that summarized the current state of HIV infection, the emerging issues and the factors that contribute to infection and disease progression
- holding two Delphi Groups comprising key experts in HIV in Ontario to begin to identify strategies to address the emerging issues and contributing factors
- developing a draft strategy
- working with a group of experts to develop outcome indicators and performance measures that would make it possible to monitor and evaluate the strategy
- holding regional focus groups representing a broad range of perspectives in the region to “test” the proposed strategy
- refining the strategy based on the feedback from the focus groups
- presenting the strategy to OACHA.

Appendix II: Ontario's HIV Infrastructure

Over the past 16 years, Ontario has developed an extensive network of HIV programs and services. The following diagram illustrates the range of services funded by the Ministry of Health and Long-Term Care. The services in bold were established within the last five to seven years as a result of the last provincial strategy.



*At the current time, this is a temporary service provided by the B.C. Centre for Excellence. The Central Public Health Laboratory is making arrangements to develop a permanent program in Ontario.

History of Ontario's Response to HIV

In the early days of HIV, prevention and support programs were largely volunteer-driven, formed by communities to fill an obvious gap in services. When traditional health care services (i.e., physicians, hospitals) were reluctant to respond to the needs of HIV, community activists used a range of strategies (volunteerism, community development, public protest, media, lobbying) to draw attention to the issue and obtain funding for independent, community-driven, AIDS programs.

Even when the government moved to establish more formal, care-focused services – such as community-based AIDS organizations, the HIV out-patient clinics, anonymous testing programs, needle and syringe exchange programs, dedicated AIDS hospices – these programs were distinct and AIDS-specific, rather than being integrated into larger health care organizations or into broader health issues, such as sexual health. For example, the province established separate HIV clinics rather than integrating them with existing infectious disease clinics. It also funded community-based organizations to provide AIDS prevention and education, rather than using existing public health/health promotion programs. This was due to a number of factors, including:

- the stigma associated with AIDS
- the unwillingness or inability of the established health care system to deal with a new, frightening, contagious disease
- the inability or unwillingness of government to talk openly about sexual practices that put people at risk.
- the distrust (often justified) of government, public health and the health care system by the population most affected: gay men
- the ability of community-driven organizations to reach the target audience.

Over the past 10 years, with the broadening of the populations affected by HIV and more “mainstreaming” of HIV/AIDS, some HIV services have become more integrated with other health services. As a result, a wide range of health services, such as mental health services, addiction services, home care, ethnocultural-specific health services, and supportive housing, have developed the knowledge and skills to provide services for people with HIV. This, combined with treatment advances and the greater availability of information through sources such as the internet, means that some people with HIV are no longer relying as heavily on HIV-specific services for support, education or prevention.

Recent Developments

Over the past five to seven years, the most significant new developments in Ontario's response to HIV have been:

- the Trillium Drug Program, an income-based program that provides drug coverage for people with disproportionately high drug costs
- laboratory tests/services that can help guide clinical care
- investments in HIV research through HOOD, the AIDS Program Committee, the OHTN and the AIDS Bureau funding for university-based research; and

federal investments in the Clinical Trials Network, and the recent reorganization of research funding at the national level (i.e., reorganization of national health research development program into Canadian Institutes for Health Research)

- the development of services for IDUs
- the implementation of the Aboriginal AIDS Strategy.

How HIV Programs and Services Funded Are Managed

In 2001-2002, the government spent approximately \$50 million to support HIV-related services, *not* including physician costs, drug programs, inpatient hospital services, home care services and palliative care services. However, the Ministry of Health and Long-Term Care is not the only funder of HIV services in the province. Many community-based AIDS organizations also receive funding from their municipalities, the federal government and private donations. Researchers receive funding from the federal government and other granting agencies.

Although the AIDS Bureau is responsible for co-ordinating the Ministry of Health and Long-Term Care's response to HIV, it does not directly fund or manage all the province's HIV services. The diagram on page 12 illustrates funding/management responsibility for HIV programs and services in the ministry. Only those programs that have a line connecting to the AIDS Bureau receive funding directly from the AIDS Bureau. The others are funded through other programs in the ministry.

While this approach to funding HIV services promotes integration of HIV into other health services (i.e, mainstreaming) and increases the resources available to HIV programs and services, it also means that:

- decisions about the funding and management of certain HIV programs are made by those for whom HIV may not be a priority, and that the AIDS Bureau must negotiate with other parts of the ministry to maintain or increase funding for HIV programs
- it is extremely difficult to shift resources from one part of the infrastructure to another. For example, funds cannot be taken from long-term care services to pay for new laboratory tests. Funds cannot be shifted from hospital inpatient services to cover increasing drug costs.

Summary of Perceived Strengths and Weaknesses

Type of Service	Strengths	Weakness
Prevention	<p>Diversity, variety and comprehensiveness of prevention programs</p> <p>Strong public health system (testing, surveillance, counselling)</p> <p>Availability of anonymous testing</p> <p>Community expertise</p>	<p>Fragmentation of services, lack of co-ordination among HIV/AIDS programs and between HIV programs and other services</p> <p>Lack of sustained, high-profile ad campaign</p> <p>Lack of focus on the determinants of health</p> <p>Lack of services in rural areas</p> <p>Lack of education for youth</p>
Care and Treatment	<p>Comprehensive care provided by HIV clinics; effective collaboration among clinics</p> <p>Trillium and ODB – willingness to cover new drugs</p> <p>Clinical care infrastructure</p>	<p>Lack of services in rural areas and for marginalized populations</p> <p>Impact of hospital restructuring</p> <p>Restrictions on CCAC services</p> <p>Lack of rehabilitation services</p> <p>Lack of co-ordination among these services</p> <p>Administrative problems/time delays with the Trillium Drug Program</p> <p>Lack of addiction/methadone services and mental health services</p> <p>Lack of services for people in prisons</p>
Support	<p>Availability of comprehensive programs in large urban centres that can serve diverse populations</p> <p>Strong social safety net</p> <p>Support provided by the AIDS Bureau</p>	<p>Lack of services in rural areas</p> <p>Lack of affordable housing</p> <p>Lack of focus on social determinants of health</p> <p>Lack of outreach services, workplace support, mental health services and other social services</p>
Research	<p>Strong HIV research infrastructure</p> <p>High calibre of research/teams</p> <p>The public health laboratory system that supports HIV testing, viral load testing, genotyping and phenotyping and collection of HIV data and epidemiology</p>	<p>Lack of collaboration among researchers</p> <p>Lack of research in key areas</p> <p>Lack of global research strategy</p>

Appendix III: Determinants of Health³⁶

Income and Social Status

Health status improves at each step up the income and social hierarchy. High incomes determine living conditions such as safe housing and ability to buy sufficient good food. The healthiest populations are those in societies which are prosperous and have an equitable distribution of wealth.

Social Support Networks

Support from families, friends and communities is associated with better health. The importance of effective responses to stress and having the support of family and friends provides a caring and supportive relationship that seems to act as a buffer against health problems.

Education

Health status improves with level of education. Education increases opportunities for income and job security, and equips people with a sense of control over life circumstances – key factors that influence health.

Employment/Working Conditions

Unemployment, underemployment and stressful work are associated with poorer health. People who have more control over their work circumstances and fewer stress-related demands of the job are healthier and often live longer than those in more stressful or riskier work and activities.

Social Environments

The array of values and norms of a society influence in varying ways the health and well-being of individuals and populations. In addition, social stability, recognition of diversity, safety, good working relationships, and cohesive communities provide a supportive society that reduces or avoids many potential risks to good health. Studies have shown that low availability of emotional support and low social participation have a negative impact on health and well-being.

Physical Environments

Physical factors in the natural environment (e.g., air, water quality) are key influences on health. Factors in the human-built environment such as housing, workplace safety, community and road design are also important influences.

³⁶ Taken from Health Canada: www.hc-sch.gc.ca/hppb/phdd/docs/common/e_appendix_c.html

Personal Health Practices and Coping Skills

Social environments that enable and support healthy choices and lifestyles, as well as people's knowledge, intentions, behaviours and coping skills for dealing with life in healthy ways, are key influences on health. Through research in areas such as heart disease and disadvantaged childhood, there is more evidence that powerful biochemical and physiological pathways link the individual socio-economic experience to vascular conditions and other adverse health events.

Healthy Child Development

The effect of prenatal and early childhood experiences on subsequent health, well-being, coping skills and competence is very powerful. Children born in low-income families are more likely than those born to high-income families to have low birth weights, to eat less nutritious food and to have more difficulty in school.

Biology and Genetic Endowment

The basic biology and organic make-up of the human body are fundamental determinants of health. Genetic endowment provides an inherited predisposition to a wide range of individual responses that affect health status. Although socio-economic and environmental factors are important determinants of overall health, in some circumstances, genetic endowment appears to predispose certain individuals to particular diseases or health problems.

Health Services

Health services, particularly those designed to maintain and promote health, to prevent disease, and to restore health and function contribute to population health.

Gender

Gender refers to the array of society-determined roles, personality traits, attitudes, behaviours, values, relative power and influence that society ascribes to the two sexes on a differential basis. "Gendered" norms influence the health system's practices and priorities. Many health issues are a function of gender-based social status or roles. Women, for example, are more vulnerable to gender-based sexual or physical violence, low income, lone parenthood, gender-based causes of exposure to health risks and threats (e.g., accidents, STDs, suicide, smoking, substance abuse, prescription drugs, physical inactivity). Measures to address gender inequality and gender bias within and beyond the health system will improve population health.

Culture

Some persons or groups may face additional health risks due to a socio-economic environment, which is largely determined by dominant cultural values that contribute to the perpetuation of conditions such as marginalization, stigmatization, loss or devaluation of language and culture, and lack of access to culturally appropriate health care and services.

Appendix IV:

Ontario Aboriginal HIV/AIDS Strategy

A Strategic Plan for the Years 2001 - 2006

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1.0 PREAMBLE

In 1995, the Ontario HIV/AIDS Strategy was implemented. As a result of an evaluation of the Strategy undertaken in 1999, and in consideration of the changing face of HIV/AIDS in the Aboriginal community, this document was developed.

The Ontario Aboriginal HIV/AIDS Strategy has been successful in that it has raised the profile of the disease both within the Aboriginal community and the larger Ontario population. It has been successful because it is a strategy that is Aboriginal controlled, responsive to our unique needs and implemented by Aboriginal people.

The Province of Ontario respects the ability of the Reference Group and facilitates the Strategy by providing supportive funding and expertise. The partnership that has been created with the Province is a critical factor in the success of the Strategy.

Many other partnerships have been established through the Strategy with; mainstream HIV/AIDS service providers, local and regional Aboriginal organizations, educational institutions, various levels of government (from municipal to federal) and with our own 2 Spirited People of the 1st Nations. Without the continuous support of these key partners little progress can be made.

There are a number of hurdles and issues that continue to impede the work of the Strategy. The Aboriginal community and the Aboriginal leadership have largely viewed HIV/AIDS as non-threatening to the Aboriginal population. The disease is often characterized as non-Aboriginal, gay and urban-based. There are issues related to homophobia, a lack of tolerance for alternative lifestyles and judgmental attitudes that very likely have resulted from residential schools and other culturally denigrating experiences. It is important that Aboriginal communities recognize the threat HIV/AIDS poses to this and future generations and prepare to care for Aboriginal people in their communities of origin. The First Nation at Wikwemikong provide an excellent example of a caring community organizing themselves to take responsibility for the care of its people living with and affected by HIV/AIDS. It is only by strengthening partnerships with Aboriginal communities and the leadership that the Strategy can continue to make progress.

This document articulates the issues related to HIV/AIDS in the Ontario Aboriginal community and sets out strategies to address these issues. The progress that is made when we once again evaluate the Strategy in 2004 will depend on the demonstrated commitment of the Aboriginal community and the support of our partners.

This document articulates the issues related to HIV/AIDS in the Ontario Aboriginal community and sets out strategies to address these issues. The progress that is made when we once again evaluate the Strategy in 2004 will depend on the demonstrated commitment of the Aboriginal community and the support of our partners.

2.0 OVERVIEW of HIV/AIDS

Issues and Trends in the Ontario Aboriginal Community

In 1995, when the Reference Group proceeded to implement the Strategy it all seemed simple. If we merely accomplished the goals and objectives outlined in the Strategy everything would be fine.

Looking back, it did seem as if we had it all laid out. If we achieved everything we set out to do, we would be a long way towards functioning healthy Aboriginal communities.

We have done a great deal of work but we have a great deal more to do before we can rest.

What is the rate of HIV in the Aboriginal community in Ontario? Data on race and ethnicity with respect to HIV have not been collected consistently across Canada. In Ontario, we have extremely limited information because the province does not collect ethno-cultural HIV data. The information which follows is based on information from Health Canada's Laboratory Centre for Disease Control HIV/AIDS Epi Update. (1)

We do know that in the provinces in Canada that report ethnicity (British Columbia, Alberta, Saskatchewan, Manitoba, Yukon, Newfoundland, Nova Scotia, Prince Edward Island), the proportion of HIV diagnoses attributed to Aboriginal people was 19.4% in 1998 and 24.8% in 1999 with a significant increase in the numbers of Aboriginal women.

The Laboratory Centre for Disease Control notes an increase in the proportion of Aboriginal AIDS cases, as a proportion of all newly diagnosed cases, from 1% before 1990 to 15% in 1999. Ethnic origin is identified in just over half of the AIDS cases reported to the Laboratory Centre for Disease Control. We must recognize the fact that these data probably seriously under-represent the real numbers, that these numbers only reflect known Aboriginal AIDS cases, and that the number of Aboriginal people living with HIV is much higher.

Aboriginal AIDS cases are younger than non-Aboriginal AIDS cases (28.6% vs 17.1% were diagnosed at less than 30 years of age). The proportion of women among Aboriginal AIDS cases is higher than among non-Aboriginal AIDS cases (22.2% vs 7.7%). The proportion of AIDS cases attributed to injection drug use as an exposure category is higher among Aboriginal persons than among non-Aboriginal persons (24% vs 4.2% for men, 58.5% vs 18.1% for women.)

We also know that HIV did not pass over Ontario's Aboriginal communities. As a matter of fact, many people came to Ontario for information and assistance because of its advocacy experience with HIV and AIDS. They came for access to HIV primary care physicians and for access to the first AIDS service organizations, including 2-Spirited People of the 1st Nations, which was the first Aboriginal AIDS service organization in Canada.

The Laboratory Centre for Disease Control data also makes determinations of infection trends (which risky activities may be responsible for HIV transmission). Since the information collected comes from areas of Canada where ethno-cultural data is collected, the HIV infection trends enumerated in the data do not likely reflect the infection trends for the Aboriginal population in Ontario. From our discussions with non-Aboriginal AIDS service organizations in Ontario, we have determined that the transmission trends in Ontario differ from other provinces in Canada. For example, injection drug use is seen as a major transmission method in British Columbia. In Ontario, while injection drug use is a factor, it does not represent the major transmission trend. About 24% of HIV infections in the northern part of Ontario and 15% of HIV infections in Ottawa are in injection drug users. This is significantly higher than the 6.2% of infections in Toronto. For non-Aboriginal AIDS service organizations and from the information that the Strategy and 2-Spirited People of the 1st Nations have gathered, gay and two-spirited men continue to be the most adversely impacted by HIV in Ontario. Recent information in Ontario indicates that gay men still account for almost half of all new infections each year.

Why is this important? Transmission trends are used to determine funding priorities and criteria for proposals at all levels of governmental and non-governmental funding. If we do not have a true picture of the epidemic in Ontario's Aboriginal community, we may be forced to set priorities or undertake projects which are not timely or relevant merely to be able to obtain funds. Aboriginal AIDS service organizations have been in this position for years. Most of the funding priorities and criteria have been based on the data and priorities of non-Aboriginal AIDS service organizations. It has only been in the last few years that we have been able to influence funding priorities and criteria for the major governmental funders. We need appropriate and accurate information to design and deliver relevant programs and services to not only prevent the further transmission of HIV but also to address the needs of those Aboriginal people who are currently living with HIV/AIDS.

To this end, 2-Spirited People of the 1st Nations, one of the Strategy's member organizations, recently completed a survey of the knowledge, attitudes, beliefs/behaviours of two-spirited men across Canada in order to determine what prevention and health promotion messages might be accessible and appropriate for two-spirited men. We will use this information to design and deliver prevention and health promotion messages and to update and improve our programs and services.

HIV Testing:

Even if Ontario collected ethno-cultural data, there are other barriers to determining the numbers of Aboriginal people who are HIV positive. Generally, Aboriginal people do not get tested for HIV. There are many reasons for this. Many Aboriginal people continue to believe that HIV is a gay, urban disease and if you are not gay or if you live in an isolated community, you will not get HIV or AIDS. Anonymous HIV testing is not accessible to the vast majority of Aboriginal people in Ontario. HIV testing may be available in the local Aboriginal health center or at the nurse's station in the community, but it may be a relative or someone the individual knows who does the testing, so there is a fear that confidentiality is not protected if you are tested at these sites. We have heard and confirmed many stories from our clients about breaches of confidentiality so this is a very real fear. There are health professionals in rural communities who are not knowledgeable about HIV and consequently do not suggest an HIV test until all other options have run out. This is one of the reasons that Aboriginal people are diagnosed with HIV later and receive treatment at later stages in their illness than others living with HIV/AIDS.

Any strategies to promote testing in the Aboriginal community must also address these broader issues such as accessibility to testing sites, lack of or perceived lack of confidentiality in Aboriginal communities which do HIV testing, racism in mainstream health services, and the availability of counselling and support services in Aboriginal communities.

These obstacles are common to many groups of people within Canada. However, testing and confidentiality issues must be examined with a recognition that Aboriginal people have lived within a context of colonization, oppression, racism and cultural denigration. These issues have contributed to the over-representation of Aboriginal people in many of the most marginalized groups: poor people, prisoners, injection drug users, sex trade workers and homeless people. Ill health is also a common factor to these groups and this also contributes to being vulnerable to HIV.

While we would like accurate up-to-date information on the rate of HIV in Aboriginal communities in Ontario, we would only support obtaining this data with full and informed consent of the individual, guarantees of confidentiality and the availability of culturally appropriate counselling and support services.

Aboriginal Women:

According to the limited data which we have, it is abundantly clear that Aboriginal women are at increased risk for HIV infection. Cases of AIDS and new HIV diagnoses have risen among Aboriginal women more rapidly than among Aboriginal men and non-Aboriginal women. From the data, two of the key routes of transmission for Aboriginal women are injection drug use and heterosexual sex. (2)

Social conditions brought on by the legacy of oppression, racism and sexism-such as poverty, poor health, high rates of STDs and sexual violence, have disproportionately placed

Aboriginal women at risk for HIV and AIDS. The myth in many communities, and in Aboriginal communities that HIV is a gay, male disease, has exposed Aboriginal women to further risk. Generally, women have been ignored in HIV/AIDS research, policy and services and Aboriginal women have been almost invisible. Women have continued to be seen as “vectors of disease” through prostitution or pregnancy and their own health has been seen as inconsequential compared to that of the men with whom they have sexual contact and that of their unborn children. Very little attention has been paid to how women’s position in society has affected clinical research, diagnosis, treatment, and health care. Lack of understanding of HIV-related symptoms as they affect women has led to delayed diagnosis and treatment, counselling and support and care to HIV positive women which contributes to higher mortality rates among women living with AIDS. Given the poverty and poor health of most Aboriginal people, this lack of attention has been a key factor in the rapid increase of HIV among Aboriginal women.

Aboriginal women living with HIV/AIDS place themselves last on their agendas. Many are single parents and are trying to survive on social assistance. The vast majority of their time is spent on obtaining basic needs-food, shelter, clothing, and transportation for their children and then for themselves.

Their fear for the future of their children can be overwhelming. Who will take care of their children? When they become ill will their children be taken away by the same child welfare agencies who scooped Aboriginal children from their communities in the 1960s?

Aboriginal women living with HIV/AIDS are extremely vulnerable. Disclosing HIV status to a partner can expose her to violence and abuse. If she discloses to her home community, she can face rejection, emotional, physical, mental and sexual violence from friends, family members and other community members. This is especially true for Aboriginal women living in remote and rural communities where shelters or HIV/AIDS services and programs are not available.

Many Aboriginal women also feel they cannot disclose their HIV status in their home communities because they fear violence against their children. These fears are not groundless. We have heard many stories of threats and violence against HIV positive Aboriginal women and their children. As one Aboriginal woman living with HIV put it: “I cannot protect my children 24 hours a day. I had to leave my community”.

We need to develop specific messages, services and programs for Aboriginal women which take into account their special needs and we need to act very quickly.

Aboriginal Prisoners:

A very sad development in Aboriginal communities has been the exclusion of certain people from the circle. Aboriginal people who use alcohol or drugs, who are two-spirited, who are living with HIV/AIDS or who are in the corrections system have been excluded from or unwelcome in the community. This happens in rural, remote, isolated and urban Aboriginal communities. One of the most marginalized groups has been Aboriginal prisoners.

Prisons have been acknowledged as HIV incubators. Estimates of the rate of HIV among prisoners vary from 1% to 4% in men and from 1% to 10% in women. The rate of HIV is ten times higher in prisons than it is in the general population. Often their imprisonment and their HIV infection are strongly associated with injection drug use and many continue to inject while in prison. In a federal prison survey in British Columbia, 67% of prisoners reported injection drug use either in prison or outside, with 17% reporting drug use only in prison. In a 1995 prisoner survey conducted by the Correctional Service of Canada, 11% of 4285 federal prisoners reported injection drug use since arriving in the institution.

Injecting drugs, tattooing and piercing activities continue in prisons. Unsafe sexual activities continue in prisons. Since all of these activities are illegal in a prison environment, corrections authorities feel justified in not initiating needle exchange programs, and safe tattooing and piercing projects. Methadone maintenance is limited in most institutions to prisoners who were on methadone prior to their incarceration. Access to condoms in a confidential and dignified manner is not widespread throughout the system and unsafe sexual activities continue. Bleach may be available but its efficacy in preventing hepatitis C and other diseases is questionable.

Aboriginal people are over-represented in prison populations. While they represent 2% of the Canadian population, they represent an average of 14% of the federal prison population. Some provincial prisons have Aboriginal incarceration rates of up to 75%. According to a survey of Aboriginal injection drug users completed by the Canadian Aboriginal AIDS Network, 36% of the respondents reported sharing needles on the street and 73% reported sharing needles in prison.

Prisoners living with HIV/AIDS are not in a supportive environment mentally, emotionally, physically or spiritually. Access to expert health professionals in the area of HIV is not often available. Appropriate nutrition, counselling, access to elders and healers is not readily available. Often other prisoners and corrections officers wrongly feel at risk for HIV by the mere presence of individuals living with HIV in the prison which can make day to day life stressful if not outright dangerous.

We need to advocate much more strongly with and on behalf of Aboriginal prisoners to enable them to have the tools to protect themselves from HIV and to ensure that they have appropriate access to nutrition, treatment and culturally appropriate programs and services when they are living with HIV/AIDS. The Strategy is currently involved in an Aboriginal

Action Committee which is working on a National Aboriginal HIV/AIDS Corrections Strategy and activities which we hope will begin to address the HIV crisis in prisons.

Substance Use

The legacy of colonization, poverty and racism has contributed to an overwhelming sense of loss in the Aboriginal community. The use of alcohol, drugs and other substances to alleviate the pain of all of this loss is endemic in the Aboriginal community. The loss of lives, the violence, the low self-esteem which results should not need to be analysed and repeated again and again.

Substance use and its impact on risk for HIV infection have also been documented in countless research studies and reports. This holds as true for Aboriginal people as for other Canadians. Health Canada reports that injection drug use accounts for 17.6 % of the AIDS cases among Aboriginal men and 51.3% of those among Aboriginal women. This compares to 3.5% of the AIDS cases among men and 18.1% among women in the non-Aboriginal community. Aboriginal people represent between 25% and 75% of the people using various urban needle exchange programs and counselling/referral services.

What is lacking in Aboriginal programs and services which attempt to address the social impacts of substance use is a philosophy of harm reduction. All Aboriginal treatment centers are based on a philosophy of abstinence. The non-Aboriginal treatment centers and programs available are not culturally appropriate for the majority of Aboriginal substance users. For those people who cannot quit drugs or alcohol, there seems to be nothing available.

The high rate of mobility of Aboriginal people between urban, rural and reserve communities means that HIV is not restricted to pockets of injection drug users in the cities. Aboriginal people have sex and share needles in all of their communities.

We need to focus on the fact that Aboriginal people will continue to use substances. How they use the substances may expose them to HIV (sharing needles) or may impair their judgment in critical situations (unsafe sex). Abstinence-based programs do not work for the majority of substance users.

Harm reduction does not take a stand on substance use or judge the user, it is a response to the very serious issues of HIV infection. Many substance users eventually quit. What we need to focus on is how to protect them and others from HIV while they are using. The 2-Spirits survey on two-spirited men and the Canadian Aboriginal AIDS Network study on Aboriginal injection drug users report a high sense of personal commitment of the respondents to stopping the spread of HIV and a high awareness of HIV risk.

We need to focus on harm reduction measures which will inform the substance user about risk and how to protect themselves and their loved ones. We need to deal with Aboriginal people where they are and provide them with culturally-appropriate HIV/AIDS programs and services whether or not they are using. The goal is to empower Aboriginal users to make changes in

their behaviours which will reduce their risk of HIV infection and prevent the further spread of the virus.

Leadership and Networking:

There continues to be a major sense of denial in the Aboriginal community about the risk of HIV despite the evidence that HIV is on a rampage in all of our communities. Aboriginal leaders continue to be absent in public debate on this issue. HIV/AIDS continues to be at the bottom of the Aboriginal health agenda.

There continue to be a very small group of dedicated Aboriginal people who are working in the HIV/AIDS field with inadequate human and financial resources, and with very little support from Aboriginal leadership at all levels. There is a great deal of burnout among staff in Aboriginal AIDS service organizations. Often we rely far too much on Aboriginal people living with HIV and AIDS to travel around the country and tell their stories to small groups of people at risk to their own health. The people who attend our HIV/AIDS workshops and conferences may already be convinced of the threat that HIV poses to all of our communities. We have made few inroads in the Aboriginal populations which need to be convinced the most-heterosexual men, our leaders and elders.

Homophobia continues to prevent our important messages from reaching the hearts and minds of people who need to take action with us. Anti-drug and alcohol sentiment in Aboriginal communities continues to allow people to feel that they can judge others and blame them for their HIV infection. Prisoners must have committed a crime or they would not be in prison so who cares if they die there of AIDS.

These sentiments are not traditional to Aboriginal peoples. Our traditions speak of caring and sharing and taking care of our people who are not well. HIV is the disease, not the people living with it.

We will continue to work hard to inform our communities and to take care of our people living with HIV and AIDS. And we will continue to dream of a time when there is a cure.

1. **Epi Update, Laboratory Centre for Disease Control, Health Canada.**

www.hc-sc.gc.ca/hpb/lcdc/bah/epi/aborig_e.html

2. **Native Social Work Journal, HIV/AIDS : Issues Within Aboriginal Populations, Volume 3, September 2000**

3.0 VISION STATEMENT

In the development of an HIV/AIDS Strategy for Ontario, the Ontario Ministry of Health and Long-Term Care recognized the distinct needs and concerns of Aboriginal people in Ontario and committed to support the creation of a distinct strategy developed and driven by the Aboriginal community.

The Ontario Aboriginal HIV/AIDS Strategy will continue to operate distinctly and in parallel with the vision, goals and objectives of the Canadian Strategy on HIV/AIDS and the Ontario HIV/AIDS Strategy.

The Ontario Aboriginal HIV/AIDS Strategy also shares a common Vision with the Aboriginal Health Policy.

VISION STATEMENT OF THE ABORIGINAL HEALTH POLICY:

“The Ontario provincial Aboriginal Health Policy exists in the context of the inherent right of self-government.

Aboriginal health is wholistic and includes the physical, mental, emotional and spiritual aspects of life. Through this understanding of self, a vision of wellness which balances body, mind and spirit is promoted throughout the healing continuum.

Committed partnerships of Aboriginal and non-Aboriginal people and governments will recognize and respect the diversities in lifestyles and traditions of Aboriginal people regardless of residency and status.”

Goal of the Aboriginal Health Policy:

“To improve the health of Aboriginal individuals, communities and nations through equitable access to health care, improved standards of care, the provision of culturally appropriate health services and promotion of a healthy environment. Self determination in health will be supported by appropriate levels of financial and human resources for Aboriginal designed, developed and delivered programs and services that respect and promote community responsibility, autonomy and local control.”

Goal of the Ontario Aboriginal HIV/AIDS Strategy:

“To provide culturally appropriate, inclusive education and prevention programs, and support and care strategies, consistent with harm reduction principles, to Aboriginal people living with and affected by HIV/AIDS.”

4.0 PRINCIPLES

The Ontario Aboriginal HIV/AIDS Strategy will be a joint undertaking by the Aboriginal Community and the Ontario Ministry of Health and Long-Term Care and must:

1. Respect Aboriginal individual, family and community autonomy and diversity, regardless of status, age, residency, gender, or sexual orientation.
2. Be Aboriginal community-based in design, development and delivery and have direct participation by male and female Aboriginal youth, Aboriginal Elders, and/or Aboriginal Spiritual leaders and which respects and promotes positive Aboriginal traditional history and values.
3. Directly involve Aboriginal people who are living with and affected by HIV/AIDS.
4. Recognize, affirm and promote traditional healing and wholistic approaches that are consistent with the strategic directions.
5. Promote a wholistic system of care that is Aboriginal directed and provides a continuum of support, training, and education throughout the life cycle for Aboriginal people living with and affected by HIV/AIDS that transcends political, religious, geographic and socio-economic restraints.
6. Promote networking, coordination and sharing of information and resources among Aboriginal individuals, families, caregivers, agencies, service providers, communities, leadership on and off reserve, and spiritual/religious leaders.
7. Link with and support other Aboriginal and supportive non-Aboriginal health and social service initiatives and strategies.
8. Utilize an Aboriginal community-based evaluation process designed by the Reference Group to assess the implementation and delivery of the Strategy.
9. Acknowledge and respect an Aboriginal person's choice of programs and services and respect a person's right to privacy.
10. Acknowledge and respect an Aboriginal person's freedom to make decisions concerning their own development, healing and care.
11. Recognize that caring for those living with HIV/AIDS must be a shared responsibility for both men and women.
12. Support an individual's right to engage in activities that reduce harm to themselves and others.
13. Provide opportunities and encourage communities to establish supports that are safe and secure for people living with and affected by HIV/AIDS.

5.0 BACKGROUND

The Ontario Aboriginal HIV/AIDS Strategy Steering Committee was established in 1993 to develop an HIV/AIDS plan for off-reserve Aboriginal people. In 1995, the Reference Group, which is comprised of the Ontario Metis and Aboriginal Association, the Ontario Native Women's Association, the Ontario Federation of Indian Friendship Centres, 2- Spirited People of the 1st Nations, the AIDS Bureau and the Aboriginal Health Office of the Ontario Ministry of Health and Long-Term Care, implemented the Strategy.

The goal of the Strategy at the time of implementation was to design, develop and deliver a comprehensive plan for an effective and accessible continuum of physical, mental, emotional and spiritual care, support and education for Aboriginal individuals, families and communities living with and/or affected by HIV/AIDS. The following strategic directions were designated: programs and services, delivery supports and networking and coordination.

The Strategy, which is presently 100% funded by the AIDS Bureau, Ontario Ministry of Health and Long-Term Care, is governed by the Reference Group and the staff consists of the Provincial Coordinator located in Toronto and the equivalent of 7.5 HIV/AIDS Workers. Strategy Workers are located in strategic locations in Northern, Central, and Southern Ontario. Each worker is located within a host site and is managed by the Provincial Coordinator and supervised on day-to-day basis by a supervisor within each site.

It was determined that in year four of the Strategy, an evaluation would be undertaken so that in year five a new Strategic Plan would be developed based on recommendations for improvement and growth. The evaluation was completed in April, 1999 and over the course of a year the Reference Group implemented a number of recommendations. In addition the Reference Group developed new Strategic Directions to guide the work of the Strategy over the course of the years 2001 to 2006.

5.1 The Reference Group

To ensure that Reference Group members share the same level of commitment to the Strategy the Group agreed to affirm the following criteria for membership;

Reference Group members should:

- (a) Demonstrate commitment to addressing issues related to HIV/AIDS and particularly harm reduction strategies.
- (b) Possess a high degree of comfort with all issues related to HIV/AIDS and as a result, become an advocate and be willing to design and undertake proactive approaches to problems.
- (c) Act as a team player within the Reference Group, never competing with the Strategy but rather promoting the best interests of the Strategy.

- (d) Possess an understanding and sensitivity to Aboriginal communities and their cultures.
- (e) Possess knowledge and understanding of the roles and responsibilities necessary to take a leadership position.
- (f) Willing to share specific views and expertise both organizational and cultural.
- (g) Actively identify key partnerships, potential funding sources, and supportive initiatives/opportunities to support the strategy.

In addition to the above, Reference Group members agreed that the membership should reflect the perspectives of women, Metis, off-reserve and urban Aboriginal people, two-spirited people, youth and elders.

Finally, it was agreed that members should bring their unique perspectives to an Aboriginal issue which crosses all barriers and political groups with a view to building a consensus toward resolving critical issues. Members, therefore, should not be representing a certain group or organization but rather should bring that perspective forward to support a collective voice.

Membership - will be primarily comprised of Aboriginal people to a maximum of ten members as follows:

- 1 Member - Ontario Metis and Aboriginal Association (OMAA) or Alternate
- 1 Member - Ontario Native Women's Association (ONWA) or Alternate
- 1 Member - Ontario Federation of Indian Friendship Centres (OFIFC) or Alternate
- 1 Member - 2 Spirited People of the 1st Nations or Alternate
- 1 Member - Aboriginal Member at Large or Alternate
- 1 Member - Aboriginal Youth (under 30) or Alternate
- 1 Member - Elder or Alternate
- 1 Member - Aboriginal Person Living with HIV/AIDS (PHA) or Alternate
- 1 Member - AIDS Bureau or Alternate
- 1 Member - Aboriginal Health Office or Alternate

Roles and Responsibilities

The Strategy Reference Group has the following roles and responsibilities:

IMPLEMENTATION:

- Oversee the implementation of the Ontario Aboriginal HIV/AIDS Strategy.
- To establish appropriate links with other joint initiatives, such as the Aboriginal Health Policy, the Aboriginal Family Healing and Wellness Strategy, Long-Term Care Reform etc.

- To seek and make provisions to secure available funding from relevant ministries for areas of the Strategy for which appropriate linkages are not readily available.
- To identify any potential legislative barriers to implementation and propose alternate directions which are consistent with Aboriginal community needs, culture and governance structures.
- To identify and secure appropriate opportunities for proceeding with implementation of the Strategy.
- Ensure that the Strategy is implemented in an efficient and effective manner through planning and coordination.
- Develop and implement processes for allocating funding under the Strategy based on community capacity, readiness, and existing resources.
- Develop an accountability framework to ensure program and financial accountability to both the Aboriginal organizations and the government.
- Identify processes within the government to facilitate the successful implementation of the Ontario Aboriginal HIV/AIDS Strategy.
- Identify and establish appropriate links with First Nations programs and services.

OPERATIONS:

- To identify and address operational issues related to implementation of the Strategy, including the development of appropriate funding mechanisms and proposing effective and appropriate linkages with other initiatives.
- To address immediate funding needs in a manner which is equitable and respects the internal processes of the Aboriginal organizations/communities.
- To share information, comments and recommendations with other constituents and communities whether or not they are affiliated with the organizations represented on the Strategy Reference Group.
- To promote and support communication and networking between communities, organizations, service providers, agencies etc.
- Identify ways to better coordinate existing approaches.
- To provide instruction, support and counsel to an employed coordinator on an ongoing basis.
- Provide an annual report to the province and Aboriginal representatives on funds spent, programs funded by the organization and location, services delivered, and the number of jobs created by the Strategy.
- Design and manage an evaluation process.
- Promote coordination of related services.

5.2 Host Sites / Organizations

In developing the 2001 - 2006 Strategic Plan, the Reference Group recognized the need to expand the number of sites across Ontario (if resources become available). However, to ensure that the Strategy is successfully implemented in new locations, site selection criteria

has been developed. Host organization/sites entering into a partnership with the Strategy should meet certain criteria as follows:

(1) Location

- Priority should be given to an urban community with a significant Aboriginal population.
- Consideration should also be given to the number of Aboriginal people living with HIV/AIDS and the appropriateness of existing service organizations and supports.

(2) The Host Organization/Agency should:

- Provide a Board Resolution expressing the need for the service and recognizing the skills of the Strategy Worker to do the job.
- Be a multi-service organization that has the demonstrated support of the community and is financially viable.
- Be willing to sign an MOU agreeing to work in partnership with the Strategy, facilitate the flexibility required by the Strategy Worker and supportive of the fact that 100% of the Worker's time will be spent on the Strategy.
- Be willing to have the Worker train the staff of the host agency and have a plan to integrate Aboriginal HIV/AIDS issues into the organization.
- Have a non-discrimination policy in place.
- Recognize the diversity among Aboriginal cultures, traditions and values.
- Be easily accessible, protect confidentiality, provide an appropriate workspace and demonstrate a high comfort level with issues related to Aboriginal peoples and HIV/AIDS.

6.0 Strategic Directions - Goals and Strategies

Strategies have been developed and designed based on the need to continue certain important programs and services and the identification of new approaches to issues related to HIV/AIDS. While research continues to be critical to the effectiveness of an Aboriginal HIV/AIDS Strategy for Ontario, it has been incorporated throughout the Strategic Plan as opposed to having a discrete section.

Strategic Directions include:

- Promotion
- Prevention
- Treatment/Rehabilitation
- Palliative Care
- Delivery Supports
- Linkage with Aboriginal Prisoners
- Operations/Management
- Evaluation

6.1 Promotion

DEFINITION:

Aboriginal designed, developed and delivered education and primary prevention approaches that promote awareness of HIV/AIDS and related issues. These approaches include identifying choices for healthy living.

GOALS:

- 1) to increase awareness on HIV/AIDS and promote safer sex.
- 2) to increase awareness of healthy sexuality, healthy relationships and alternative lifestyles.
- 3) to provide opportunities to increase awareness and understanding of Aboriginal traditional teachings within the Aboriginal community.
- 4) to provide opportunities to increase awareness and sensitivity in the non-Aboriginal community regarding Aboriginal culture, beliefs and values.

OVERALL STRATEGIES:

- (a) Develop and implement a communications strategy that is responsive to all Aboriginal audiences including, women, youth, elders etc.
- (b) Design a web site to support the strategy and to provide current information on issues and trends related to HIV/AIDS in the Aboriginal community.
- (c) Produce a brochure that promotes the expertise and services available through the strategy.

Goal #1: To increase awareness of HIV/AIDS and promote safer sex.

- A. Continue to develop Aboriginal specific messages and information on HIV/AIDS for the Aboriginal community.
- B. Develop promotional presentations and resources on HIV/AIDS testing with a list of where to get pre/post-testing counselling, support, and follow-up services. Include identification of high-risk behaviours.
- C. Continue to promote Aboriginal initiatives during AIDS Awareness Week.
- D. Continue to develop, maintain and publicize regional Aboriginal HIV/AIDS hotlines and promote it in communities to make people aware that it exists.
- E. Continue to develop and sponsor local workshops, conferences, speakers etc. on such topics as Aboriginal women and HIV/AIDS, violence and AIDS, etc.
- F. Continue to develop basic HIV transmission information sheets in both polite and common wording, and in appropriate Aboriginal languages.
- G. Develop an AIDS information/resource booklet for use by Aboriginal communities/others. This booklet should include AIDS information, lists of educational materials, such as videos, pamphlets, support services for PHAs and others and their availability.
- H. Secure funding to support the development of a training module for use with leadership, youth and elders to change negative attitudes related to two-spirited people and HIV/AIDS in the Aboriginal community.
- I. Seek the support of two respected elders as Reference Group members and educate and involve elders in promoting positive HIV/AIDS harm reduction messages in the Aboriginal community.
- J. Continue to develop, maintain and promote lists of Aboriginal HIV/AIDS resource people.
- K. Continue to develop messages on how to treat Aboriginal PHAs with sensitivity, and share these messages with communities. Where possible, have Aboriginal people living with HIV/AIDS also present the information directly in communities, schools etc.

Encourage organizations to develop policies around AIDS in the workplace, ensuring the sensitive, equitable treatment of PHAs in their employ.

- L. Develop a promotional package/other approaches that recruit men to increase their involvement in identifying the problems that HIV/AIDS presents for communities. Such approaches could be:
 - distribution of materials at sporting events

- obtaining support from male controlled organizations, as in sports teams
 - asking prominent men in the community (elders, political leaders, musicians, actors, political figures etc.) to speak out about AIDS.
- M. Design, develop and deliver awareness programs to better prepare and equip personnel of Aboriginal organizations and agencies to promote prevention of HIV/AIDS. This approach might include developing promotional packages on work done by Aboriginal people living with HIV/AIDS in their communities which could be distributed to the National Aboriginal organizations.
- N. Develop and participate in community events to share HIV/AIDS information.
- O. Provide open forums between all community members (i.e., practitioners of western/Traditional medicine, Aboriginal/Christian denominations etc.), to discuss how to deal with homophobia, condom use, high-risk behaviour and sexual abuse.
- P. Develop HIV/AIDS awareness and sensitivity workshops for Aboriginal and non-Aboriginal people working in the chemical dependence treatment continuum.
- Q. That intergenerational (i.e., between different age groups) discussions be encouraged at the community level to address homophobia and HIV/AIDS related issues.

Goal #2: To increase awareness of health sexuality, healthy relationships and alternative lifestyles.

- A. Ensure that any HIV/AIDS programs developed by and for Aboriginal people promote healthy lifestyles, self-sufficiency and self-government.
- B. Develop culturally specific and cross-cultural HIV/AIDS and sexuality programs for Aboriginal students and faculty at both Aboriginal and non-Aboriginal schools.
- C. Assist in developing parenting programs to help parents educate themselves, their children and their communities about HIV/AIDS. Included in this would be a component on coping skills.
- D. That the full range of safer sex alternatives be positively examined and promoted.
- E. Develop Aboriginal sexuality education programs that focus on promotion of empathy for people living with HIV/AIDS and of people living alternate lifestyles, in a manner appropriate to the community.
- F. Assist in engaging youth to develop their own approaches to promoting healthy sexuality and healthy relationships.
- G. Promote same sex benefit packages in all Aboriginal organizations and non-Aboriginal organizations who employ Aboriginal people across the province.

- H. Promote a greater understanding among Aboriginal women of pre and post-natal transmission risks.
- I. Provide leadership and assertiveness training opportunities for women and practical skills to negotiate safer sex and to promote education and information exchange in a non-judgmental way.

Goal #3: To provide opportunities to increase awareness and understanding of Aboriginal traditional teachings within the Aboriginal community.

- A. Develop opportunities for Aboriginal communities to access Aboriginal traditional teachers perhaps utilizing the Healing Lodges available to them.
- B. Develop opportunities to research the history and teachings on Aboriginal sexuality, two-spiritedness, traditional roles of men, women, children and Elders.
- C. Design, develop and deliver education and awareness programs to better prepare and equip Aboriginal elders to understand and be tolerant of harm reduction strategies.
- D. Develop opportunities for traditional Elders to pass on traditional teachings, thereby promoting choices for healthier lifestyles and decreasing the spread and transmission of HIV/AIDS.
- E. Encourage Aboriginal employers to provide paid compassionate and cultural leave which recognizes Aboriginal spiritual values and which recognizes the diversity of Aboriginal cultures and families.

Goal #4: To provide opportunities to increase awareness and sensitivity regarding Aboriginal culture, beliefs and values in the non-Aboriginal community.

- A. Encourage the development of Aboriginal cultural sensitivity and awareness workshops and provide opportunities for non-Aboriginal service providers and caregivers to access this training.
- B. Encourage non-Aboriginal employers to recognize and provide paid cultural/compassionate leave that recognizes Aboriginal family systems for Aboriginal employees without penalty.
- C. Encourage Aboriginal communities/agencies to identify supportive non-Aboriginal individuals or service providers and recognize their contribution towards Aboriginal communities.

6.2 Prevention

DEFINITION

Approaches and measures that assist in reducing the transmission of HIV among Aboriginal people.

When designing education and prevention programs all appropriate links between HIV/AIDS and other issues faced by the Aboriginal community must be considered; these include sexual assault, incest, alcohol, drug and solvent use, teen pregnancy, birth and STD rates and suicide.

Goal #1: To develop general and focused awareness and prevention programs. Focused awareness programs include: people in the addiction continuum, both residents and staff, injection drug users, substance users, sex trade workers and other hard to reach groups.

Strategies

- A. Provide staff and clients throughout the substance use treatment continuum with complete and accurate information regarding HIV transmission, infection, and risk reduction behaviour on a continuous basis with regular evaluations and updates. AIDS awareness, harm reduction techniques and healthy sexuality should be standard components of substance use treatment.
- B. Develop awareness and support projects and plans for urban Aboriginal street outreach.
 - These approaches might include the hiring of street outreach nurses, integrating HIV education/condom and needle distribution into street patrols.
- C. Strengthen partnerships with “outreach providers” to ensure that messages and strategies are culturally appropriate.
- D. Strengthen partnerships with IDU prevention initiatives and develop culturally appropriate harm reduction strategies that are based on emerging trends.
- E. Work with others to ensure that harm reduction programs educate their clients about the risk of the chosen behaviour in a non-judgmental manner.
- F. Work with others to increase access to methadone treatment in all urban settings province-wide.
- G. Work with Aboriginal Health Access Centres to increase needle distribution services and education about safe needle disposal in community settings.

- H. Work to engage the communities in an HIV/AIDS prevention planning process.
- I. Undertake community-based knowledge, attitude, behaviour/belief studies so that targeted messages can be developed.

Goal #2: To develop HIV/AIDS awareness and prevention programs for presentation in educational facilities attended by Aboriginal people.

- A. Develop HIV/AIDS awareness, prevention and risk reduction programs with Aboriginal youth which address and promote self-esteem and life skills.
- B. Encourage school, college and university boards to invite Aboriginal community leaders, service organizations, high profile role models including Aboriginal youth living with HIV/AIDS to participate in education, prevention and healthy sexuality programs.
- C. Design and develop creative methods to raise awareness, advocate and provoke discussion related to HIV/AIDS.
 - Create a CD ROM for wide distribution.
 - Create an installation that can travel province wide.
- D. Keep abreast of new effective messages and share information with others.
- E. Organize focus groups to measure the effectiveness of current messages and brainstorm new approaches.

6.3 Treatment/Rehabilitation

DEFINITION

Treatment/rehabilitation has been defined as “accessible, affordable and culture/community based methods of physical, mental, emotional, spiritual healing and aftercare which allow individuals to maintain or regain optimum levels of wellness.”

Goal#1: To develop and promote culture/community-based traditional treatment and rehabilitation programs and services while ensuring improved access to western medical approaches.

Strategies

- A. Provide more information to Aboriginal people living with HIV/AIDS on alternative medicines and treatments, and this information should be available in all appropriate languages particularly through Aboriginal Health Access Centres.
- B. Provide space for and access to traditional ceremonies in hospitals, hospice facilities and clinics; wherever an Aboriginal person requests this service.
- C. Promote traditional medicines and herbs as legitimate approaches to managing HIV/AIDS. Also efforts should be made to complement Western medical approaches to treatment and rehabilitation with traditional Aboriginal healing practices.
- D. Facilitate improved cooperation and networking of traditional Aboriginal healers and Western physicians and other medical caregivers, i.e. nurses, psychologists, psychiatrists etc., wherever possible.
- E. Promote HIV/AIDS harm reduction strategies/measures with Aboriginal Health Access Centres, Healing Lodges and other events for example Health Conferences and Annual General Meetings of Aboriginal Organizations.
- F. Establish partnerships and assist them in developing Aboriginal appropriate addiction treatment service models that are based on harm reduction.
- G. Continue to influence drug treatment approaches by establishing, maintaining and strengthening partnerships with resources such as CATIE and OHTN.
- H. Promote non-discriminatory and timely access to substance use treatment centres by HIV positive Aboriginal people who require the service.
- I. Assist in developing measures to prevent the penalization of Aboriginal people living with HIV/AIDS who experience work or medical absenteeism caused by HIV/AIDS related illness.
- J. Provide for appropriate individual and systematic advocacy services to allow Aboriginal people living with HIV/AIDS to take action against those individuals and facilities which practice discriminatory behaviour on the grounds of race, sexuality or AIDS-phobic beliefs.
- K. Educate health care professionals who prescribe medicines or therapies for Aboriginal people living with HIV/AIDS to complement and take into account other factors such as substance use/addiction histories, etc.
- L. Advocate for the numbers of HIV/AIDS sensitive Aboriginal health liaison workers in hospitals to be increased.

- M. Provide Aboriginal translators for Aboriginal people living with HIV/AIDS and their families/partners who require translation in order for them to understand medical information presented to them.
- N. Continue to seek opportunities for cross training with CAMH HIV program and other partners.

Goal #2: To develop and provide adequate and sensitive social support systems and services to Aboriginal people living with HIV/AIDS, their families, partners and significant others.

Strategies

- A. For many Aboriginal people living with HIV/AIDS the disease can lead to isolation from the community, often because of community fear. Providing for a range of social supports for Aboriginal people living with HIV/AIDS is an integral part of emotional and mental healing. Continue with approaches that include;
- Establishing drop-in centres,
 - Coordinating social events, feasts, movie-nights, which are for or include Aboriginal PHAs
 - Organizing and coordinating regular friendly visiting
 - Phone-checking
 - Talking circles
 - Assisting with food preparation
 - Grocery delivery/prescription pick-up
 - Escorting people to medical appointments
- B. Provide for the inclusion of family members/partners/significant others in any treatment consultations (at the request of the Aboriginal PHA).
- C. Provide for the development of individual (legal, medical and employment) advocacy services for Aboriginal people living with HIV/AIDS.
- D. Partner to ensure that treatment, rehabilitative and palliative care contingency plans be developed by Aboriginal people and communities to ensure the best care and support of Aboriginal people living with HIV/AIDS and their families and partners.
- E. Partner to ensure that additional financial assistance programs be provided for Aboriginal people living with HIV/AIDS who are on low or fixed incomes and that this assistance be extended to cover alternative therapies or other recommended treatments.
- F. Partner to ensure that resources be provided to Aboriginal organizations/service providers to enable them to provide for the emergency medication, travel or crisis intervention needs of Aboriginal people living with HIV/AIDS and their family/partners.

- G. Partner to ensure that there be a review of income security options for people living with HIV/AIDS and all relevant legislation and policies, to increase access to disability payments.
- H. Partner to ensure that all legislation is amended which bars same-sex partners from claiming any of those benefits currently available to other forms of family.
- I. Advocate for an Ontario wide consultation with Aboriginal communities to make medications required by Aboriginal people living with HIV/AIDS fully accessible.
- J. Examine the coordination of drug benefits provided to Aboriginal people by the Ontario government and the federal government, identify issues and propose solutions.
- K. Advocate for health transportation funding (Northern Health Travel Grants) to allow for Aboriginal people living with HIV/AIDS who require access to treatment and rehabilitative services (including those offered by healers and elders) to travel to the most appropriate centre for service, regardless of location.

6.4 Palliative Care

DEFINITION

The provision of physical, mental, emotional and spiritual care of Aboriginal people living with HIV/AIDS in the final journey of life. Personal choices of care by people living with HIV/AIDS must be respected.

Goal #1: To provide culture/community based palliative care services and facilities which allow Aboriginal people in the final stages of HIV/AIDS related illness to live in the surroundings of their choice.

Strategies

- A. Advocate to ensure that supportive home care services and equipment is available for those Aboriginal people living in the final stages of AIDS wherever that service is required. Such an approach would require;
 - The development of a network of Home-Care nurses who are culturally sensitive and are experienced and trained in HIV/AIDS related palliative care.
 - Increased recruitment of Aboriginal people into Home Care programs.
 - Increased flexibility around program eligibility.
- B. Advocate to ensure that where required, Care-Team/Palliative care coordinators are employed in appropriate Aboriginal agencies to assist in the development, coordination, and training of care teams.

- C. Encourage and assist communities be encouraged and assisted in the development of care teams to respond to the needs of those living with HIV/AIDS related illness.
- D. Partner with hospice providers and transitional housing facilities to provide supportive environments for Aboriginal people living with HIV/AIDS.
- E. Ensure that appropriate accommodation is available for loved ones who wish to be with an Aboriginal person living with HIV/AIDS while they are attending a facility for treatment, counselling or tests.
- F. Promote the appropriate use of universal precautions by all people who provide HIV/AIDS health care and relative services when working with people living with HIV/AIDS.
- G. Actively involve traditional Elders and medicine people with Aboriginal people who request their involvement.
 - This approach would require all hospital facilities to ensure close links with Aboriginal communities and be in contact with Aboriginal resource centres/health centres for appropriate assistance.
- H. Provide for Aboriginal designed, developed and delivered palliative care services to be delivered for Aboriginal people living with HIV/AIDS who are in non-Aboriginal hospices or hospital facilities.
- I. Ensure that people living with AIDS not be denied pain medication regardless of their past history with substance use. Rather this element should be taken into consideration with regard to appropriate dosage in light of possible tolerance to drugs. Consultation with client/patient and care team members is reiterated.

6.5 Delivery Supports

6.5.1 Training

DEFINITION

Culture-based experiential activities that develop the necessary knowledge, skills and attitudes for the provision of programs and services related to the Ontario Aboriginal (off-reserve) HIV/AIDS strategy. Included in training are opportunities for on-going professional development.

Goal #1: To increase access and support for Aboriginal people living with HIV/AIDS who wish to pursue education, employment and training opportunities.

Strategies

- A. Continue to provide opportunities to access upgrading/employment training for Aboriginal people living with HIV/AIDS who wish to upgrade their employment skills. Suggested approaches could include:
 - Educating employment counsellors to increase their sensitivity to people living with HIV/AIDS to ensure that PHAs are given an equal opportunity to enter the work force.
 - Ensuring that Aboriginal organizations/service organizations/counsellors and agencies are made aware of and promote existing Aboriginal training and educational opportunities.
- B. Provide information, lobbying and advocacy for Aboriginal people living with HIV/AIDS who require support in their efforts to secure resources to access education and/or employment training.
- C. Encourage teachers, staff, parent/teacher associations and Aboriginal education counsellors to conduct HIV/AIDS awareness and education in their workplaces.

Goal #2: Develop and provide opportunities for training and curriculum development for Aboriginal HIV/AIDS programs and services

Forward: In many cases English will not be the first language of the caregiver or educator, therefore, the training and curriculum must be translated into Aboriginal languages.

Strategies

- A. Training for health care professionals and volunteer care teams working with Aboriginal people living with HIV/AIDS and their families must include: in-service education emphasizing team approach to case management, formal courses, educational videos etc.
- B. Undertake training needs assessments with Strategy Workers to ensure that their knowledge of HIV/AIDS emerging trends and issues as well as new drug treatments is current to facilitate continuous improvement of program and service delivery.
- C. Identify and train appropriate advocates to be knowledgeable in relevant health and human rights legislation and about the programs and services offered by HIV/AIDS organizations, governmental bodies, and federal, provincial and municipal health authorities.

Goal #3: To recognize and acknowledge the experience and training of Aboriginal people working in traditional or western health programs or services related to HIV/AIDS.

Strategies

- A. Identify Aboriginal community members who are knowledgeable and skilled in responding to HIV/AIDS and create opportunities to promote and support them. Such approaches could include:
- development of an Aboriginal HIV/AIDS educators/speakers register
 - maintenance of the register through a central data-bank identified in the networking and coordination system

Goal #4: To develop and provide training opportunities for program management and leadership development.

Strategies

- A. Provide leadership and assertiveness training opportunities to youth to promote peer-based HIV/AIDS safer sex education and information.
- B. Provide program management training opportunities for Program Directors and Executive Directors of Aboriginal urban or rural service delivery agents on the responsibilities of delivering an Aboriginal HIV/AIDS program or service.
- C. Provide policy development training to Boards of Directors of Aboriginal urban or rural service agencies who have responsibility for overall management of Aboriginal HIV/AIDS programs or services.
- For example, designing, developing and assisting in implementing policies, procedures and protocols around HIV/AIDS in the workplace and community.

Goal #5: To develop and provide for the on-going education and training of people who provide HIV/AIDS health care and related services to Aboriginal people living with HIV/AIDS and their families/partners.

Strategies

- A. Review and update, as needed, training programs for community based workers.
- B. Provide Aboriginal people working in the HIV/AIDS health care and related fields, where they exist, opportunities to receive instruction/training on all HIV/AIDS issues.
- For example, one such approach would be to encourage all new hiring and wellness initiatives to include HIV/AIDS awareness training for staff.

- C. Increase the focus on issues of sexuality, cultural awareness and sensitivity in all continuing education and health degree programs developed in universities and colleges. Suggested approaches could include, but are not limited to:
- Ensuring that appropriate college, university and training facilities/departments establish links with Aboriginal community recognized individuals/agencies competent in issues of HIV/AIDS. Ensure that efforts are made to include such individuals in developing classes, holding workshops and making presentations.
- D. Support the development and delivery of cross-cultural training for health care professionals and other people currently providing support to Aboriginal people living with HIV/AIDS, including: physicians, nurses, psychologists, mental health workers, home care workers, social assistance workers, social workers etc.
- E. Develop and provide training opportunities for Aboriginal justice and correction workers on HIV/AIDS and related issues and how they impact the justice and correctional system.

6.5.2 Support to Families and Caregivers

DEFINITION

Care and support opportunities required to assist families and caregivers who are involved in the design, development and delivery of Aboriginal HIV/AIDS programs and services or who are directly impacted by HIV/AIDS.

Goal #1: To provide opportunities for the care and support of families and caregivers who are involved in the design, development and delivery of Aboriginal HIV/AIDS programs and services.

Strategies

- A. Acknowledge and support the role of families/caregivers including Strategy workers working with Aboriginal people living with HIV/AIDS and their families/partners.
- B. Provide finances, materials and equipment for families, caregivers and service providers, as required.
- C. Provide respite care for people providing care services to Aboriginal people living with HIV/AIDS.
- D. Provide opportunities for culture based, wholistic healing for families, caregivers and service providers that includes, but is not limited to: stress reduction/control, burnout prevention and loss/grief/bereavement counselling.

- E. Provide support, encouragement, assistance and advocacy as requested by Aboriginal people living with HIV/AIDS, their families, partners, volunteer caregivers and/or their powers of attorney.
- F. Where required, provide travel and accommodation assistance to families and partners who wish to visit relatives/partners who are living with HIV/AIDS who are in hospitals/hospice facilities in other parts of the province.
- G. Provide for the development of hostels for families and/or partners who require extra assistance when visiting their relatives/partners in hospitals and/or hospice facilities.

Goal #2: To provide support and appropriate care for Aboriginal people who are directly impacted by HIV/AIDS.

Strategies

- A. Develop approaches that address the unique needs of Aboriginal women and children impacted by HIV/AIDS including orphaned children.
- B. Identify potential partners and facilitate dialogue on the most appropriate way to care for children directly impacted by HIV/AIDS.
- C. Incorporate messages related to the needs of Aboriginal families directly impacted by HIV/AIDS into the communications strategy.
- D. Develop approaches that facilitate the testing of Aboriginal women who want to be or who are pregnant with their specific informed consent.

6.5.3 Supportive Housing

DEFINITION

Safe, accessible, affordable and supportive housing for Aboriginal people living with HIV/AIDS, their families and/or partners.

Goal #1: To create opportunities for safe, accessible, affordable and supportive housing for Aboriginal people living with HIV/AIDS and their families/partners.

Strategies

- A. Make provision for the identification of supportive housing needs of Aboriginal people living with HIV/AIDS, their families and partners.

- B. Provide supportive urban and rural Aboriginal community housing for Aboriginal people living with HIV/AIDS and their families/partners. Priority should be placed on securing Aboriginal-specific housing for Aboriginal PHAs.
- C. Provide housing advocacy and support workers, such as home-care workers, for Aboriginal people living with HIV/AIDS who require supportive and affordable housing.
 - Where required, 24 hour care must be available on-site.
- D. Establish partnerships to provide for the development of alternative housing arrangements to existing hospices where the need is identified.
- E. Ensure that temporary accommodation is available for Aboriginal people living with HIV/AIDS and their families/partners when travel to another city is required for treatment/diagnosis.
- F. Develop HIV/AIDS support service awareness and education programs for Aboriginal housing authorities and for non-Aboriginal housing authorities where necessary, to promote the need for safe, affordable, accessible and supportive housing for Aboriginal people living with HIV/AIDS, their families and partners.
- G. Examine the full range of housing needs of Aboriginal PHAs, develop practical options to address these needs and design a business plan to be incorporated into a housing fundraising strategy.

6.5.4 Research and Planning

DEFINITION

Activities that are designed to assist Aboriginal off-reserve communities in researching and assessing individual, family and community needs, setting priorities for ongoing resource development and management.

Goal #1: Promote and provide for community needs assessments, research on HIV/AIDS and Aboriginal sexuality, identification of priorities and planning for ongoing resource development and management.

Strategies

- A. Conduct an assessment of research needs by summarizing and critiquing existing research and identifying gaps.

- B. Partner with other Aboriginal community stakeholders, various levels of government and the research community itself on necessary research related to Aboriginal people and HIV/AIDS.

Goal #2: Ensure that appropriate and ethical Aboriginal driven data collection and seroprevalence studies are developed.

Strategies

- A. Design an appropriate and confidential data collection method related to Aboriginal people living with HIV/AIDS.
- B. Ensure that specific information is collected on Aboriginal children living with HIV/AIDS.
- C. Where appropriate and financially feasible, undertake knowledge, attitude and behaviour studies to facilitate planning, designing, implementing and evaluating HIV/AIDS programs and services.
- D. Undertake HIV seroprevalence studies within Aboriginal communities, utilizing methods and approaches which are ethical and have been approved, designed and/or supported by the Aboriginal community.
- E. That a strategy for encouraging voluntary HIV antibody testing for Aboriginal people be designed, developed and delivered following examination and discussion of issues related to:
- Barriers to Access: personal and psychological, transportation and financial (access to confidential and free HIV testing), social discrimination, and;
 - Organization of testing and health services: criteria for establishing testing sites, counselling services, personnel, method of specimen collection.
- F. Provide for the development of Aboriginal community agency internal guidelines and protocols for confidentiality with respect to service provision and ensure that suitable sanctions for breaches of confidentiality are included.

6.5.5 Working with Leadership

DEFINITION

Developing appropriate relationships with Aboriginal, municipal, provincial and federal government leadership and promoting concentrated lobby and advocacy efforts with and on behalf of Aboriginal people living with HIV/AIDS, their families, partners and communities.

Goal #1: To develop appropriate relationships with Aboriginal, municipal, provincial and federal government leaderships.

Strategies

- A. Linkages to all levels of government (including Aboriginal governments) should be strengthened and maintained to ensure that opportunities are identified, policy decisions are understood and responded to, and, regulatory and/or legislative issues are understood as they affect Aboriginal people and HIV/AIDS.
- B. Support the education of leadership to become positive role models promoting acceptance of alternative lifestyles in order to effectively face the challenges presented by HIV/AIDS and in order to break down barriers such as homophobia.
- C. Support the Ontario Aboriginal HIV/AIDS Strategy Reference Group's work with Aboriginal organizations and leadership to develop advocacy strategies and gain political support from governments.
- D. Advocate that key public service positions (Federal/Provincial/Territorial/Municipal) responding to HIV/AIDS or general health should be occupied by Aboriginal people wherever the population warrants.

Goal#2: To promote concentrated lobby and advocacy efforts with and on behalf of Aboriginal people living with HIV/AIDS, their families, partners and communities.

- A. Educate Aboriginal leadership about the full implications of HIV/AIDS and recognize, include and support Aboriginal people living with HIV/AIDS in their struggle to address care, support and treatment issues.
- B. Advocate for leadership to provide increased time, energy and priority to lobby and advocate for increased funding, particularly for remote and northern areas.
- C. Lobby and advocate for supportive care systems for Aboriginal people living with HIV/AIDS in correctional facilities and in the substance use treatment continuum.
- D. Continue to impress upon leadership that HIV/AIDS is a political issue as well as a medical issue, and therefore, in this context, it is important to deal with HIV/AIDS in the context of large issues such as self-government and the transfer of responsibility for health care.

- E. Assist leadership in addressing cross border issues, particularly promoting awareness of the transport of sacred medicine bundles across the U.S./Canadian border by Aboriginal people, and advocate for the protection of Aboriginal peoples from invasions upon their sacred properties.

6.6 Linkages with Incarcerated Aboriginal People

DEFINITION

Programs, Services and Advocacy activities that respond to the needs of Aboriginal People who are in correctional facilities and who are affected by HIV/AIDS.

Goal #1: To ensure that relevant aspects of the Ontario Aboriginal HIV/AIDS Strategy are provided to Aboriginal prisoners.

Strategies

Promotion

- A. Provide ongoing HIV/AIDS education and prevention activities in prisons. Drug use and sexual activity do continue in these institutions and there is a need for specific programs/approaches which involve Aboriginal prisoners in responding to HIV. Such approaches might include peer led workshops/videos etc.
- In order to effectively support the development of peer-led HIV/AIDS education/prevention activities in prisons, the number of Native Inmate Liaison workers would have to be increased to adequately cover all provincial correctional facilities.
- B. Continue to work with the National Aboriginal Corrections Strategy on HIV/AIDS.
- C. Link to Provincial Corrections Authorities, Attorney General and the Solicitor General to strengthen the Aboriginal presence and to promote the unique needs of Aboriginal PHAs who are prisoners.
- D. Strengthen partnerships with existing organizations such as Prisoners with HIV/AIDS Support Action Network (PASAN).

Prevention

- A. Provide prisoners and correctional staff with mandatory, complete and accurate information regarding HIV transmission and infection and risk reduction behaviour on a

continuous basis, with regular evaluation and updates. Particular efforts must be made to dispel myths concerning transmission and decrease AIDS-phobic beliefs. Make HIV/AIDS education a standard component which should begin at the time of admission as part of the general orientation process.

- B. Provide an entry kit to all inmates containing HIV/AIDS information materials. The kits should contain condoms, water-based lubricant and HIV information materials and must also be made available in a free, accessible and confidential manner through the medical unit on the facility.
- C. Advocate that bleach, sterilized water, alcohol swabs and needles be made available in an anonymous and accessible manner in all correctional facilities.
 - One approach to needle distribution could be through utilizing the Native Inmate Liaison Workers and Native court workers in tandem with Aboriginal health/AIDS educators. These workers may be able to introduce needle and condom distribution into facilities in a confidential and non-judgmental manner. Such an approach would require increasing the number of Native Inmate Liaison officers and changing corrections policy.
- D. Provide culturally appropriate HIV/AIDS prevention/education materials in a variety of forms (video, written presentations) for use by Aboriginal prisoners. The materials should be sensitive to language needs and literacy levels.
- E. Make resources available for Aboriginal HIV/AIDS educators, elders/healers to attend correctional facilities to conduct prevention and wholistic healing with Aboriginal prisoners. One task that such people could perform would be utilizing the existing knowledge and resources in the population and encouraging the development of peer support/education initiatives.
- F. Upon release from incarceration advocate for the provision of exit kits containing condoms, water-based lubricant and HIV/AIDS awareness materials. In addition, a second exit kit should be available upon request which also contains bleach, needles, sterilized water and information on safer injection practices. These kits could be requested from Native liaison workers or other agencies that offer these kits free of charge.

Treatment /Rehabilitation

- A. Provide access for Aboriginal prisoners living with HIV/AIDS in correctional facilities to traditional Aboriginal healers, healing ceremonies, traditional medicines and other supportive Aboriginal care systems, in addition to improving access to existing Western medical approaches.

- B. Facilitate a process whereby Aboriginal prisoners living with HIV/AIDS be given access to Aboriginal or culturally sensitive individuals and services “on the outside”. This access or “link” should be pragmatic; either bringing the individual to the resource or the resource to the individual. In this way, the support system is in place before the individual is returned to the community.

Training

- A. Ensure that Strategy Workers are equipped to work with prisoners and corrections staff through specific training initiatives.
- B. Identify the training needs of corrections officers related to Aboriginal people and HIV/AIDS and facilitate appropriate training for corrections staff.

Working with Leadership

- A. Advocate that leadership support and advocate for same sex conjugal visits for Aboriginal people in prison.

6.7 Management, Operations, Evaluation

DEFINITION

Activities undertaken by the Strategy Coordinator, the Workers, the Host Organizations and the Reference Group to ensure the effective and efficient management of the Ontario Aboriginal HIV/AIDS Strategy.

Goal # 1: To ensure that the Strategy Coordinator and the Workers carry out their activities in supportive environments.

Strategies

- A. Negotiate with Host Organizations to ensure that they meet the criteria developed by the Reference Group and are willing to sign an MOU detailing their commitment.
- B. Educate co-workers within the Host Organizations about HIV/AIDS in the Aboriginal community and assist them in integrating HIV/AIDS issues into the organization.
- C. Build an understanding and recognition within the Host Organization and the Aboriginal community about the need for sensitive, trained and committed HIV/AIDS workers in lieu of credentials.

Goal # 2: To ensure that appropriate policies and procedures are in place to guide the operations/management of the Strategy.

Strategies

- A. Undertake a periodic review of policies and procedures, identify gaps and recommend changes to the Reference Group.
- B. Whenever possible, document best practices and share these with the Coordinator, Workers and the Reference Group.

Goal # 3: To plan and undertake an Evaluation of the Strategy in Year Four.

Strategies

- A. Develop an evaluation framework to determine what activities will be measured, what results are expected, and what indicators will be used to evaluate progress.
- B. Develop a consistent approach to collecting data that are relevant to the evaluation framework and complete "roll-ups" on an annual basis.
- C. Where quantitative data is not available as an indicator, document anecdotal evidence.
- D. Identify ways to improve the strategy on an annual basis and take action where possible.

7.0 GLOSSARY

ABORIGINAL:

Indian, Metis, and Inuit people (Constitution Act, 1982)

ABORIGINAL COMMUNITY/COMMUNITIES:

A group of aboriginal people who share similar beliefs, traditions and culture. These groups exist through shared political, cultural, spiritual identity and/or are organized for the purposes of jointly improving the quality of life for Aboriginal people in the community. Aboriginal communities include First Nation/Aboriginal communities, Metis people, Friendship Centres, ONWA locals, aboriginal urban-based organizations, and political organizations.

ABORIGINAL FAMILY:

Children, parents and their extended family, which may include blood relatives, in-laws and significant others.

ABORIGINAL (COMMUNITY) HEALTH ACCESS CENTRE

These centres are similar to community health centres, most of which currently operate in cities in Southern Ontario. They offer culturally appropriate primary care to Aboriginal people. Programs may include pre- and post-natal care, nutrition, health education, disease prevention, counselling and traditional healing. There are currently 10 Aboriginal Health Access Centres in various stages of design and implementation.

ABORIGINAL LEADERSHIP:

The formal Aboriginal leadership consists of Grand Chiefs, Chiefs and Band Councils and Boards of Directors and Executive of Aboriginal Organizations. Informal Aboriginal leadership includes matriarchies, Elders, and influential individuals and/or families in Aboriginal communities.

ACCOUNTABILITY:

A process through which a person is responsible for his or her actions to a designated group or body. In terms of appointments and representation, it involves the nomination of a person by a group and a reporting relationship between the parties.

ADDICTIONS:

Obsession of the mind coupled with a compulsion of the mind to substances like drugs, alcohol, solvents, or behaviours like sex and eating.

ADVOCATE:

A person who contributes to the empowerment of persons living with HIV/AIDS and promotes respect for their rights, freedoms, autonomy and dignity.

AGENCIES:

Includes programs and services both within and outside Aboriginal communities.

AIDS (Acquired Immune Deficiency Syndrome)

“Acquired” means you get the condition at some point in your life. “Immunodeficiency” is a weakness in your immune system. “Syndrome” is a combination of symptoms and/or diseases. AIDS is not a disease. It is a syndrome associated with HIV infection, decreased numbers of T4 cells and one or more opportunistic infections.

ANONYMOUS TESTING

The name or identity of the person being tested is not requested, recorded or reported. The test is ordered using a code known only to the person being tested. Epidemiological information (e.g. age, sex, risk factor) is collected and reported. The person is responsible for notifying partners, but can ask the counsellor for assistance. Pre- and post-test counselling is a requirement at anonymous test sites.

ALTERNATIVE SERVICE PROVIDER

Is an agency/organization established to provide HIV/AIDS related services to the general public and is not “Aboriginal specific”.

CASEY HOUSE

A palliative care hospice in Toronto.

CLIENT ADVOCACY

Assisting a person by speaking on his or her behalf or explaining his or her wishes with respect to health care and community support systems.

COMMUNITY SUPPORT SYSTEM

Refers to non-health services, i.e. housing education, social services etc.

DISABILITY

Limitation on everyday living.

FIRST NATION

An Aboriginal community, also known as a Band under The Indian Act, with or without a land base.

GOVERNMENT

Aboriginal, municipal, provincial and federal governments.

HARM REDUCTION

There are no moral, legal or medical judgments made about drug use. There are no moral judgments made about the injection drug user because drug use is not seen as immoral or irresponsible. The dignity and value of all human beings is respected. The concern is the potential harm from injection drug use. The focus is the problem of reducing the potential for HIV infection among injection drug users. The Harm Reduction approach provides options in a non-judgmental and non-coercive way. The focus is not on abstinence. Harm reduction

accepts that injection drug users may continue to use drugs. Abstinence can be part of the program for injection drug users who want to quit using drugs, but it is not the goal: reducing harm from drug use is the goal. Harm reduction recognizes that injection drug users are competent to make choices and change their behaviours.

HEALING LODGES

Healing lodges offer traditional healing approaches to the treatment of sexual assault, physical abuse, addictions, and family dysfunction. Some of the treatment centres focus specifically on addictions affecting youth. Usually a continuum of care from prevention to aftercare is available for individuals and families either on a residential or day basis. Education and community outreach are often integrated into programming and traditional healers and elders provide essential culture-based skills and knowledge.

HEALTH EMPOWERMENT

The personal sense of control over health and health-related issues to individuals or group of individuals. An individual or group's sense of control over health and health related issues.

HIV (Human Immunodeficiency Virus)

The virus believed to cause AIDS. Having HIV is not the same as having AIDS. Some people who have the virus are healthy, and have none or only a few symptoms. A person may have HIV for several years before AIDS-related diseases appear.

HIV ANTIBODY TEST

A blood test that detects HIV antibodies, indicating that a person has been exposed to HIV and now carries the virus.

HOSPICE

Provision of a supportive environment for a person in the last stages of a terminal illness.

HOSTEL

A place where client and/or their families stay when accessing health services away from their community.

MEDICAL INTERPRETER/TRANSLATOR

A person who explains the meaning of health information to patients or their families and who may also translate this information from one language to another.

NON-NOMINAL TESTING

The physician orders the test using the patient's initials or a code and takes responsibility, with the patient, for notifying partners who may have been exposed. The local medical officer of health will check with the physician about the case and, if satisfied that partners have been notified, will not ask for the person's name.

NOMINAL TESTING

The physician orders the test using the person's name. If the test is positive, the physician is legally obligated to report the name to the local medical officer of health. Under the Health Protection and Promotion Act, the medical officer of health is legally obligated to safeguard the person's confidentiality. The medical officer of health is also legally responsible for ensuring that the person's sexual and drug use contacts are notified.

OMOH

Ontario Ministry of Health and Long-Term Care

OPPORTUNISTIC INFECTION

When your immune system is damaged, you can get sick from germs that would not normally cause diseases. These germs take advantage of the opportunity created by your weakened immune system to cause an infection.

PHA

Person/People Living with HIV/AIDS

PREVENTION

Programs and services aimed at groups at risk of ill health or already affected by a health or social condition.

PROMOTION

Activities which focus on improving or maintaining the health of the individual, family or community before the presence of a health condition.

RESPITE CARE

Temporary or short-term support provided to a person who is caring for someone who is elderly, terminal, disabled or recuperating from treatment.

RESIDENCY

The place where an Aboriginal person lives, including on-reserve or off-reserve, in rural or urban communities.

SAFER SEX

Sexual activities that help prevent the spread of HIV and other sexually transmitted diseases, (i.e. correct use of a latex condom, non-penetration etc.)

STD (SEXUALLY TRANSMITTED DISEASES)

A bacteria, virus or infection that may be passed from one individual to another by sexual contact. Also referred to as V.D. (venereal disease). Examples of STD's are; herpes, syphilis, gonorrhea, chlamydia, HIV.

T4 CELLS

These are the white blood cells most likely to decrease in people with HIV and play an important role in controlling infections.

TRADITIONAL MEDICINE

Herbal or other preparations used by a traditional healer for healing purposes.

TRADITIONAL HEALER/MEDICINE PERSON

An Aboriginal person who assists the healing of a person or group using traditional medicines, ceremonies, counselling and other means, and is recognized as a traditional healer by the Aboriginal community.

TRADITIONAL TEACHINGS

The values, beliefs, customs and instructions with respect to ways of living passed from generation to generation.

TRAINING

The development of required knowledge, skills and attitudes needed to develop, implement, deliver and evaluate health programs and services. Training ranges from basic training to ongoing professional development.

TRANSGENDER

These are individuals who live in a gender other than the one assigned to them at birth on the basis of their biological sex. For instance, individuals who were born male, but who live as women. Transgenderists usually take hormones to live in their chosen gender.

TRANSSEXUALS

Transsexuals also live in a gender other than the one assigned to them at birth. Like transgenderists, they take hormones to change their physical appearance. Hormones change the physical structure of the body, including secondary sex characteristics like facial hair, skin tone, and voice pitch.

TREATMENT

Active intervention to diagnose, treat or care for an illness.

TWO-SPIRITED

Gay, lesbian, bisexual and transgendered Aboriginal people.

WELLNESS

The balance of physical, mental, emotional and spiritual aspects of being.

WHOLISTIC HEALTH

Physical, mental, emotional and spiritual aspects of the human being.

ACRONYMS

<i>ACAP</i>	<i>AIDS Community Action Program</i>
<i>AHAC</i>	<i>Aboriginal (Community) Health Access Centre</i>
<i>AIDS</i>	<i>Acquired Immune Deficiency Syndrome</i>
<i>AZT</i>	<i>Zidovudine, a drug used to fight HIV disease; effective at interrupting mother to child HIV transmission.</i>
<i>CAAN</i>	<i>Canadian Aboriginal AIDS Network</i>
<i>CAMH</i>	<i>Centre for Addictions and Mental Health</i>
<i>CAS</i>	<i>Children's Aid Society</i>
<i>CATIE</i>	<i>Community AIDS Treatment Information Exchange</i>
<i>CHN</i>	<i>Community Health Nurse</i>
<i>CHR</i>	<i>Community Health Representative</i>
<i>HCT</i>	<i>Heterosexual Contact</i>
<i>HIV</i>	<i>Human Immunodeficiency Virus (the virus that causes AIDS)</i>
<i>IDU</i>	<i>Injecting Drug Use, Injecting Drug User</i>
<i>LCDC</i>	<i>Laboratory Centre for Disease Control</i>
<i>MSB</i>	<i>Medical Services Branch (Health Canada)</i>
<i>MSM</i>	<i>Men who have Sex with Men</i>
<i>OHTN</i>	<i>Ontario HIV/AIDS Treatment Network</i>
<i>PASAN</i>	<i>Prisoners with HIV/AIDS Support Action Network</i>
<i>PHA</i>	<i>Person/People Living with HIV/AIDS</i>
<i>STD</i>	<i>Sexually Transmitted Disease</i>
<i>TB</i>	<i>Tuberculosis</i>
<i>TPFN</i>	<i>2- Spirited People of the 1st Nations</i>

Appendix V:

**'Draft' Strategy to Address
Issues Related to HIV Faced by People in Ontario
From Countries Where HIV is Endemic**

Prepared by the
HIV Endemic Task Force

June 2002

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Introduction

Terminology

For some people the term HIV-endemic is problematic. It is in fact an epidemiological term that refers to countries or populations where there is a high prevalence of HIV infection in the general population (i.e. generally greater than 0.8%), *and*, the most important mode of transmission is heterosexual contact. Currently a number of countries in the Caribbean and Sub-Saharan Africa have been classified as HIV-endemic. The Joint United Nations Programme on HIV/AIDS (UNAIDS) refers to HIV-endemic as a ‘generalized epidemic’ as opposed to an epidemic within distinct groups of the population.

This ‘Draft’ Strategy strives to address issues related to HIV faced by people in Ontario from countries where HIV is endemic. Consequently, given the current composition of Ontario’s population and the present state of the HIV epidemic in Ontario, the ‘Draft’ Strategy is primarily geared to people of African and Caribbean descent. Thus the document refers to “people of African and Caribbean descent” (PACD) rather than HIV-endemic communities.

The Process Guiding the Development of the Strategy

In an effort to promote a timely, coordinated and adequate response to issues related to HIV faced by people in Ontario from countries where HIV is endemic (i.e. communities of African and Caribbean descent), the HIV Endemic Task Force (HETF) has developed this ‘Draft’ Strategy. Two Phases of consultation will inform the final version of the Strategy.

The Phase One consultation is now complete. It consisted of telephone interviews with selected service providers, researchers, advocates and non-governmental organizations (NGOs) working with people of African and Caribbean descent (PACD); a mail out survey consultation to a wide range of African and Caribbean community members and service providers, and the broader health and social service sector working with PACD; and the “*For Us, By Us, About Us*” Community Forum held in Toronto in November 2001.

Phase Two of the consultation process is now in progress. Building on the input gained in Phase One, it will reach out to PACD living with and affected by HIV/AIDS, to Francophone communities and to those outside of the Toronto area.

This Strategy is very much a ‘work in progress’, hence the title ‘Draft’ Strategy. The Strategy will be revised as a result of key input and expertise gained through Phase Two of the consultation process.

The HIV Endemic Task Force (HETF)

The goal of the HIV Endemic Task Force (HETF) is to reduce the incidence of HIV among people in Ontario from countries where HIV is endemic (i.e. communities of African and

Caribbean descent) and to improve the quality of life for those infected and affected by HIV/AIDS. The general objectives of the HETF's work are:

1. to coordinate the work of agencies, institutions and policy makers working with and for people of African and Caribbean descent (PACD) regarding prevention, education, health promotion, care and support;
2. to facilitate community development in response to HIV/AIDS challenges; and,
3. to identify research needs, priorities and opportunities.

The HETF has identified the need for urgent action by government departments, health care agencies, HIV/AIDS service organizations, public health, settlement agencies, social service agencies and the communities themselves. The Task Force engages in ongoing education and advocacy work on the issue and is building links with existing HIV/AIDS strategies, including the Ontario Provincial HIV/AIDS strategy and the federal Canadian Strategy on HIV/AIDS, to ensure that there is both provincial and national attention and action to address this urgent issue.

Background to the HETF

The HETF was formed by Toronto-area HIV/AIDS groups and researchers at the University of Toronto Department of Public Health Sciences to address the rising incidence of HIV/AIDS among people of African and Caribbean descent (PACD). Founding members included representatives from HIV/AIDS Service Organizations and other community-based organizations such as the Black Coalition for AIDS Prevention, Africans in Partnership Against AIDS, African Community Health Services, Youth Clinical Services Inc, Women's Health in Women's Hands, Rexdale Community Health Centre, and the Centre médico-social communautaire. The HETF also works closely with representatives of all three levels of government, including the City of Toronto Public Health Department, Ontario Ministry of Health and Long Term Care AIDS Bureau, and Health Canada Population and Public Health Branch (Ontario Region).

In late 1998, the HETF commissioned Dr. Robert Remis to prepare an epidemiological situation report to better understand the issue of HIV infection in communities of people from countries where HIV is endemic. An updated Executive Summary of this report is attached as Appendix 1. The report examined available data for the period 1981 to 1998 from databases in Ontario in order to better characterize and quantify HIV incidence and prevalence in these populations. Since the report was released in November 1999, the HETF has been working to address the increasing rates of HIV infection among PACD.

The 'Draft' Strategy

The *'Draft' Strategy* was developed collectively by the founding members of the HETF in a series of meetings from May 2000 to September 2001. HETF members gathered background information through telephone interviews with selected service providers, researchers, advocates and non-governmental organizations (NGOs) working with people of African and Caribbean descent (PACD).

The data generated by the telephone interviews contained a number of common themes, issues and recommendations including the need for:

- immediate attention and dedication of resources to the increasing rates of HIV infection among people of African and Caribbean descent (PACD);
- ongoing consultation with PACD and service providers working with these communities geared to building a community-based response that recognizes the diversity within and between communities of people from countries where HIV is endemic across Ontario;
- approaches that address the broader social context that affects the health of individuals and communities (i.e. culture, gender, socio-economic status, social support networks, social environments);
- an integrated health care approach to the delivery of HIV prevention, care, treatment and support;
- culturally competent programs and services that are accessible and relevant to all PACD; and
- policies rooted in the day-to-day reality of service and program delivery.

Data from the telephone interviews also indicated a number of key directions and suggested activities including:

- advocating for additional funding for linguistic and cultural interpretation, translation of resource materials and coverage for the costs of medications;
- identifying, supporting and promoting culturally appropriate & accessible HIV prevention, care, treatment & support programs and services;
- developing/piloting alternative modes of service/program delivery (e.g. off-site/mobile service delivery; assistance with basic needs – housing, food, medical care, immigration; and peer support that is culturally competent);
- supporting community education and mobilization initiatives among PACD, and working with the informal support networks that exist in these communities;
- breaking the silence and creating a supportive environment for prevention work; and
- promoting a broad base of relevant research (e.g. epidemiological, psycho-social, research with a service delivery component; best practices research, needs assessments).

As you will note these themes, issues and recommendations have become an integral part of the *'Draft' Strategy*.

The *Strategy* is truly a 'draft'. The HETF welcomes your comments and input on its guiding principles, goal, objectives, directions and suggested activities. Developing an appropriate and effective response to the issue of HIV among people of African and Caribbean descent requires ongoing consultation, dialogue and discussion among PACD and the groups and service providers working with them. It is hoped that this *'Draft' Strategy* will provide a catalyst for this dialogue

and discussion, and a framework for the ongoing collaboration that is required to effectively respond to this important issue.

Principles Guiding the ‘Draft’ Strategy

The following key principles are inherent in the *‘Draft’ Strategy’s* goal, objectives, directions and suggested activities. The *Strategy*:

- asserts that the increasing rates of HIV infection among PACD is an urgent issue that requires immediate attention and dedication of resources to prevention of HIV transmission and to the care, treatment and support of those living with and affected by HIV/AIDS;
- recognizes that efforts to address the issue of HIV among PACD requires consultation and collaboration with PACD and groups and service providers working with and within these communities;
- is geared to building and promoting a community-based response that recognizes the diversity within and between communities of people of African and Caribbean descent across Ontario;
- recognizes that in order to be most effective, HIV programming needs to work in a broad social context that addresses the determinants of health. These determinants of health influence the health of individuals and communities and include such things as culture, gender, socio-economic status, social support networks, and social environments;
- acknowledges the need for gender-based analyses and programming given the physiological differences between men and women (including the fact that women are biologically more vulnerable to HIV infection through heterosexual
- sex than are men ¹), the reality that gender inequality and gender-based hatred and violence affect all women’s lives, and the fact that women of African and Caribbean descent must deal with all the barriers and issues that PACD face plus the additional isolation and marginalization of being women within these communities;
- recognizes that racism and other types of discrimination influence PACD’s response to HIV/AIDS. Racial discrimination limits not only access to employment and housing, but access to HIV/AIDS information and services developed to reduce transmission, provide treatment, care and support of those infected and affected by HIV/AIDS within communities of African and Caribbean descent. All initiatives targeted to PACD must recognize and deal strategically with this factor;
- promotes the delivery of HIV prevention, care, treatment and support strategies, programs and services within an integrated comprehensive health care approach (i.e. a broad range of health care services not only HIV specific services);

¹ Conservative estimates place the risk at two to four times greater for women. Hankins, Catherine. Sexual transmission of HIV to women in industrialized countries. *Rapp.trimest. statist. sanit. mond.* 49(1996). Page 106.; Canadian AIDS Society. 1997/98 National AIDS Awareness Campaign: The Changing Face of AIDS. Ottawa: Canadian AIDS Society. 1997. Module 2-4.

- acknowledges that HIV prevention, care, treatment and support strategies and initiatives occur within a continuum of program and service delivery;
- requires that programs and services involve PACD; be culturally competent; and be accessible and relevant to all PACD including children & youth, women, gays/lesbians/bisexuals/transgendered/ heterosexuals, men who have sex with men (MSM), and injection drug users (IDUs);
- identifies the need for mechanisms to link the macro and the micro levels (i.e. policy and programs/services), and acknowledges that policies must be rooted in the day-to-day reality of service and program delivery (i.e. policies should be informed by, and supportive of service and program initiatives);
- makes every effort to increase coordination and reduce duplication, and to be integrated into other Provincial and Federal HIV/AIDS Strategies and Policies;
- identifies the potential for the HETF to play a key role in coordinating a response among government departments, HIV/AIDS service organizations, public health departments, health care and social service agencies, and the different levels of government; and
- once finalized, will include targets and outcome indicators for success and a process for systematic evaluation and revision of the *Strategy* based on lessons learned, targets achieved, development/modification of policies, programs and services, and evolution of the HIV epidemic.

These principles guided the development of the '*Draft*' *Strategy*, and they will be a central component of its implementation.

Goal and General Objectives of the ‘Draft’ Strategy

Goal:

to reduce the incidence of HIV among people of African and Caribbean descent in Ontario and to improve the quality of life for those infected and affected by HIV/AIDS.

General Objectives:

1. To coordinate the work of agencies, institutions and policy makers working with and for people of African and Caribbean descent (PACD) regarding prevention, education, health promotion, care and support.
2. To facilitate community development in response to HIV/AIDS challenges.
3. To identify research needs, priorities and opportunities.

The next section of the document outlines some key Directions and Suggested Activities that will contribute to achieving the goal and objectives of the *‘Draft’ Strategy*. Some of the Directions and Suggested Activities are relevant to more than one of the General Objectives, however for the purposes of clarity and brevity they appear under the General Objective that they are most directed toward.

In effort to promote realistic planning the Suggested Activities have been defined as short-term or mid-term. Suggested Activities have been allocated to the time frame in which they are likely to begin, it is recognized that some of them are ongoing and/or may span more than one category.

When Phase Two of the consultation process is completed and the Strategy is finalized targets and outcome indicators will be developed for each Direction, as will a process for systematic evaluation and revision of the *Strategy* based on lessons learned, targets achieved, outcomes, and evolution of the HIV epidemic.

Directions and Suggested Activities

Objective 1: to coordinate the work of agencies, institutions and policy makers working with and for people of African and Caribbean descent regarding prevention, education, health promotion, care and support.

DIRECTIONS		SUGGESTED ACTIVITIES	
	Short-Term	Mid-Term	
Advocate for a commitment to and resources to implement a province-wide strategy to reduce HIV infection among PACD that includes prevention; care, treatment & support; research; and advocacy/community mobilization.	<p>Link into existing initiatives & organizations wherever possible and put PACD on the agenda – e.g. OACHA, OAN, CAS, Ministerial Council on HIV/AIDS, National Women’s Reference Group on HIV/AIDS.</p> <p>Involve PACD in the strategy ASAP, including well-respected community & religious leaders, organizations of PACD.</p> <p>Link with, and learn from the existing advocacy/lobby expertise and the connections within the HIV/AIDS movement.</p>	<p>Promote recognition of PACD’s issues/needs within federal public health policies and health promotion strategies.</p> <p>Ensure that provincial and local public health units develop policies and programs on HIV prevention, care, treatment and support that are geared to, and appropriate to PACD.</p> <p>Recruit a high profile champion of African or Caribbean descent (e.g. Maestro).</p> <p>Conduct and promote direct advocacy (i.e. writing to MPs and MPPs re the need to deal with PACD & HIV).</p> <p>Develop a ‘how to advocate’ guide by adapting and updating existing ones.</p>	
Break the silence and create a supportive environment for prevention work.	Develop prevention objectives for PACD that are targeted at men & women; condom use; pregnant women; people using/abusing		Use the inventory of points of access to service (described in the next section) to target prevention initiatives where

DIRECTIONS	SUGGESTED ACTIVITIES	
	Short-Term	Mid-Term
<p><i>(It is important to note that all of the following organizations need to be involved in prevention work: settlement services; health services; youth agencies; schools; community organizations for endemic communities; language training and job training programs; clinics; physicians' practices; community health centres; mosques; churches; expatriate national services (country specific); HIV/AIDS organizations; AIDS Bureau; funders, universities and student associations.)</i></p>	<p>substances; and disclosure & partner notification.</p> <p>Include secondary prevention issues (i.e. work with HIV + people re prevention of transmission, vertical transmission) in all prevention strategies.</p>	<p>significant numbers of women and men of African and Caribbean descent access services.</p> <p>Building from existing work, draft HIV testing, prevention, disclosure & partner notification guidelines for men and women of African and Caribbean descent.</p> <p>Promote & support culturally appropriate and gender sensitive healthy sexuality programs, and STD prevention, care and treatment programs with active HIV prevention components.</p> <p>Research, assess and adapt to PACD (as needed) initiatives to counter stigmatization within communities, particularly for MSM.</p> <p>Utilize municipal, provincial and federal healthy babies/healthy children programs to develop and implement prevention strategies.</p>
<p>Hold organizations accountable for providing services to PACD.</p>	<p>Draft a statement of principles & list of key actions that organizations can adopt and commit to implementing.</p>	<p>Promote “creating supportive environments” – e.g. encourage agencies to recognize, plan for and resource the advocacy work that front-line workers must do on behalf of PACD.</p>
<p>Provide an accountability and coordinating</p>	<p>HETF members to work with existing policy</p>	<p>Organize a roundtable meeting with key</p>

DIRECTIONS	SUGGESTED ACTIVITIES	
	Short-Term	Mid-Term
<p>mechanism for work with PACD in Ontario through the HETF.</p> <p><i>Provide an accountability and coordinating mechanism for work with PACD in Ontario through the HETF - continued.</i></p>	<p>forums re having them integrate issues related to PACD into their mandates/strategies – i.e. existing provincial and national HIV/AIDS strategies, Ministerial Council on HIV/AIDS, OAN, CAS, National Women’s Reference Group on HIV/AIDS, OACHA, Canadian Research Institutes on Health, SSHRC, OHTN.</p> <p>HETF to expand its membership so it is more provincially representative and so it includes more agencies working with PACD (e.g. CHCs, settlement agencies, hospital clinics, etc.).</p> <p>Write letters to policy forums and national bodies re issues of importance to HIV/AIDS among PACD (e.g. letter to Health Canada opposing mandatory testing of immigrants).</p> <p>HETF to assess the need for a staff-person to coordinate the HETF, and if needed to identify resources for the position.</p>	<p>stakeholders (HIV & non-HIV) to launch/promote the <i>‘Draft’ Strategy</i> - could be a working meeting and the HETF could have some concrete suggestions re ‘this is what you can do to help out’.</p> <p>Develop a process for establishing priorities in research, prevention initiatives, and care, treatment & support initiatives that is open, transparent and accountable, and that involves PACD and agencies/ organizations (including non-HIV specific ones) working with PACD.</p> <p>Once the priorities have been established approach agencies and organizations with specific/concrete requests – e.g. public health – we need a brochure on HIV prevention for African women; OHTN we need you to issue a</p> <p>call for research on the following issue through the priority-driven research fund, etc..</p> <p>HETF could function as a co-ordinating & overseeing group to monitor the implementation of the ‘Draft’ Strategy & as a mechanism to assess and re-direct programs as needed.</p>

Objective 2: to facilitate community development in response to HIV/AIDS challenges faced by people of African and Caribbean descent.

DIRECTIONS	SUGGESTED ACTIVITIES	
	Short-Term	Mid-Term
<p>Identify and promote culturally appropriate, gender-sensitive & accessible HIV prevention, care, treatment & support programs and services delivered within a framework of comprehensive health and social services.</p> <p><i>Identify and promote culturally appropriate & accessible HIV prevention, care, treatment & support</i></p>	<p>Do an inventory of where women and men of African and Caribbean descent are accessing health and social programs and services to identify points of access for HIV prevention, care, treatment & support initiatives. (e.g. where women and men of African and Caribbean descent gather, ESL classes, settlement agencies, etc.)</p> <p>Establish anonymous HIV testing sites where women and men of African and Caribbean descent are currently accessing services.</p> <p>Develop an up to date, reliable, comprehensive resource of what programs/services exist; the resource would also highlight services of particular relevance to women and men of African and Caribbean descent (e.g. CHCs offer health care to people without OHIP cards, identify programs/services that are relevant and accessible to women of African and Caribbean descent, BCAP has Caribbean/African service providers, CMSC offers services in French, etc.)</p> <p>Establish a mechanism to distribute the resource (detailed above) and keep it up to date.</p>	<p>Identify, document and promote culturally sensitive/competent and gender sensitive 'best practices'.</p> <p>Identify current gaps in culturally sensitive/competent and gender sensitive 'best practices' and research ways to fill the gaps.</p> <p>Advocate for additional funding for the unique services needed by women and men of African and Caribbean descent such as linguistic & cultural interpretation, translation of resource materials, accompaniment to health & social service appointments, coverage for costs of medications, health care for 'undocumented' people, etc.</p> <p>Develop/pilot alternative modes of service/program delivery (e.g. off-site/mobile service delivery; alternative therapies such as</p>

DIRECTIONS	SUGGESTED ACTIVITIES	
	Short-Term	Mid-Term
<i>programs and services delivered within a framework of comprehensive health and social services - continued.</i>		<p>art therapy, story telling, relaxation that are culturally appropriate; assistance with basic needs – housing, food, medical care, immigration; and peer support that is culturally competent and gender sensitive).</p> <p>Look to other sectors (e.g. cancer care models may be useful re children living with/affected by HIV).</p>
Support capacity building initiatives within communities of African and Caribbean descent and existing African and Caribbean organizations to respond to HIV/AIDS.	<p>Support community education and mobilization initiatives within communities of African and Caribbean descent.</p> <p>Identify and work with informal support networks that exist within communities of people of African and Caribbean descent.</p>	<p>Link larger more established agencies with smaller and/or newer organizations to provide infrastructure and/or mentoring.</p>
Educate/train health care providers in cultural competency/cultural sensitivity and gender equity/gender-based analysis.	<p>Provide forums to share & learn for service providers.</p>	<p>Establish standards and guidelines for cultural competency and gender equity/gender-based analysis training of health care providers.</p> <p>Provide training & resources re how to advocate for immigrants & refugees regarding immigration and settlement issues.</p>

DIRECTIONS	SUGGESTED ACTIVITIES	
	Short-Term	Mid-Term

Objective 3: to identify research needs, priorities and opportunities.

SUGGESTED ACTIVITIES	
DIRECTIONS	Mid-Term
Short-Term	Mid-Term
<p>To establish research priorities that promote a broad base of relevant research.</p>	<p>The Working Group will strive to promote a range of research including:</p> <ul style="list-style-type: none"> - epidemiological (e.g. #s infected, # partners, etc.); - prevention (e.g. effective program models); - psycho-social (e.g. people's norms, practices, behaviours, etc.); - gender-based analysis; - participatory & action research; - research with a service delivery component; - formal program evaluation; - best practices research (e.g. are there service models that work within communities of PACD); - needs assessments; - program inventories; - policy impact studies (e.g. impact of immigration & refugee policy re access to health care); - priority populations (e.g. MSM of African and Caribbean descent); - unpacking and understanding 'stigma'; etc. <p>Assess key government policies regarding their potential negative impact on HIV prevention, care, treatment & support among PACD (e.g. immigration policies), and suggest how they need to be changed.</p>
<p>To establish research priorities that promote a broad base of relevant research.</p>	<p>Contact existing funding bodies (e.g. OHTN) and request that they promote research in priority areas identified by the HETF through 'challenge grants', directed calls for proposals, priority-driven research fund, etc.</p> <p>Approach researchers known to be interested in this area and ask them to work with the HETF to research particular issues.</p> <p>Establish a Working Group of HETF members, researchers, organizations working with PACD, and research funding bodies to establish research priorities and support research in areas of critical importance to addressing HIV among PACD.</p>
<p><i>To establish research priorities that promote a broad base of relevant</i></p>	

DIRECTIONS		SUGGESTED ACTIVITIES	
	Short-Term	Mid-Term	
<i>research - continued.</i>			Promote research into the use and effectiveness of ethno-specific medicines and therapies.
To reduce the potential negative impacts of research on PACD.	<p>Co-ordinate research initiatives so communities are not overwhelmed by research requests.</p> <p>Ensure researchers are aware of and are building on existing migration and integration research, and that they have contacted sites of current research, such as the Metropolis Centres of Excellence on Immigration and Integration, re studies in progress.</p> <p>Support capacity building for community based research within communities of people of African and Caribbean descent (e.g. research partnerships, mentoring, etc.).</p>	<p>Establish research guidelines re working with PACD, guidelines should promote community involvement from beginning to end, and foster ownership of the research process and participation</p> <p>Work with other organizations trying to establish a process for community-based groups to obtain ethics approval for non-university/hospital based research.</p>	
Promote access and adherence to drug therapies and treatments by reducing barriers related to culture and/or	Develop resources to support teaching regarding drug therapies and treatments (e.g. pictograms, plain language materials,		Look to other sectors for models/ideas (e.g. drug therapy with seniors).

DIRECTIONS	SUGGESTED ACTIVITIES	
	Short-Term	Mid-Term
language.	interpretation services, translation of existing resources, etc.) so the most current information is available and accessible to PACD.	

Conclusion

This *'Draft' Strategy* is intended to provide a framework that will enhance the capacity of groups, agencies and community members to address the increasing rates of HIV infection among people of African and Caribbean descent, and to improve the quality of life for those infected and affected by HIV/AIDS. The *Strategy* attempts to outline a roadmap for the future, to set some directions and suggest activities and initiatives to address some of the issues and challenges related to HIV that are faced by people of African and Caribbean descent.

Your input and comments on the *'Draft' Strategy* are valued and very much appreciated.

Thank you.

Appendix 1

EXECUTIVE SUMMARY THE HIV/AIDS EPIDEMIC AMONG PERSONS FROM HIV-ENDEMIC COUNTRIES IN ONTARIO, UPDATE TO 2000: SITUATION REPORT

**Robert S. Remis, Elaine P. Whittingham
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In our original report of November 1999, we presented analyses of available data and the results of statistical modeling to characterize the HIV epidemic among persons living in Ontario who were born in countries in the Caribbean or sub-Saharan Africa (AHIV-endemic regions@) historically and as of December 1998. For the present update, we extended the analyses to December 2000. This was carried out by using newly available data on immigration to 1999 and estimated HIV prevalence among immigrants and factoring in the estimated number of Aindigenous@ HIV transmissions and HIV-related deaths since December 1998.

In general, since HIV data does not reliably capture data on birth or residence in an HIV-endemic country, it is difficult to draw precise conclusions about patterns of HIV diagnoses in this population or whether persons from HIV-endemic regions tend not to go for testing. The analysis of reported AIDS cases indicated that persons from HIV-endemic regions accounted for an increasing proportion of cases in Ontario, especially since 1996; this group represented 17% of AIDS cases in 1999. Most cases were less than 45 years old at time of diagnosis. Further, an increasing number of AIDS cases in later years were among persons born in sub-Saharan Africa. The majority of deaths due to AIDS in this population occurred after 1990 and mainly among persons under 50 years old, although women tended to die at an earlier age than men. The majority of HIV-positive women in a database of HIV-infected mothers and their infants were born in the Caribbean or sub-Saharan Africa; further, over half the confirmed HIV-positive infants in the database were born to women from these regions.

Our updated model indicates that, as of December 2000, approximately 2,800 persons from HIV-endemic regions and residing in Ontario were living with HIV infection (1,800 from the Caribbean and 1,000 from sub-Saharan Africa). The HIV epidemic among this population dates primarily since 1990 for most countries modeled, with the exception of Jamaica where the epidemic appears to have been present earlier. More HIV-infected persons were born in the Caribbean, though prevalence rates were higher for the sub-Saharan African countries. The annual rate of increase of HIV infections approximated 10%, representing about 240 more HIV infections each year in the past few years. Though modeled figures were obtained using methodologies which have important limitations, the estimations represented a good fit with available reported data and were consistent with 1996 projections for HIV prevalence among this population. For these reasons, we are confident our results are a plausible indication of the extent of HIV infection among this population.

Appendix 1

EXECUTIVE SUMMARY (CONTINUED)

Persons who immigrate to Ontario from an HIV-endemic region represent an important part of the Ontario epidemic, preceded only by men who have sex with men (MSM) and injection drug users (IDUs). Whereas overall HIV prevalence rates among immigrants from these regions may not appear substantial, rates are about 50-fold higher than among other heterosexual non-injecting persons in Ontario. Furthermore, modeling techniques which estimated the number of HIV infections acquired in Canada revealed that considerable transmission may be occurring after residence is established here, suggesting that a substantial proportion (30-45%) of HIV infections are not Aimported@.

A non-negligible proportion of HIV-infected men emigrating from HIV-endemic regions reported having had sex with men. Though not the primary focus of the present study, we estimate there may be 400 or more HIV-infected MSM from HIV-endemic countries and several thousand men at risk for infection. These persons represent an important segment of the immigrant population who until now have not been the focus of specific research or preventive interventions. MSM from HIV-endemic countries explains in part the high male: female ratio observed in our analyses (6:1 among persons from the Caribbean and 3:1 among those from Africa).

The results of this report highlight the need for epidemiologic research to validate results obtained through statistical modeling, specifically with regard to the substantial rate of HIV transmission in Canada. Social and behavioural studies are also needed to better understand the determinants of transmissions among immigrants from HIV-endemic regions. Political will at the community, provincial and national level is required to support further investigations of this public health problem and develop effective preventive interventions.

Appendix 2

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Appendix 2

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