

# **Stemming the Tide**

## **The Case for More Investment in Community-based HIV/AIDS Prevention and Support Services**

**Report of the Funding Enhancement Working Group  
of the Ontario AIDS Network**

**January 2004**

## **The Issue: More Infections, Too Few Resources**

Ontario's AIDS service organizations (ASOs) are a key link in Ontario's chain of HIV services. We play a crucial role in stopping the spread of HIV and providing high quality care and support for people who are infected. Our services – prevention, education, counselling, social support, buddy programs, co-ordination with other health and social services, advocacy to prevent discrimination, vocational counselling, financial assistance – make a significant difference in the health and quality of life of people living with HIV and those at risk. We are also highly cost effective: our services prevent new cases of HIV and help people living with HIV avoid or defer the use of more expensive health services, such as hospital care and psychiatric services.

ASOs come in many different forms. Some – like the AIDS Committees of Durham, North Bay, Thunder Bay, London or Windsor – can be the only agency within a geographic area whose principal mandate is to address HIV/AIDS issues. Some developed to meet the needs of specific groups or populations who were not being served well by existing health care providers. These include Aboriginal AIDS specific organizations and other ethno-cultural AIDS specific organizations, such as 2-Spirited People of the 1st Nations, Africans in Partnership Against AIDS, Black Coalition for AIDS Prevention or the Alliance For South Asian AIDS Prevention. Other ASOs, such as Casey House, Fife House, Bruce House, Maison “la Paix” and the John Gordon Home, emerged to address specific needs of people living with HIV, like palliative care and housing. Some ASOs have a mandate to provide services for the entire province, including Voices of Positive Women, Prisoners HIV/AIDS Action Support Network, the Ontario Aboriginal AIDS Strategy and the Ontario AIDS Network. For the purposes of this brief, ASO means all of these groups. The work we do - collectively and cumulatively - defines the community-based response to HIV/AIDS in Ontario.

***AIDS service organizations are providing services for more people with fewer resources than they had in the early 1990s.***

Although community-based AIDS organizations have been part of Ontario's response to HIV since the mid-1980s, our ability to fulfill our role and mission is severely limited by lack of stable, predictable funding and by the general weakening of the broader health and social service environment. In 2003, we are providing services for more people with fewer resources than we had in the early 1990s, and the pressure continues to grow.

With the number of new cases of HIV in Ontario again on the rise, it is time to increase investment in AIDS service organizations and capitalize on our ability to prevent the spread of HIV and support those who are infected. It is time to re-gain lost ground in the fight against HIV. This paper presents our case for rectifying and stabilizing core funding for AIDS service organizations and meeting future needs.

## **Acknowledgements**

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### **About the Ontario AIDS Network**

Founded in 1986, the Ontario AIDS Network (OAN), is a provincial association composed of 53 HIV/AIDS service organizations (ASO's) from throughout Ontario (See Appendix A). These ASOs are crucial to Ontario's HIV/AIDS education, prevention, care and support efforts. In addition, the Association has an active caucus of approximately 350 people with HIV/AIDS (PHAs) involved in its governance and activities. The purpose of the OAN is to enable its members to work together to establish a just and effective response to AIDS. The OAN:

- works collaboratively with member agencies to represent the collective voice of community-based ASOs and participating PHAs
- advocates on their behalf for appropriate public policy and legislation in response to the HIV/AIDS epidemic
- supports and strengthens its membership by facilitating education, skills development, capacity building and community-based research.

*For more about the Ontario AIDS Network and its member agencies, see [www.ontarioaidsnetwork.on.ca](http://www.ontarioaidsnetwork.on.ca)*

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## **1. A Brief History**

When they were first established in Ontario, community-based AIDS service organizations were a bold, innovative experiment. They were the result of two factors:

- the inability of the traditional health/medical model to respond to a new sexually transmitted disease that affected predominantly a highly marginalized population (i.e., gay men)
- the desire of communities affected by HIV to play a stronger role in the care and decisions that affect their lives.

Their success and effectiveness has fundamentally changed the way community health services are delivered and provided a model for other health agencies and other diseases.

***Community-based HIV/AIDS services help prevent new cases, help people who are infected, and reduce or delay the use of more expensive health services.***

### **The Need**

In the early days, the health care system faced five key challenges in its efforts to respond to AIDS:

- the lack of treatments or tests, which meant the health care system had little to offer and people were dying within a few months of being diagnosed
- the stigma associated with AIDS which affected people's ability to receive care and information
- a health care system that was frightened of AIDS and ill-equipped to meet clients' needs
- an affected group that, because of past discrimination, distrusted the health system, particularly the public health system which is responsible for controlling the spread of communicable diseases
- a general public that was uncomfortable about openly discussing the sexual practices that put people at risk.

### **A Community Based Response**

To prevent the spread of HIV and support those who were infected, the Ontario Ministry of Health and Long-Term Care realized that the health care system would have to take advantage of the few existing community organizations that had the trust of people with HIV and those at risk, and mobilize new ones.

At that time, few HIV organizations existed. Those that did, such as the AIDS Committee of Toronto or the Hemophilia Society, were voluntary groups that relied on donations from private citizens and the time of volunteers to develop and deliver prevention messages, advocate for better health services, fight discrimination, and provide buddies, palliative care teams, and other forms of emotional and practical support. They did not have the resources to mount extensive prevention and education campaigns, reach other vulnerable groups (e.g., injection drug users, sex trade workers), or develop more comprehensive support services.

The Ministry of Health and Long-Term Care agreed to provide base funding that would allow community-based AIDS service organizations to hire staff to manage their HIV programs and services, and cover overhead and administrative costs. The funding was designed to ensure that each AIDS service organization had the standard mix of skills required to be effective: an executive director, a volunteer co-ordinator, an education position, a support position, and an administrator or book-keeper.<sup>1</sup> The organizations' role was to fill the gaps in the existing health system, which included educating high risk populations<sup>2</sup> about ways to protect themselves, providing support for people living with HIV, providing palliative care, and providing housing.

***After several years of steady decline, the number of new HIV infections diagnosed each year in Ontario is on the rise.***

By 1994, Ontario had more than 60 community-based AIDS service organizations receiving base or core funding from the Ministry of Health and Long-Term Care.

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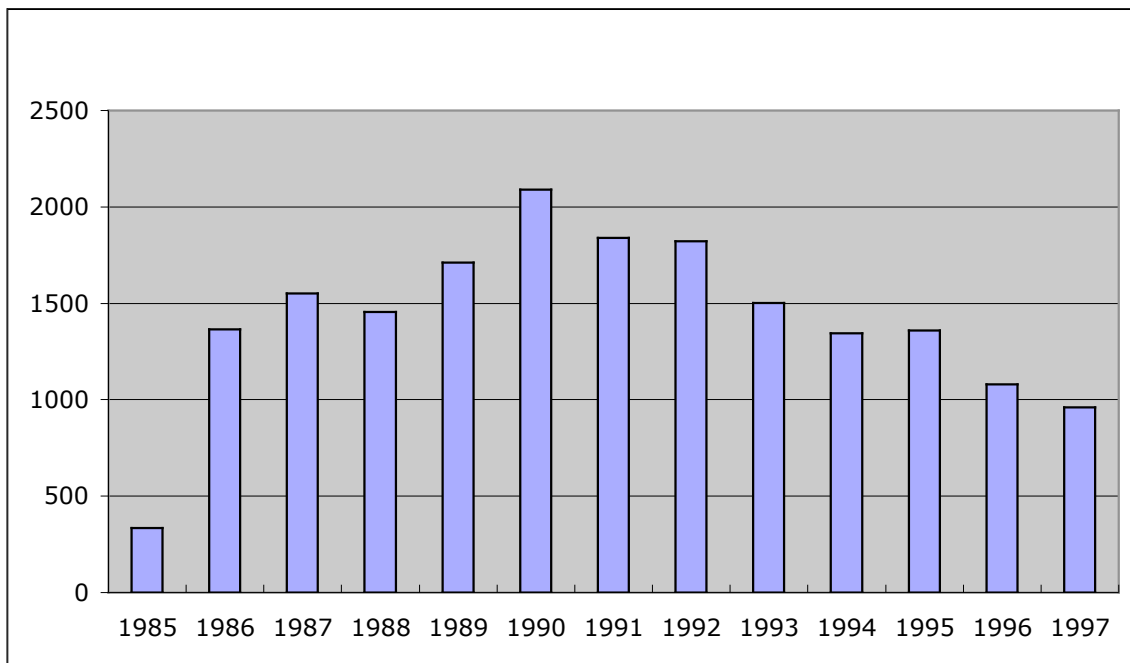
<sup>1</sup> Note: not all AIDS service organizations were funded for five full-time positions. Some, depending on the needs in their communities, were funded for part-time positions.

<sup>2</sup> At that time, public health units were funded to educate the general public.

## **The Impact**

The investment in community-based AIDS organizations was highly effective. Between 1990 and 1997, Ontario saw a steady and dramatic decline in the number of new HIV diagnoses each year, particularly in gay men.

**Figure 1: Diagnosed Cases of HIV in Ontario, 1985-1997**

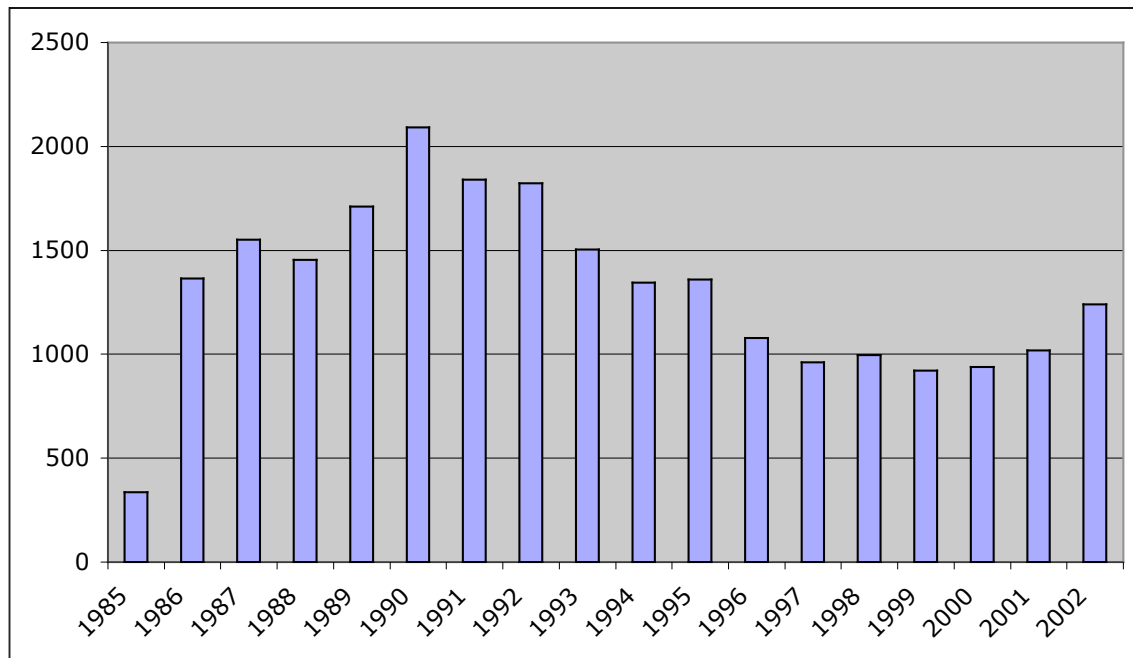


Investments in targeted community-based prevention and outreach programs make a difference. Ontario saw the same type of drop in new infections in injection drug users (IDUs), beginning in 2000, after increasing its funding for outreach services and needle and syringe exchange programs for IDUs.

## 2. The Situation Now

In 2003, Ontario is at risk of losing the ground it gained during the early 1990s in the fight against HIV. Between 1997 and 2000, the number of new HIV cases each year remained relatively steady. Since 2000, the number has again started to climb.

**Figure 2: Diagnosed Cases of HIV in Ontario, 1985-2002**



This new trend is due primarily to the fact that funding for community-based AIDS services has not kept pace with changes in the disease or client needs. The lack of funding for AIDS service organizations has been compounded by decreases in spending on other community-based health and social services, which have weakened the social safety net, putting more people at risk.

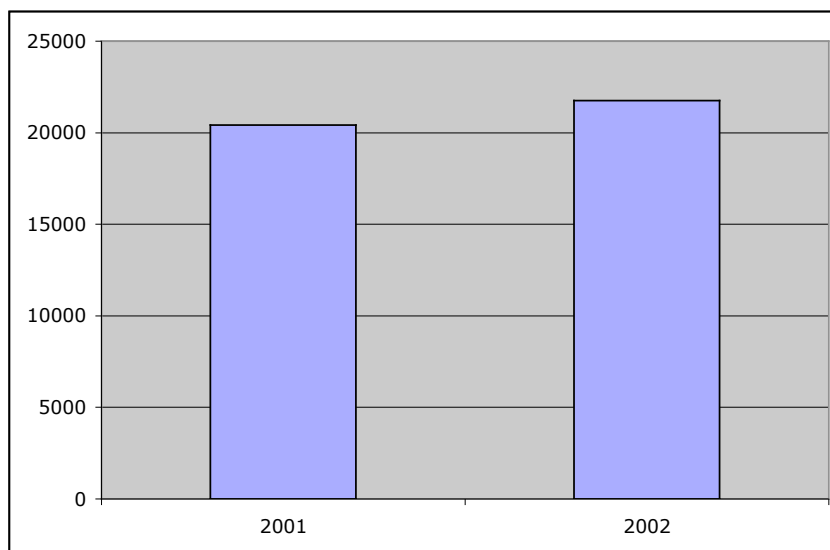
### **Growing Caseloads and More Complex Needs**

Over the past 20 years, Ontario has made tremendous progress in its ability to treat HIV. Since the mid 1990s, the number of deaths from AIDS has dropped significantly, and the number of people living with HIV has increased. By the end of 2002, a total of 23,523 people in Ontario had been diagnosed with HIV, and about 16,000 -- or 68% -- were still alive. (Remis et al, 2003)

The growing number of people living with HIV puts more rather than less pressure on community-based AIDS services. Since 1990, they have seen more than a 200% increase in the number of people living with HIV (not to mention those at risk) who could use their services, and a significant increase in their actual caseloads.

This chart illustrates the increase in the total number of people using the services of a total of 35 community-based AIDS organizations in Ontario between 2001 and 2002<sup>3</sup>.

**Figure 3: Number of People Using Services of 35 Community-Based HIV/AIDS Organizations, 2001 and 2002**



*Source: CLEAR Unit, November 2003*

Individual organizations have experienced significant increases in caseload. For example:

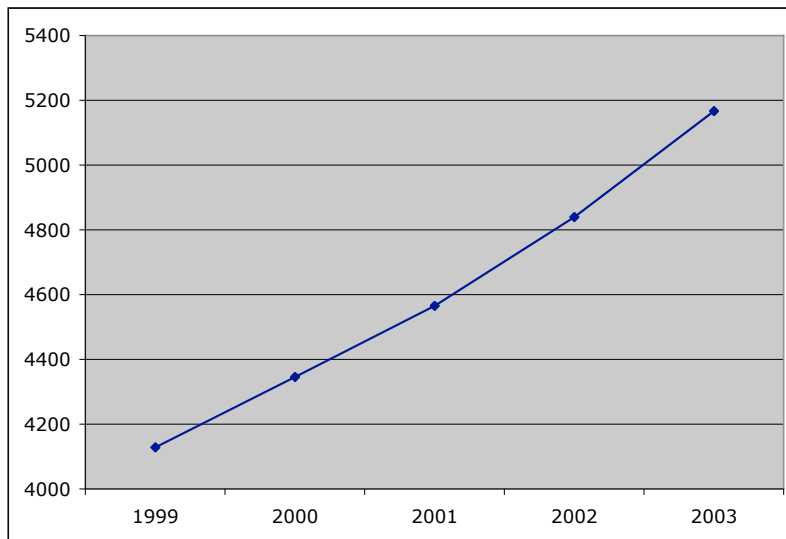
- HIV/AIDS Regional Services (HARS) in Kingston has seen the number of prison inmates it serves grow from 11 in 1999 to over 100 in 2003
- Fife House, a supportive housing program, has seen its units of service increase 40% from 18,533 in 2000/01 to 25,829 in 2002/03, the number on its waiting list grow from 13 to 34, and the number of people served through its homeless outreach program increase from 57 to 145. Between 1999/00 and 2002/03, the number of people with HIV accessing Fife House's supportive housing and support services doubled, from 128 to 259. While its caseload has grown, its base funding provided by the Ministry of Health and Long-Term Care has remained almost the same.

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<sup>3</sup> This reflects the period of time that the AIDS Bureau of the Ministry of Health and Long-Term Care has been collecting these statistics. Only those ministry-funded agencies that reported complete data for every quarter were included in the analysis. (CLEAR Unit, 2003)

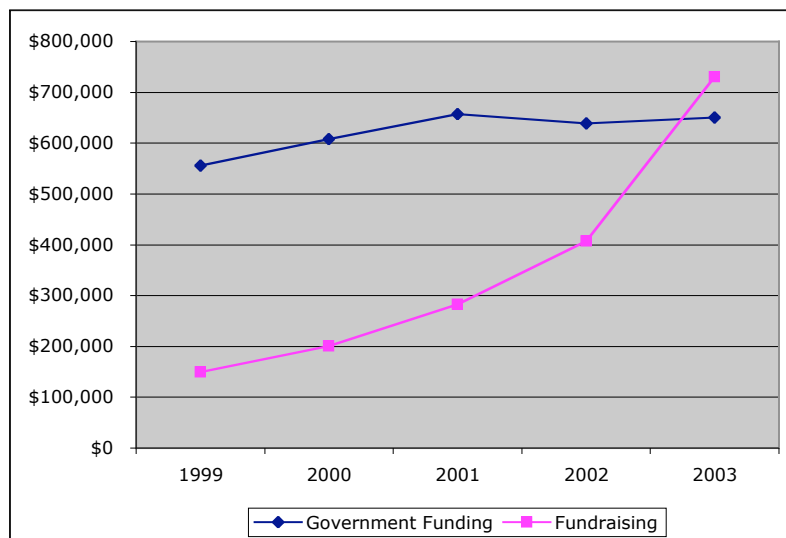
- The Toronto People with AIDS Foundation has seen a 25% increase in the number of clients since 1999. Over the same period, government funding for its services has remained flat.

**Figure 4: Numbers of Clients Served by the Toronto People With AIDS Foundation, 1999-2003**



Source: Toronto People With AIDS Foundation, Annual Report 2002-2003.

**Figure 5: Sources of Revenue for the Toronto People with AIDS Foundation, 1999 - 2003**



Source: Toronto People With AIDS Foundation, Annual Report 2002-2003.

Workloads are not only larger, they have changed. Organizations that used to serve people for a relatively short period of time (i.e., six months to two years) and focus more on end-of-life services now provide more services for the same clients for 10 to 15 years or even longer. Organizations originally established to meet the needs of a specific population (e.g., gay men) are now serving a broader range of client groups, including injection drug users, women, Aboriginal people, people from countries where HIV is endemic, and people who move in and out of the correctional system. The populations most vulnerable to HIV tend to be marginalized and often experience barriers accessing services they need from mainstream health organizations. They can benefit greatly from the services of community-based AIDS organizations, but organizations require more knowledge and skills to meet their diverse needs.

***The needs of people with HIV are becoming more complex. Organizations are providing a wider range of services to more diverse clients for a longer period of time.***

The needs of people living with HIV have also become more complex. According to a survey conducted by the Ontario Ministry of Health and Long-Term Care for the new provincial strategy, a significant proportion of people using the services of community-based AIDS organizations also have an addiction and/or a mental health problem. Many are living in poverty and/or lack affordable housing. There are now about 600 people living with HIV on a medical priority waiting list for rent-geared-to-income housing in Toronto. Community-based AIDS organizations are not only helping clients cope with HIV, they are helping them deal with a range of other problems and linking them with other services in their communities, many of which are stretched and under-resourced.

## **Continuing High Expectations**

Because AIDS organizations have been a crucial part of Ontario's response to HIV, the ministry continues to have extremely high expectations of them. Most of the strategies set out in the ***Ontario Provincial Strategy on HIV/AIDS to 2008*** include a role for community-based AIDS service organizations and will increase their workload (see Appendix B).

While community-based AIDS service organizations strongly support these initiatives, they question their ability – given current funding levels -- to cope with growing caseloads, respond to complex clients needs, and fulfill ministry expectations.

## **Funding of AIDS Service Organizations**

***Inequities in Provincial Core Funding.*** Although the Ministry of Health and Long-Term Care funds more than 60 AIDS service organizations, not all 60 are funded equally, and there are some agencies are not funded at all. Groups established after 1990 did not receive the same level of funding as those established earlier. Many did not

receive core funding for the five positions considered the standard for an effective HIV agency. This anomaly has created inequities. Community-based AIDS organizations cannot provide the same standard of service across the province.

**Growing Reliance on Other Short-Term Sources of Funding.** Ontario's AIDS service organizations have never relied solely on the Ontario Ministry of Health and Long-Term Care for their funding. Most have a long history of fund raising in their communities. Many receive funding from their municipal governments and some have been successful in applying to the federal government for project grants. While AIDS service organizations have other sources of funding, the ministry is the only funder that provides stable, predictable core funding.

***Only 45% of the funding received by community-based AIDS organizations is stable and secure.***

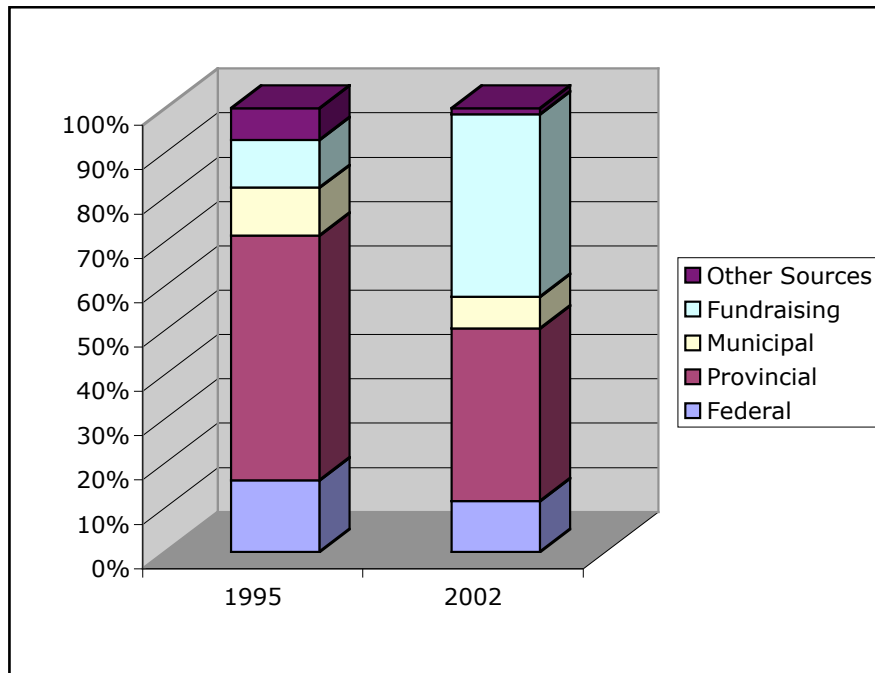
The funding environment has changed dramatically between 1986 and 2003. Like all other organizations funded by the Ontario Ministry of Health and Long-Term Care, AIDS service organizations had their funding reduced in the early 1990s as part of the "social contract". Since that time, AIDS organizations have received only one increase in core funding, in the late 1990s, which replaced the earlier cuts. (This increase allowed some organizations to increase salaries and stem staff turnover rates that had, at that time, reached 42% or 73 of 182 full-time staff over a period of two years.) In 2003/04, community-based AIDS organizations are operating with the same base funding as they had 10 to 12 years ago except that, over the past 10 years, inflation has reduced the real value and purchasing power of that funding by at least 15%. (Spigelman, 2003)

To compensate for the freeze on provincial funding and continue to meet client needs, Ontario's AIDS organizations have been remarkably creative in finding other sources of funding. A number have joined the United Way group of charities to take advantage of that fund raising capacity. Several have been successful in obtaining Trillium Grants. Several now rely on federal government grants for part of their operating funding.

When asked about the sources of their funding over the past few years, organizations noted that their provincial base funding is covering a smaller proportion of their budget costs, and they are becoming increasingly reliant on unstable, unpredictable, short-term sources of funding to maintain their programs. As the following graph illustrates, in 1995, over 53% of AIDS organizations' budgets were made up of stable core provincial funding. By 2002, only 45% of their program funding was stable and secure.

***AIDS service organizations are working in unstable, unpredictable and fiercely competitive funding environments.***

**Figure 6: Sources of Revenue for Community-Based AIDS Organizations, 1995 and 2002**



While the ability of small community-based organizations to find other sources of funding could be seen as a strength, it must be viewed in context. These other sources of funding are highly unpredictable and vulnerable. Federal government grants are usually for a period of one to four years only. Trillium grants are for a maximum of three years, are on a depreciating scale, and organizations cannot reapply for funding for the same program or project when the granting period is over. As a result, community-based AIDS services are now dependent on funding that may well not be available within the next two years.

Although AIDS organizations have been relatively successful in attracting private donations, they face fierce competition from other health organizations and issues (e.g., breast cancer, heart & stroke), and from other community and social services (e.g., homelessness, women’s shelters). In the competition for private donations, they are at a distinct disadvantage. Because HIV affects a relatively small proportion of the population (compared to many other illnesses), it has never received the same level of private philanthropic support as other diseases. Since the late 1990s, corporate and individual donations to HIV organizations have dropped dramatically: a reflection of both the public perception that HIV is now a treatable disease, the increasing marginalization of many affected by HIV, such as drug users, and the stigma still associated with HIV. (Spigelman, 2003)

The challenges associated with competing with other health issues for private donations

***Most AIDS organizations are dependent on funding that may not be available within the next two years.***

have led a number of AIDS service organizations to become members of United Way. However, even United Way funding comes with strings attached. Any organization that agrees to be part of the United Way must be willing to forego individual fund raising efforts, which could compete with the United Way fund campaign.

## **Funding of Other Health and Social Services**

AIDS organizations are not alone in their efforts to provide services with fewer funds and less secure funding sources. Over the past 10 to 12 years, mental health and addiction services in Ontario have also had no increase in funding. This has led to long waiting lists for some of these services. As many people with HIV also have an addiction or a mental health problem, this has a direct impact on their health and well-being. It also has an impact on AIDS organizations, which have to support clients who are waiting for these other services.

People living with HIV who use the services of AIDS organizations often require other social services, such as social assistance, food banks, assistance with housing, and vocational counselling. Many of these government-sponsored programs have also been severely cut in the past 10 years to the point where they are no longer meeting needs. According to a recent University of Toronto study, welfare recipients in Ontario no longer receive enough in social assistance to be able to feed themselves. Another study from McMaster, reporting on the changing social context, noted that “[s]ome services have been restructured and new rules have been put in place, so workers in AIDS organizations are often unsure which services are available to their clients and who is eligible to receive them. Workers find themselves increasingly responsible for rationing services and for watching over clients to ensure they do not ‘abuse the system.’ The climate ... often feels more punitive and intrusive [and] workers are often left trying to support clients who are in greater need just at a point when they are able to offer less help than before.”<sup>4</sup>

These changes to the broader health and social service environment make it extremely difficult for people with HIV, most of whom have incomes below the poverty line. (According to a survey conducted for the Canadian AIDS Society, 60% of people living with HIV have annual incomes less than \$20,000). Because many of these services are now inadequate or not available, clients are turning to AIDS organizations for more practical assistance, which puts even more pressure on their limited resources.

***Because of cuts to many other health and social services, clients are turning to AIDS service organizations for more practical assistance.***

Clients also make use of other nonprofit and voluntary agencies in addition to AIDS organizations, which are facing the same kinds of financial pressures. Most have had little

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<sup>4</sup> Cain R. Shifting Sands: The Changing Context of HIV/AIDS Social Services.

or no increase in funding in recent years. According to a recent report from the Canadian Council on Social Development, “[t]he capacity of the nonprofit and voluntary sector to fulfill its important role in Canadian society is being undermined and eroded by new funding strategies.” These funding strategies include: a marked shift away from a core funding model, an unwillingness to fund administrative costs, shorter and more unpredictable funding periods, and increased reporting requirements. As a result of the change in funding, “much organizational time is now devoted to chasing short-term sources of funding, often at the expense of the organizations’ mission and core activities.”

The lack of new investment in the community sector has occurred over a period when four other sectors – hospitals, drug programs, long-term care and physicians – have seen significant increases in their budgets.

## **The Impact on AIDS Service Organizations**

Faced with at least a 40% increase in demands, a 15% decrease in real funding, and fewer community resources, AIDS organizations have reported the following impacts:

**Cutbacks in Programs and Services.** In a 2003 Ontario AIDS Network survey of Ontario’s AIDS organizations, at least 50% reported that they have either cut back or eliminated the following services:

- prevention programming
- education programming
- buddy programs
- employment services
- transportation services
- food banks
- financial support/services.

A significant proportion (25 to 50%) also reported cutbacks in counselling programs, community development, community awareness, community outreach, special events, the production/provision of safer sex materials and other resources, and emergency services.

About 20% have also cut either the number of staff positions or staff hours in an effort to manage within their resources.

The reasons for service cutbacks or eliminations are, in order of influence:

- lack of funding
- lack of staff to conduct activities
- lack of volunteers.

**Inability to Meet Client Needs.** All organizations report that they are no longer able to adequately meet client needs in any of their key roles.

**Table 1: Degree to Which Organizations Are Meeting Client Needs**

*Ranked on a scale from 1 to 5, where 1 = low 5= high*

<b>Service / Program</b>	<b>Average</b>
Safe sex literature/materials	3.9
Prevention programming	3.7
Risk reduction – safe sex	3.7
Community outreach	3.6
HIV anonymous testing	3.6
Counseling services/programs	3.5
Education programming	3.5
Community awareness	3.3
Community development	3.2
Harm reduction – drug use	3.1
Special events	2.9
Volunteer programs	2.9
Emergency support	2.9
Library / resource centre	2.8
Transportation	2.7
Alternative therapy	2.6
HIV/AIDS treatment	2.6
“Buddy program”	2.5
Complementary therapy	2.5
Legal support/services	2.4
Massage therapy	2.4
Financial support/services	2.3
Food services/food bank	2.2
Translation & interpretation	2.1
Shelter support/services	2.1
Employment services	2.0
Medical equipment	1.8

According to people working in the field, inadequate funding is severely compromising their ability to fulfill their mission.

**Staff Turnover.** AIDS organizations report that they are finding it increasingly difficult to retain staff. They are experiencing high levels of turnover in all key service areas (i.e., practical assistance, counselling and support, special events, prevention and education, research and program development, and management and administration). The main reasons employees give for leaving are, in order of importance:

- a higher paying job elsewhere
- limited opportunities for advancement
- burn-out
- the uncertainty/instability associated with short-term contracts
- job stress
- lack of benefits
- organizational instability.

All of these “influencers” are the result of small organizations trying to function with inadequate funding. Given the current level of core funding, many AIDS organizations cannot compete with salaries paid by some other health or social service organizations. Because of the precariousness of their financial situation and overdependence on short-term funding, they also cannot offer staff the stability, benefits or opportunities for advancement that would make work in this field attractive.

As has been well documented throughout the health care field, high staff turnover rates result in lack of continuity of care, lower quality services, higher recruitment and training costs, and fewer resources for front-line services. When staff turnover is high, those who do remain have to work longer and harder to compensate for the changes, which leads to more burnout and dissatisfaction.

***High rates of staff turnover lead to lack of continuity of care, higher recruitment costs, and more burnout of staff who stay.***

**Greater Reliance on Volunteers.** About 42% of AIDS organizations report that they have increased their use of volunteers to compensate for lack of financial resources. These organizations have traditionally been highly volunteer driven. However, given the change in the disease (i.e., more complex client needs) and the public perception that HIV is no longer as serious a concern, it is becoming more difficult for agencies to find volunteers

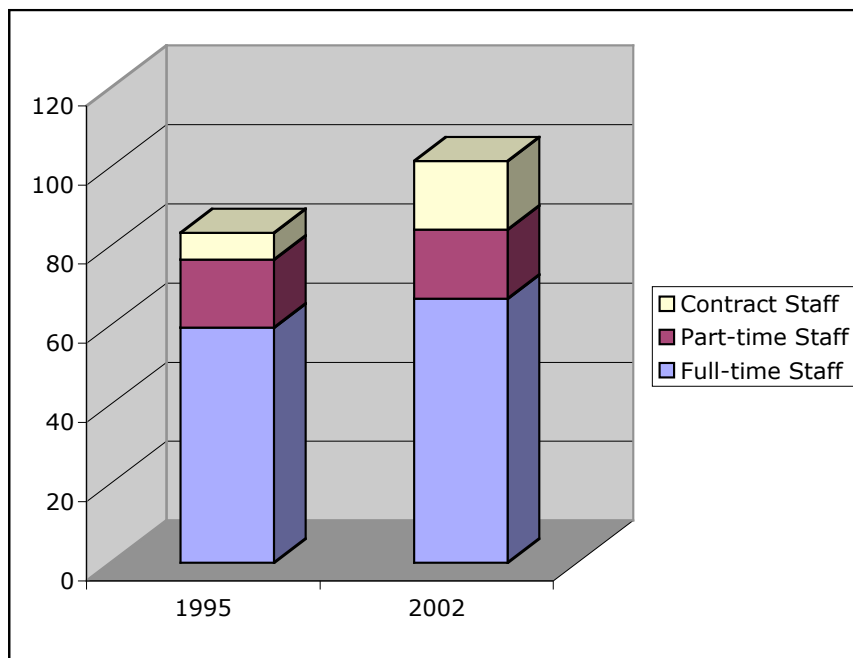
***AIDS organizations are competing with many other organizations for a shrinking pool of volunteers.***

to help deliver their programs and services. They are competing with other health and social service organizations for a diminishing pool of volunteers. It is also important to note that, while volunteers are a valuable resource, they are not cost free to an organization. AIDS service organizations have to spend a significant amount of time recruiting, training, co-ordinating, supporting, evaluating and appreciating volunteers – time that is not then available for front-line work.

**More Time Devoted to Fund Raising.** Because AIDS organizations have had to find other sources of funding to maintain their services, they are devoting a significantly larger proportion of their time and staff resources to fundraising. Between 1995 and 2002, the hours per week spent on fund raising increased 25%. The following graph shows the increase in hours spent by full-time staff, part-time staff and contract staff to raise funds.

***AIDS organizations are devoting 100 hours a week – 5200 hours a year to fundraising. Time spent fund raising is not available to provide direct client service.***

**Figure 7: Staff Time Devoted to Fund Raising 1995 and 2002**



Organizations are now devoting on average 100 hours of staff time a week – or 5200 hours a year -- to raising funds. Time spent on fund raising is time not available to provide direct client service.

**Increase in Administrative Requirements.** Having several different funding sources significantly increases administrative, reporting and accountability requirements. When asked about changes in administrative responsibilities, 100% of agencies surveyed reported they had increased (83% said they had increased significantly) and 100% reported that staff time spent on administrative tasks had also increased (81% said it had increased significantly).

Organizations have dealt with the increase in administrative responsibilities by adding it to the work of existing staff, diverting staff from front-line work, creating new paid positions to manage these tasks, relying on volunteers, and decreasing services for clients.

**Changing Priorities.** One of the most serious side effects of AIDS organizations' reliance on short-term project funding from a number of sources is that it gives non-core funders a disproportionate amount of influence over agency priorities and mission. For example, the priorities for short-term granting programs can change from year to year. If the new vision or priority is not based on good policy research or a community needs assessment, it can prevent organizations from continuing to develop long-term solutions that meet community needs.

While AIDS organizations continue to try to “work the system” to meet clients' needs, they feel highly constrained by the current rigid, piece-meal funding environment. Those organizations that rely on government funding tend to focus only on the priorities for which they are funded. They do not have the flexibility to be as innovative as they would like to be or to do the rough edgy front line work they were first formed to do. They are less likely to take risks for fear of losing their funding. They may also be less likely to be outspoken advocates for clients, because of the possible impact on short-term funding.

### **3. The Case for Change**

It is imperative that the Ministry of Health and Long-Term Care provide more funding for prevention and support programs and services now. The benefits of increased investment are clear and persuasive.

#### **1. Preventing HIV is more cost effective than treating it.**

In 2001, each case of HIV was estimated to cost about \$155,000 in direct costs and \$600,000 in indirect costs, such as lost productivity and costs to social programs. (Spigelman, 2003) This is a conservative estimate because it does not take into account increasing drug costs or the extra costs faced by people with HIV in smaller communities who have to travel to receive care. While it is possible to calculate the treatment costs associated with HIV, the personal and social costs of each case of HIV – for the person infected, his or her friends and family, and society – are immeasurable.

***Each case of HIV prevented saves Ontario at least \$750,000 in direct and indirect costs.***

With every infection that is prevented, Ontario avoids approximately three-quarters of a million dollars in direct and indirect costs. Consistent appropriate levels of ongoing core funding for prevention programs have the potential to significantly reduce both the prevalence of HIV and the number of new cases. Countries that have made those kinds of investments have reaped the benefits. For example, in 1997, the United Kingdom spent 1.9 times as much per HIV case on prevention than Canada and had a smaller epidemic (48 people with HIV per 100,000 population compared to 120 per 100,000 in Canada). In contrast, the United States spent 36% less than Canada on prevention and had over twice the prevalence of HIV. (Albert & Williams, 1998) Since that time, the United States has set aggressive new prevention targets and increased funding for prevention services significantly.

#### **2. Community-based AIDS organizations are the most effective way to reach people with HIV and populations at risk.**

Ontario first decided to fund community-based AIDS organizations because they could reach marginalized populations that either did not trust or would not use mainstream health services. That situation still exists today. The communities with the highest prevalence and the greatest risk of HIV – gay men, injection drug users, Aboriginal people and people from countries where HIV is endemic – continue to be marginalized. Failure to invest adequately in outreach programs to marginalized communities will lead to an increase in HIV infections. In fact, that is already the case. Because of lack of funding, new infections are occurring that could have been prevented.

According to testing data, the majority of people in Canada diagnosed with HIV over the past two to three years (i.e., new HIV infections) already have drug resistant virus, which means the virus was transmitted from someone who was being treated for HIV. ( add reference) This highlights a major gap in Ontario's prevention programs: the lack of effective life-long prevention and support programs for people who are living with HIV. These programs are lacking because of financial constraints. Ontario already has the infrastructure in place to address these gaps, and stem the tide of new infections. However, AIDS organizations that are handling increasing caseloads with budgets that are steadily being eroded by inflation and administrative demands, are unable to develop new programs to meet changing client needs. AIDS organizations already have contact with people living with HIV. They just need the resources to use those contacts to, once again, reverse the trend in new infections. Without more stable resources, Ontario risks losing the community-based HIV infrastructure that it carefully built through the 1980s and early 1990s.

***Ontario's AIDS organizations have the knowledge and skills to stop the increase in new infections. They just need the resources to do their job.***

### **3. Investing in community-based care and support services reduces the demand for other more costly health services.**

The relatively small amount Ontario invests in care and support services for people with HIV (.04% of the provincial health budget) helps avoid other health care costs, and reduce the demand on other parts of the health care system.

According to research conducted in 2002, a significant proportion of people who use AIDS service organizations suffer from depression, and they are heavy users of the organizations' support services. Those who do take advantage of those services make significantly less use of other more expensive health services, such as physician and specialist services. (Lush et al, 2002.)

## **4. Recommendations**

Ontario's HIV/AIDS strategy to 2008 sets out an ambitious role and agenda for AIDS service organizations (see Appendix B). Given the growing number of people living with HIV, the different populations affected, and their unique needs, we -- Ontario's AIDS service organizations -- are no longer able to meet ministry expectations at current levels of core funding. Over the past 10 to 12 years, we have sought out other sources of funding to compensate for both the lack of base funding increases and their growing caseload. These other sources of funding -- all of which are short-term and unpredictable -- now account for over 50% of our operating budgets. This situation is untenable.

At a time when the number of new HIV infections in Ontario is increasing, lack of adequate stable funding is forcing us to reduce services, and eliminate programs and staff. If this does not change, Ontario will pay the price in more infections, higher treatment and drug costs, more discrimination, and more lives lost.

For less than the direct and indirect costs of treating 11 cases of HIV, the ministry could give AIDS service organizations the stability to do what we do best and to do what the ministry expects us to do: develop and implement relevant, effective programs to reach vulnerable populations, educate people, provide support, and prevent the spread of HIV.

***For less than the cost of treating 11 cases of HIV, the Ministry of Health and Long-Term Care could stabilize AIDS organizations, and reverse the rise in new infections.***

We strongly recommend that the Ministry of Health and Long-Term Care take the following steps to ensure that the province's AIDS service organizations are able to fulfill our current role in the health system and meet the expectations of the new provincial strategy:

- 1. To give Ontario's community-based AIDS organizations the stability and capacity to respond to the growing HIV epidemic:**
  - The MOHLTC program areas that fund community-based AIDS organizations -- particularly the AIDS Bureau and Long-Term Care -- should immediately increase core funding for all currently funded community-based AIDS organizations by 15%. (estimated \$5-6 million)
- 2. To address the anomalies and inconsistencies in community-based HIV services, and ensure all Ontarians have access to effective, evidence-based HIV prevention and support services:**
  - Ontario's community-based AIDS organizations should work with the MOHLTC to identify the standard level of service to be provided by all community-based AIDS service organizations in the province, including the staff positions/resources organizations required to provide that standard. (\$100,000)

- The MOHLTC should then immediately increase funding to those community-based AIDS organizations across the province that do not currently meet the established standard. (\$2-3 million).
3. **To enable Ontario's community-based AIDS organizations to fulfill their ambitious role in the new provincial HIV/AIDS strategy:**
    - The MOHLTC should contract with a qualified consultant to assess the cost/resource implications of the new strategy.
    - Ontario's community-based AIDS organizations should participate in the costing exercise.
    - The MOHLTC should provide the resources AIDS service organizations will need to fulfill their role. (est. \$2-3 million)
  4. **To meet the broader health/social needs of people vulnerable to or living with HIV:**
    - The MOHLTC should increase funding for addiction treatment services and community-based mental health services.
    - The MOHLTC should make a strong, persuasive case with other ministries and other levels of government to immediately increase the supply of affordable housing.
  5. **To establish a consistent, needs-based approach to funding HIV prevention and support services:**
    - The MOHLTC should work with community-based AIDS organizations to develop a funding formula that reflects the prevalence of HIV, the needs of people infected and at risk, changing ministry expectations, changing demands for services, new knowledge, and inflation.
  6. **To make the most effective use of Ontario's HIV resources:**
    - The province's community-based AIDS service organizations and the MOHLTC should establish a process designed to continually improve how community-based services are organized and delivered now and in the future.

## **Appendix A**

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*Stemming the Tide: The Case for More Investment in Community-based HIV/AIDS Prevention and Support*

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Note: "NMV" indicates non-voting member

## **Appendix B**

### **Provincial Strategy Recommendations With Implications for AIDS Service Organizations**

Community-based AIDS organizations have a role to play in implementing the following strategies in the new **Ontario Provincial Strategy on HIV/AIDS**. To fulfill these expectations, the organizations will need adequate resources.

#### **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.
  - 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.
  - 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.

- 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
  - 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
- 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.
  - 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.

- 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.
- 3.5 Identify and implement strategies to ensure that young people in Ontario receive education about HIV and other STDs, including:
- 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.
- 3.8 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.
- 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.
- 3.13 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.
- 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 are accountable for the quality of their services and their use of resources.
- 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.