



Shifting Priorities

The Response of the BC Persons With AIDS Society to
*Priorities for Action in Managing the Epidemics
HIV/AIDS in BC: 2003-2007*
(Workshop Draft – March 2003)

Approved by the Board of Directors, BC Persons With AIDS Society
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Introduction

[Priorities for Action in Managing the Epidemics; HIV/AIDS in BC: 2003-2007](#) was released generally in the first half of March, 2003 (BCPWA received a copy by e-mail from the Provincial Health Services Authority on Wednesday, March 19; it had been preceded on Monday, March 17 by an e-mail invitation to attend a workshop on the document hosted by the PHSA).

The release of **Priorities** was the culmination of almost a year's effort by many provincial government employees and at least two successive contracted/seconded "producers" (most notably Dr. Martin Spiegelman, and Warren O'Briain). That it was produced at all is due to some considerable degree to the persistent, oft-repeated and near universal demand in BC's HIV/AIDS community (given strong voice in the final report of the Ministerial Advisory Committee on HIV/AIDS, issued in 2001) for a published, officially sanctioned strategy to guide the work of all the respondents to the epidemic in BC.

While all those associated with **Priorities** have been exceedingly careful to make it clear that it is *not* a "strategy", the fact remains that – in the absence of any other "strategy" promulgated by the BC provincial government – **Priorities** will fill that role *de facto*.

This makes it very important indeed.

By and large, the British Columbia Persons With AIDS Society (BCPWA) welcomes the release of the Workshop Draft of **Priorities**. We find much in the document to be praiseworthy and deserving of swift implementation. We find the overall goals set out in the document to be commendably clear, to the point and bold.

As well, of course, we find there is more than just a little in the document open to criticism. Setting aside the internal inconsistencies in **Priorities** (which we are confident will be dealt with appropriately in succeeding iterations), we find that there remain three substantial areas of policy and implementation with which the document has failed to deal in any meaningful way. These are (1) the role of HIV-positive people in prevention efforts ("Positive Prevention"), (2) the role of the HIV/AIDS community in determining, effecting and monitoring large portions of the battle against the epidemic, and (3) the need for substantially increased funding if the goals set out in **Priorities** are to be at all attainable.

In furtherance of these concerns, representatives of BCPWA attended at the **Priorities** workshops hosted by each of the Vancouver Coastal Health Authority (April 4), the Provincial Health Services Authority (April 7), and the Fraser Health Authority (April 15). In furtherance of these concerns we have carefully considered and prepared this written response.

The criticisms and suggestions advanced in this document are proffered in a spirit of goodwill and determination to be as constructive and helpful as possible. If at times the language seems a bit strong, or the points raised a bit aggressive, it is only because of the passion BCPWA and its members and staff bring to the battle against HIV/AIDS.

BCPWA exists, in the words of its mission statement, “to enable persons living with Acquired Immune Deficiency Syndrome and Human Immunodeficiency Virus to empower themselves through mutual support and collective action – *from our personal struggles and challenges come our courage and strength.*” It is Western Canada's largest AIDS organization with a membership of more than 3,900 HIV-positive full voting members. The Society's services are also available to and regularly accessed by many of the 12,000 to 15,000 HIV-positive individuals in BC. Unique among major HIV/AIDS agencies in Canada, BCPWA's Board of Directors is composed entirely of HIV-positive members. And all of its programs are operated by committees headed by HIV-positive persons.

BCPWA's “Shifting Priorities” response to **Priorities** is the product of numerous discussions within the various responsible committees of the Society, and has been vetted and formally approved by its Board of Directors. Note should be made of the numerous substantial contributions made by the HIV-positive members of the Society, including Board members, who attended at the health authority workshops and participated decisively in the preparation of “Shifting Priorities”, of the major role played in its production by Dr. Carl Bognar, Coordinator of Prevention, and of the significant role played by Ross Harvey, Executive Director.

To repeat, there is much in **Priorities** to praise, much which is worthy of swift implementation. Effective realization of those elements of **Priorities** will ensure a response to the epidemic in BC of far greater positive impact than otherwise would be the case; it will make a real and positive difference in the lives of thousands of persons living with the disease, and in the lives of scores of thousands not yet infected.

Adoption of the suggestions proffered here will ensure the avoidance of errors which would mitigate, perhaps even obviate, that effective realization, and will contribute to a far stronger response in the long run, and so to better outcomes for all concerned.

A handwritten signature in black ink, appearing to read "Malsah" with a stylized flourish underneath.

Malsah, Acting Chair, for the Board of Directors, BC Persons With AIDS Society

Positive Prevention

Introduction

This section outlines concerns of the British Columbia Persons with AIDS Society in reaction to the “Workshop Draft” of **Priorities for Action in Managing the Epidemics: HIV/AIDS 2003 – 2007** (BC Ministry of Health Planning and Ministry of Health Services), with respect to omission of discussion of ‘positive prevention’.

Much of the **Priorities** document is based on a conceptual foundation that lends support to the notion of positive prevention, although positive prevention is not explicitly discussed. For example *Guiding Principle 1*, which is “to focus on prevention and include efforts to promote prevention among ... those who are already infected with HIV” (page 20) seems to refer to positive prevention, without naming it directly. Similarly, *Section 5.3, Roles and Responsibilities*, discusses “critical strategic support” that will be provided by community organizations in “engaging those already living with HIV in enhanced secondary prevention efforts” (page 27). Again, this would appear to refer to positive prevention as we have come to define it at BCPWA.

We believe that highlighting positive prevention would strengthen the discussion of prevention in the document.

A Note on Terminology

As noted above, the document includes brief discussions of ‘secondary prevention’ (see for example the first Key Strategy in “Care, Treatment and Support, pages 4 and 27). Unfortunately, the traditional nomenclature for prevention (primary, secondary and tertiary) becomes less clear when viewed from the perspective of HIV-positive people. Sometimes the term ‘secondary prevention’ is used to mean (at least in part) early testing and identification of those infected in order to prevent onward spread of disease by those who may be unaware of their infection. Elsewhere, as in the **Priorities** document, ‘secondary prevention’ appears to mean providing appropriate supports to HIV-positive people to assist them in developing and maintaining a repertoire of risk reduction behaviours. These are two quite different meanings of ‘secondary prevention’. To avoid this confusion, many prevention workers in the United Kingdom are starting to abandon the traditional primary/secondary/tertiary classification in favour of the term ‘positive prevention’.

During the “workshop” held to consider **Priorities** by the Vancouver Coastal Health Authority, it was revealed that language indicating “secondary” (or “primary” or “tertiary”) prevention would be removed. We support this improvement.

In some places where initiatives are being designed in an attempt to engage HIV-positive people in prevention efforts, the term 'prevention for positives' has emerged. At BCPWA, our Prevention Sub-Committee has rejected this term because it does not acknowledge the critical contribution of HIV-positive people in this type of prevention effort. The term 'prevention for positives' implies something that is *done to or imposed on* HIV-positive people. Because positive prevention is a new concept, there is little theory to serve as a foundation for designing interventions, and the participation of HIV-positive people in the development and delivery of such initiatives will be imperative. Given these facts, the term 'positive prevention' is preferred, because it conveys a sense of ownership and direction by people living with HIV.

Historical Background

Over the first 20 years of the HIV epidemic, prevention efforts were directed, almost without exception, towards education of HIV-negative people about risk behaviours, and the issues faced by HIV-positive people in maintaining safer behaviours were rarely, if ever, considered. This significant gap in prevention theory and programming appears to have arisen, at least in part, out of concern about further increasing the stigmatization of people with HIV disease. In addition, in the earlier days of the epidemic, a diagnosis of HIV infection appeared to imply a "death sentence", and so it was hard to imagine that HIV-positive people would continue to engage in sexual behaviours or other behaviours that might place others at risk.

As HIV-positive people live longer and healthier lives, and given that there are now more HIV-positive people alive than ever before, it is now evident that slowing the epidemic requires attention to the issues and concerns of HIV-positive people.

What is 'Positive Prevention'?

Research on the prevention issues faced by people living with HIV is starting to emerge, particularly in the United Kingdom, the Netherlands and Australia. Much of this research is framed within a health promotion framework (see, for example, Schiltz and Sandfort, 2000; Summerside and Davis, 2001). This research is starting to demonstrate that risky behaviours are often related to complex psychosocial issues, such as depression and denial, rejection and isolation, grief and loss. In the United States, some programmatic interventions are emerging, but in general the American work in positive prevention is not grounded in a health promotion framework, and therefore lacks a theoretical approach, which would make possible a systematic analysis of the issues faced by HIV-positive people.

During the first 20 years of the epidemic, community organizations designed and developed a range of programs to support HIV-positive people in dealing with the complex psychosocial issues they face in managing their disease. It seems probable that many of the issues that have been dealt with through these support programs are

the same issues that need to be addressed to assist HIV-positive people in developing and maintaining safer behaviours. While some of these issues have been addressed at the individual in the context of support for HIV-positive people, they have not yet been linked in a systematic way to prevention. Positive prevention recognizes that support and prevention are not two distinct entities, but that from the point of view of HIV-positive people, and are part of a continuum.

Similarly, there is a linkage between treatment and prevention. HIV-positive individuals who are taking antiretroviral treatment and effectively managing their HIV infections are less infectious and therefore less likely to transmit the virus. In this way, services that assist individuals in the management of their treatment, and the physical and psychosocial issues that arise from effective treatment, also contribute to HIV prevention.

Positive prevention also includes features traditionally considered as tertiary prevention, that is, efforts at maintaining the health of HIV-positive people at the highest possible levels. This includes, for example, activities that promote access to adequate nutrition and housing, prevention of acute illnesses that arise more-or-less directly from HIV infection (such as PCP), and prevention of illness that also affect the general population but which may be more serious in immune-compromised individuals (such as Norwalk virus or SARS).

Positive prevention seeks to maximize the physical, mental and sexual health of HIV-positive individuals, providing them with the necessary foundation for maintaining safer behaviours and maximizing their quality of life. Positive prevention highlights the fact that, from the perspective of HIV-positive people, prevention, care, treatment and support are part of a continuum.

Primary prevention efforts directed at the general population will still be required to stem the epidemic of HIV. Positive prevention is meant to complement other prevention initiatives, not to replace them. Best practice throughout the world indicates that achieving effective HIV prevention is only possible when such efforts are viewed as part of the continuum of Care, Treatment and Support involving HIV-positive people. We support language within **Priorities** and actions arising from it which support this widely held practice and view being implemented in BC.

References

Schiltz, MA, and Sandfort, ThGM. (2000). HIV-positive people, risk and sexual behaviour. Social Science and Medicine, 50, 1571 – 1588.

Summerside, J and Davis, M. (2001). HIV prevention and sexual health promotion for people with HIV. London, UK: National HIV Prevention Information Service, Professional Briefing 4.

Participation of HIV-positive People in HIV/AIDS Initiatives

Introduction

This section provides details about policy and practice with respect to the importance of the participation of HIV-positive people in all HIV/AIDS initiatives. Throughout the **Priorities** document, references should be inserted and terminology modified to indicate that the participation of HIV-positive people is critical to the development and implementation of ethical and effective responses to the HIV epidemic.

Historical Background

Early in the epidemic of HIV, many governments were reluctant to dedicate either financial or human resources to meeting the needs of people living with HIV. In developed countries, the majority of initial programming and service responses to the epidemic originated at the community level. In the British Columbian context, virtually all of the community organizations that arose as an initial response to HIV/AIDS emerged from the gay men's community, the first community widely affected by HIV. As the epidemic evolved, many of these community leaders in HIV/AIDS themselves were lost from community organizations as a result of high levels of mortality. This loss of leadership from the HIV-positive community led to 'professionalization' in many community-based organizations, with key positions falling to workers educated in the various helping professions, who, while genuinely concerned and interested in the complex issues faced by HIV-positive people, were not themselves HIV-positive.

The grassroots community movement in HIV/AIDS has, however, had a significant impact on health care delivery in general. As a result of advocacy and participation by HIV-positive people, the range and types of participations pioneered by the HIV/AIDS movement are now viewed nationally and internationally as a model for the participation of all citizens in the management of their own health.

Relevant Policy

The involvement of PWAs in HIV/AIDS efforts has been supported by extensive policy development, both within Canada and internationally.

Canada, along with 41 other nations, is a signatory to the Paris AIDS Summit Declaration (1994). The Paris Declaration is the foundation for the "GIPA Principle", the call for greater involvement of people living with HIV/AIDS, asserting, in part, that signatory states will

“support a greater involvement of people living with HIV/AIDS through an initiative to strengthen the capacity and coordination of networks of people living with HIV/AIDS and community organizations” (Article 1; full text of the Paris Declaration is available at <http://www.unaids.org/whatsnew/conferences/summit/dece.html>).

In 2003, UNAIDS also published revised international guidelines for access to prevention, treatment, care and support. Revised Guideline 6a states, in part, that

“National plans should be developed in consultation with nongovernmental organizations to ensure the active participation of people living with HIV/AIDS and vulnerable groups.”

Further, Revised Guideline 6f states that

“States should recognize, affirm and strengthen the involvement of communities as part of comprehensive HIV/AIDS prevention, treatment, care and support. “ (http://www.unaids.org/publications/documents/care/general/JC905-Guideline6_en.pdf)

Community Involvement

People living with HIV/AIDS have been front and centre in the response to the epidemic of HIV. There is widespread acknowledgement, both in Canada and abroad, that the participation of HIV-positive people strengthens policy and programs, by

- ensuring that policy and programs are relevant, timely and coordinated,
- supporting the contribution of HIV-positive people to prevention, care, treatment and support,
- ensuring access to the most marginalized populations, who are over-represented among those infected and affected by the epidemic of HIV,
- leveraging contributions from government by attracting and retaining volunteers, and
- contributing to local knowledge about the epidemic.

As noted in *Canada's Report on HIV/AIDS*, engaging partners from various disciplines and jurisdictions, and including HIV-positive people as partners, has many benefits:

“It ensures a more strategic approach, results in better-targeted initiatives, reduces duplication of effort and minimizes the impact of limited human and financial resources” (Health Canada, 2002).

The participation of HIV-positive people in issues that affect their lives provides benefits not only to the community-at-large, but also to HIV-positive individuals themselves. The social interactions and relationships that result from cooperative efforts have a positive

impact on factors that influence health. Citizen participation is, in its own right, a form of health promotion.

The Language of Citizen Participation

The **Priorities** document, as currently drafted, states:

“The first principle is to focus on prevention, and includes efforts to promote prevention among those who are most vulnerable to infection, those who are already infected with HIV, and among the general population.”

While we appreciate the acknowledgment in this statement that HIV-positive people have a role to play in prevention, thereby supporting our efforts in ‘Positive Prevention’, the **Priorities** document would be strengthened by the addition of a general principle supporting the participation of HIV-positive people in all initiatives that affect their lives.

Additional Funds Required

Introduction

One of the major concerns the British Columbia Persons With AIDS Society has with the “Workshop Draft” of **Priorities for Action in Managing the Epidemics: HIV/AIDS 2003 – 2007** (BC Ministries of Health Planning and Health Services, March 2003) is its implicit assumption that all of its commendable goals can be achieved without a significant infusion of new dollars into the effort.

BCPWA believes this assumption to be misguided at best. Given the ongoing incidence of new infections (which, even if reduced by 50 percent, will still number in excess of 200 annually), the higher costs of new treatments (including new forms of anti-retroviral medications and new treatments for Hepatitis C), and the increased costs inescapably associated with most of the Key Strategies proposals advanced in the document, *status quo* funding will guarantee failure.

Substantial new funding in addition to that already in place must be made available by the provincial Health ministries if the goals set out in **Priorities** are to be accorded any chance of attainment

The Assumption of *Status Quo* Funding

One of the most remarkable things about **Priorities** is its somewhat coy but nonetheless thorough refusal to discuss money. It does include heartening (and, if anything, understated) assessments of the costs to be avoided through effectively addressing the HIV/AIDS epidemic; but, it is close to silent on the question of how that effective work is to be financed.

The assumption of *status quo* funding is nowhere baldly stated in **Priorities**. It is, however, clearly implied.

The only discussion of “investment implications” to be found in the entire document (with the exception, noted below, of elements of “Appendix 1, Investment Implications”) is contained in the “Implications for the Future” section’s assessment of “Resource Implications”. This discussion advises in part, “Implementing Priorities for Action may entail *realigning the current mix* of provincial, health authority and contracted programming ...” (emphasis added). Realignment is something you do with what you’ve already got; it does not envisage the receipt of new things to align.

This implicit assumption is rendered considerably more explicit in “Appendix 1, Investment Implications”. Each of the Key Strategies canvassed in the appendix is assessed with regard to three criteria: “investment”, “impact” and “type of funding”. In

exactly two of the 18 strategies considered is a “type of funding” other than “existing” contemplated. In one of those two, “Expand provincial support for low threshold harm reduction initiatives ...”, the “type of funding” noted is “existing (and external)”; in the other, “Establish, monitor and evaluate a public health reporting requirement ...”, it is “Existing and new (external)”. “External” apparently means established federal government (or, dramatically less likely, municipal government) sources, or funds available from provincial government departments other than the two health ministries.

For everything else, the costs involved are to be covered, presumably, through “realignment” of the “existing” *status quo* funding.

The Unavoidable Cost Pressures

As **Priorities** notes in its Introduction, “Every day, between one and two people in BC contract HIV ...” and “... there are indications the epidemic may again be expanding.” This on top of “the perhaps 13,500 already living with this disease ...” in BC.

The point bears repeating: things are getting worse. There are more people attempting to live with HIV/AIDS in BC than at any previous time. Rates of new infection remain dependably above 400 annually, and seem to be on the rise.

Everywhere, the multi-pronged response to HIV/AIDS put in place in BC in the early to mid 1990’s is stretched to the breaking point.

Acute care facilities available for AIDS patients – most of whom are co-infected with Hepatitis C – are now “maxed out”. There is “no more room at the inn”.

The principal treatment system for those infected in the province, the drugs program operated by the BC Centre for Excellence in HIV/AIDS, has come up hard against the limits to its funding. Despite brilliant world-class work in determining optimally effective treatment regimes (including structured treatment interruptions) that have had the salutary coincidental effect of maximizing the impact of the funding it does receive, the Centre is simply unable to stretch that funding even further to cover the higher costs of the essential new drugs coming available – especially in the case of those co-infected with Hepatitis C -- for the ever expanding list of persons dependent on such therapy for their very survival.

And the community-based network of non-profit, volunteer-dependent agencies meeting the lion’s share of the care and support needs of infected persons in BC while simultaneously undertaking what little prevention work is being done is struggling to carry on given funding only marginally greater now than it was more than half a decade ago when the epidemic was substantially smaller and less diverse.

Even if nobody did anything differently, the fact of an additional 35+ new infections per month being reported creates additional demand, additional strain. The BC Centre for

Excellence is experiencing an additional 10 to 15 persons per month – net increase -- enrolling in its drugs program. How it is to meet this rising demand with expenditures now frozen at 2000/01's level of \$35 million is a question thus far unanswered. Numbers accessing community-based organizations continue to rise, resulting in "realignment" of programming the ultimate outcome of which is those showing up now often receive less attention and assistance than did their predecessors scant years ago. The consequently depressed health outcomes are unknowable but, generally, certain. And the looming crisis in acute care has yet to be addressed.

Commendable Goals, Woefully Inadequate Means

In the face of these stark realities, **Priorities** – to its great credit – calls for a 50 percent reduction in the incidence of HIV infection and a 25 percent increase in the numbers of HIV-positive individuals who are linked to appropriate care, treatment and support. But it does so while simultaneously adhering to the assumption that such can be achieved – indeed, that measures already in place can be sustained effectively – with *status quo* funding.

It is a fantasy.

Or a shell game. The robbing of the care, treatment and support Peter to pay the prevention Paul would render impossible the goal of 25% more HIV-positive individuals being linked to appropriate care, treatment and support – such programming wouldn't be there to be linked to. Similarly, a "realignment" of current prevention expenditures to secure the monies necessary to effect a 25% increase in care, treatment and support attachments would guarantee the dismal failure of the 50% incidence reduction goal.

As everyone's mums have sagely observed for centuries, "you can't have your cake and eat it, too."

Conclusion: Substantially Increased Funding ... Or Bust

Priorities contains much of great value. It's analysis of the development and trajectory of the HIV/AIDS epidemic in BC, and of the devices that have emerged to combat it, is thorough and accurate. Its stated goals, if achieved, would substantially alter the epidemic, and would improve the lives of many thousands of British Columbians while saving many thousands – perhaps tens of thousands – more from a life mired in personal battles against this still incurable and ultimately fatal disease. The Key Strategies it advances, if implemented, will all but certainly secure those goals.

But it will be all a sham, a conjurer's trick, if its implementation is attempted in the absence of substantially increased funding.

So, from where is this money to come?

The BC provincial Health ministries cannot shuffle the matter of additional new funding off onto the various Health Authorities. It is the Province that enjoys taxing authority, and the ability to raise monies from a variety of sources. All the Health Authorities can do is impose user fees – socially unacceptable and illegal under the *Canada Health Act*. Similarly, given the hundreds of millions of new dollars that will start flowing from the federal government into BC's Health ministries' coffers in consequence of the Romanow Report deals struck last year, it is unreasonable to look to Health Canada for much increased funding in these regards.

In a nutshell, the provincial Health ministries must act; it is not enough for them to adopt **Priorities** and pledge its implementation. Those ministries must, as well, produce the substantial additional funds essential to that implementation. To do otherwise would be to expose the pledge embodied in the document's adoption as a contemptible deception.

Indeed, in the absence of substantial new funding from the provincial Health ministries directed to the fight against the HIV/AIDS epidemic, the *status quo* itself may collapse.