

POSITIVE PREVENTION

**TOWARDS A PAN-CANADIAN
FRAMEWORK**

A DISCUSSION PAPER

CANADIAN
AIDS
SOCIETY



SOCIÉTÉ
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DU SIDA

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1. INTRODUCTION

There is no member of society exempt from having a role to play in the shared responsibility of HIV prevention. From parents to offspring, friends and lovers, employers to cultural, educational and religious institutions, all members of society share in the responsibility not only for self protection and the protection of others by understanding and adapting the behaviours that put us at risk for HIV transmission, but also by promoting acceptance, compassion and non-discrimination for those who are living with and affected by HIV/AIDS. Whether it be primary prevention (keeping negative people negative), secondary prevention (avoiding re-infection), or tertiary prevention (improving disease severity and disability) effective prevention strategies require that all members of society have access to the information, resources, and support necessary to ensure the protection of their health and general well-being.

For well over twenty-five years people living with HIV (PLWHIV/AIDS) have recognized the challenges that exist. It is these same people who have been and continue to be the leaders in prevention advocacy and who are stepping up to the plate once again to take the lead on primary HIV prevention.

PLWHIV/AIDS can play an integral role in the prevention of new infections.

*“It is only with this leadership from this community and the groups that represent their interests that primary HIV prevention designed for people living with HIV will be successful.”*¹

The concept of positive prevention has its own unique set of complications that need to be flushed out through in-depth discussion. The Canadian AIDS Society with the support of the Positive Prevention Working Group views this discussion paper as a means of opening a pan-Canadian dialogue on the issues of effective positive prevention. In order to establish effective prevention strategies consensus must be reached across the country that clearly defines positive prevention, and the best practices that will guide National, Regional and Local initiatives. Nonetheless, it is hoped that through this paper communities will be better able to begin to develop initiatives that encompass the tenants of positive prevention as set out by the British Columbia Persons With AIDS Society which aim to:

- promote the recognition that people living with HIV/AIDS are part of the solution to the impacts of the disease and should be included in prevention efforts;
- encourage and foster the involvement of people living with HIV/AIDS in all aspects of health promotion and prevention activities at all levels;
- develop health communication and prevention strategies targeted specifically to people living with HIV/AIDS;

¹ Prevention for Positives: A Compendium of Interventions, Mark Peterson Midwest AIDS Prevention Project

- recognize and empower the sexuality and sexual health of people living with HIV/AIDS;
- promote risk/harm reduction behaviors and activities;
- protect and promote human rights and dignity issues for people living with HIV/AIDS including the right to privacy, health care, confidentiality, informed consent, and freedom from discrimination; and
- to ensure programs and services are available, accessible, and relevant to the diverse populations of people living with HIV/AIDS.

The notion of focusing prevention efforts on PLWHIV/AIDS has been suggested since the beginning of the epidemic. However, it has really been only within the last few years that a flurry of initiatives, funding, research, and writing on the topic of positive prevention has taken place.

Relatively little is known about effective interventions addressing the HIV and sexually transmitted infection (STI) prevention needs of people living with HIV prior to 2000.

“Studies show that a significant minority of people living with HIV/AIDS continue to practice sexual behaviors that place their partners and themselves at-risk for HIV and other sexually transmitted infections. Efforts to reduce HIV-transmission risk behavior have concentrated on strategies adapted from interventions for uninfected populations with disappointing results.”²

Factors surrounding criminalization, enforced and voluntary disclosure, informed consent, partner notification, voluntary testing, sero-sorting, primary, secondary and tertiary prevention, sero-discordance, strategic positioning, sex positive approaches to prevention, treatment as prevention, viral load suppression and other pertinent issues reinforce the need for care-related strategies, as well as health education, risk reduction information and skills building initiatives.

The challenges can be considered unique when PLWHIV/AIDS consider decisions about behaviours that run the risk of HIV transmission, re-infection and co-infection. It is hoped that this paper will help to clarify and address these challenges in order to further the identification and development of effective prevention strategies that are relevant to the HIV positive community.

Although the British Columbia Persons With AIDS Society (BCPWA) and the Poz Prevention Working Group of the Ontario Gay Men’s HIV Prevention Strategy have been doing groundbreaking work in this area there exists, unfortunately, no pan-Canadian model or framework for positive prevention despite a recent acceleration of development in the area of positive prevention in the United States and Europe. Standardized procedures and evaluation activities would help to ensure that measures of positive prevention are both appropriate for and effective with PLWHIV/AIDS. Statistics have shown that current prevention programs only reach one in five people at risk of HIV transmission. As a result, HIV incidence in Canada has risen. The Public Health Agency of Canada estimates that in 2005 there were between 2,300 and 4,500 new diagnosis. (HIV and AIDS in Canada: Surveillance Report to December 31, 2006, Public Health Agency of

² Kalichman, et al., 2001

Canada) Even though prevention efforts have been successful in reducing sero-positivity rates in some populations, HIV has gained new ground in vulnerable populations such as women, men who have sex with men (MSM), aboriginal communities and injection drug users (IDUs). People engaging in HIV transmission risk behaviours need an array of prevention messages, skills, and support to help them reduce sexual and drug-related risks. Immediate elimination of risk behaviour may not be possible, therefore strategies need to be developed using a more comprehensive approach.

HIV/AIDS prevention goes beyond simply preventing people from transmission of HIV. It also involves identifying the presence of HIV, treating it, and maintaining a good quality of life while living with it.³

Primary prevention for people living with HIV is a critical priority on the prevention agenda. The chief role of primary prevention is to develop and use strategies such as counselling, testing, health education and strategies of behavioural risk reduction to help prevent new transmissions. This prevention arm may also include biomedical interventions and new prevention technologies such as microbicides, vaccines, pre and post-exposure prophylaxis. Ever more popular, as a primary prevention strategy, is the concept of treatment as prevention to reduce HIV viral load and possibly reducing the level of infectivity. Although primary prevention can contribute to the containment of the epidemic, focusing solely on primary prevention negates the concept of shared responsibility which promotes targeting PLWHIV/AIDS as “vectors” of the disease and raises concerns about stigma and discrimination towards PLWHIV/AIDS causing further division between those who are HIV-positive and those who are not.

PLWHIV/AIDS face multiple challenges in their lives that go beyond securing health care and dealing with a life threatening concerns. Economic emergencies, racism, homophobia, issues around caring for their children, threats of violence, drug and/or alcohol misuse are some of the factors that complicate living with HIV. Added to this list is a society that labels PLWHIV/AIDS as potential risks. Behavioural patterns dictated and controlled by social determinants of health cross over to behavioural patterns that put people at risk for transmitting HIV. Through this lens primary prevention for HIV positive people warrants a framework based on the social determinants of health that works towards decreasing societal vulnerability and lowering individual risk.

Secondary prevention targets PLWHIV/AIDS in the hopes of preventing re-infection and transmitting HIV to others. Secondary prevention also attempts to reduce HIV risk co-factors, such as the presence of sexually transmitted infections (STIs), preventing the development of opportunistic infections, and preventing HIV from progressing to AIDS.

³ hiv prevention plus Volume 6, Number 4 July/August 2005

Tertiary prevention aims to ameliorate the severity of the disease and enhance the quality of life for PLWHIV/AIDS by addressing issues of opportunistic infection treatment, drug and alcohol misuse, disability and disease management, and mental health.

Prevention efforts meet many barriers. Unanswered questions complicate the prevention message. Are people with HIV at significant risk of re-infection with HIV or super-infection with a more virulent or drug resistant strain of the virus? Is low or undetectable viral load an indication of reduced risk of transmission? What are the real risks of oral sex? How safe is pregnancy? These and other questions are on people's minds as they think about sexual and drug use behaviours and the potential risks for their partners and their own health.

Efforts directed toward HIV-positive persons must encourage a healthy sense of involvement in prevention efforts without assigning blame, and furthermore must support a lifestyle that includes a fulfilling, safer sex life and the enhancement of interpersonal and community relationships.

*"For HIV-negative populations, strategies must be adapted to the unique needs of each group affected. And for HIV-positive individuals, for whom safer behavior has become a lifetime proposition, prevention services must be expanded and sustained."*⁴

None of these challenges will be easily solved. Community based organizations, public health departments and federal agencies must grapple with these complexities as they respond to the need for expanded prevention strategies for PLWHIV/AIDS. There are already examples of successful programs and a wealth of models of practice used regarding prevention strategies for non-PLWHIV/AIDS that can help guide development of new programs.

Until recently, prevention issues have focused on people who are not living with HIV. Following the International Conference on AIDS in Durban prevention issues have become increasingly relevant and critical for people living with HIV/AIDS. This conference prompted discussions on important prevention issues such as; preventative vaccines (e.g., influenza, hepatitis B), HIV and hepatitis co-infections, tuberculosis, and mother-to-child transmission on the health outcomes of people living with HIV/AIDS.

The sole goal of positive prevention should not be only to prevent the spread of HIV, but to prevent further individual disease progression and optimize health and quality of life. For some HIV-positive persons the reality of struggling with poverty, caring for their families, living with the threat of violence, or contending with mental health concerns, substance abuse, or other health problems are so compelling on a daily basis that health care adherence and HIV transmission prevention are not primary concerns. Notwithstanding, the move towards developing prevention and risk reduction strategies as well as programs for maintaining optimal health for PLWHIV/AIDS has come primarily from the HIV positive community itself. It is an acknowledgment that the traditional prevention response to HIV/AIDS has lost some of its ongoing effect.

⁴ Ronald O. Valdiserri, Deputy Director of the United States Centers for Disease Control's (CDC) National Center for HIV, STD, and TB Prevention

The inability to accept sexual activity and sexuality as healthy, natural, and normal and to devise strategies that deal with this concept is having a negative impact on HIV incidence. It is surmised that improved health due to effective treatment options contributes to others being less fearful of contracting the virus.

“Risky behavior by positive people is not the norm. Most take extraordinary steps to make sure that they are not infecting others, and are doing so without a whole lot of support. There aren’t big campaigns supporting staying safe in relationships. We’re doing it of our own accord.”⁵

From the beginning of the epidemic, AIDS service organizations and health care authorities used a two tiered method of response to HIV/AIDS by looking to provide prevention strategies for the population not living with HIV and health care and support services for those who are, with little common ground. Pure common sense dictates that the basic needs of PLWHIV/AIDS must be met before one can concentrate on prevention measures but present prevention campaigns have too often failed to address the unique needs of PLWHIV/AIDS or acknowledge their significant efforts to avoid infecting others. A lack of empirical data comparing programs that combine help with basic needs and HIV prevention with those only addressing HIV prevention does not preclude the consensus that AIDS service organizations as well as funders should continue to provide ongoing services which help to stabilize PLWHIV/AIDS in addition to addressing behavioural change related to HIV prevention.

Failure to meet the basic needs of PLWHIV/AIDS leads to problems with risk reduction, treatment adherence and prevention. There has to be a shift in how interventions are viewed and delivered, to ensure that all barriers are addressed and the personal needs of PLWHIV/AIDS are met. Taking a multifaceted approach to prevention is critical in order to effectively respond to the needs of PLWHIV/AIDS and in turn further prevent the spread of HIV.

⁵ Terje Anderson, NAPWA

POSITIVE PREVENTION SECTION 2

EMPOWERMENT

Human rights and self-empowerment have been forefront in the minds of people living with HIV since the early years of the epidemic. In 1983, a national AIDS conference was held in Denver, USA where PLWHIV/AIDS formalized the “Denver Principles”. Included in these principles was a call to all HIV positive individuals to choose to be involved at all levels of decision making; to be included in all AIDS forums; to be responsible for their own sexual health; and to inform all their partners of their HIV status. The Denver Principles also claimed the right of PLWHIV/AIDS to a full and satisfying sexual and emotional life.

Three years later in 1986, the Ottawa Charter for Health Promotion reiterated the crucial importance of empowerment of communities when attempting to improve public health for all.

*“Health promotion works through concrete and effective community action in setting priorities, making decisions, planning strategies, and implementing them to achieve better health... At the heart of this process is the empowerment of communities – ownership and control of their own endeavors and destinies.”*⁶

In 1994 at the Paris AIDS Summit 42 nations signed on and committed themselves to what is now known as the GIPA Principle, the Greater Involvement of People living with HIV/AIDS. This principle acknowledges the central role of people living with HIV in the areas of prevention, education, care and support by calling on positive people to take on a greater role in the design and implementation of national and international policies and programs. Emerging from these three is a link between protecting human rights and promoting public health with an understanding that people living with HIV possess the knowledge and expertise necessary in an effective response to the epidemic.

The enormous and profound impact of the past 25 years of people living with HIV speaking out, challenging the myths and misconceptions about HIV/AIDS and becoming involved in policies and programs cannot be ignored. This involvement of PLWHIV/AIDS in the response to the epidemic has helped build the morale of positive people. Article 1 of the Paris Declaration states that:

“The success of our national, regional and global programmers to confront HIV/AIDS effectively requires the 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... By ensuring their full involvement in our

⁶ Ottawa Charter for Health Promotion

First International Conference on Health Promotion

Ottawa, 21 November 1986 - WHO/HPR/HEP/95.1

*common response to HIV/AIDS at all - national, regional and global - levels, this initiative will, in particular, stimulate the creation of supportive political, legal and social environments.”*⁷

HIV prevention has experienced a move towards community approaches seeking to 'empower' PLWHIV/AIDS by maximizing their leadership and participation in the implementation of health promotional programmes. (Zodwa Mzaidume et al.2000)⁸ . HIV-positive people can take control over their sexual health if they feel that they are empowered enough to control other aspects of their lives. The exchange of information from those living with HIV to those who are not, and providing community members the opportunity to exercise leadership roles in community initiatives ensures a sense of empowerment by participation. The basic understanding that forms the GIPA principle can be simply put as: Those who are not living with HIV/AIDS can never be fully understanding of the challenges experienced by those who are HIV-positive.

With access to care and treatment becoming more readily available people living with HIV are regaining their health, living longer, and planning for their futures. Decisions pertaining to sex, sexuality and the possibility of starting or expanding families, express the claim to human rights and form one of the major tenants of the Denver Principle.

However, PLWHIV/AIDS need access to the highest attainable standard of sexual health, including access to sexual health care services. Those living with HIV should be able to seek and receive information related to sex and sexuality that allows them to pursue a satisfying, safe and pleasurable sexual life for, contrary to popular opinion, it is possible for HIV-positive people to have a sexual life. Just as those who are HIV-negative, people living with HIV have the right to decide freely and responsibly on all aspects of their sexuality, including protecting and promoting their sexual health, be free from discrimination, coercion or violence in their sexual lives and in all sexual decisions, expect and demand equality, full consent, mutual respect and shared responsibility in sexual relationships.⁹

189 countries at the United Nations (UN) General Assembly Special Session on HIV/AIDS in 2001 committed themselves to ensuring that people living with HIV and AIDS experience "the full enjoyment of all human rights and fundamental freedoms." ¹⁰ This statement was reaffirmed at the

⁷ Paris AIDS Summit - 1 December 1994
<http://www.ecpp.co.uk/parisdeclaration.htm>

⁸Empowerment through participation?
Community-led HIV prevention by southern African sex workers
Zodwa Mzaidume et al. 2000 <http://hcc.med.vu.nl/artikelen/mzaidume.htm>

⁹ *In Brief: Meeting the Sexual and Reproductive Health Needs of People Living with HIV*
Heather Boonstra, Guttmacher Institute, 11/2006

¹⁰ Declaration of Commitment on HIV/AIDS

UN General Assembly High Level Meeting on AIDS in 2006. If the ability to express one's self sexually is a basic human right of HIV-positive people then logically HIV prevention efforts must address the sexual and reproductive health needs of people living with HIV. There exists then the obligation to devise laws, policies and programs that create safe and secure environments protecting the rights of HIV-positive individuals to make free and responsible choices for their sexual and reproductive health. People living with HIV must be able to make informed decisions about their sexual and reproductive health and have access to appropriate services as well as input in designing policies and programs to address the sexual and reproductive health needs and in the decisions about how and which services should be made available. This will ensure that programs fully endorse the human right of HIV-positive men and women to pursue a safe and satisfying sex life while also making sure that HIV-negative people share in that responsibility. It will also help to entrench the right of people living with HIV to informed decisions on whether and when to have children. If such human rights were paramount in the global responses to HIV/AIDS, vulnerability to HIV infection would be reduced and people living with HIV/AIDS would be able to live a life anchored in concepts of human rights and dignity.¹¹

Empowerment and strengthened social and family networks are brought about through education and health promotion. The creation of supportive environments with peers and family networks, community involvement in planning and managing health initiatives that incorporate socially and culturally appropriate communication and negotiation skills with respect to sexual health also play a pivotal role. Self-esteem and self-efficacy; laws prohibiting discrimination on the basis of sex, race and sexual orientation, equitable health care and resources for diagnosis and treatment and the social determinants of health all affect and contribute to the vulnerabilities related to STI and HIV transmission.

Historically, health in Canada has been approached from a purely medical care and treatment perspective. Thankfully there has over the past few years been a shift towards a much fuller appreciation of how social and economic factors influence the health of individuals and communities. In 1994, federal, provincial and territorial Ministers of Health officially endorsed the population health concept in a major discussion paper, *Strategies for Population Health: Investing in the Health of Canadians*. This was followed by two major reports measuring the health status of Canadians (1996 and 1999), a position paper *Taking Action on Population Health* (1998) and *The Population Health Template: A Framework to Define and Implement a Population Health Approach* (2001). The population health approach emphasizes those social determinants that influence individual and community health. The list of determinants is broad and comprehensive, and can be summarized as follows:

"Global Crisis — Global Action" <http://www.un.org/ga/aids/coverage/FinalDeclarationHIVAIDS.html>

¹¹ *In Brief: Meeting the Sexual and Reproductive Health Needs of People Living with HIV*
Heather Boonstra, Gutmacher Institute, 11/2006

- *income and the economic environment* for example employment, education, absolute and, more importantly, relative poverty;
- *the social environment and social status* for example social support networks, perceived control over one's life and exposure to discrimination;
- *the physical environment* for example homelessness, housing adequacy and neighbourhood safety;
- early childhood experiences for example education, nourishment and sexual, physical or emotional abuse;
- *cultural or community factors* including personal health and sexual practices, gender, race, community pressures and behaviors, biology and genetic endowment; and
- *health services* for example access to culturally and gender-appropriate services and equitable access to prevention, care, treatment and support services.¹²

There are many factors that influence health and well being. These factors draw a relationship between the social determinants of health and HIV/AIDS and are addressed by a population health model. Improving the social determinants that place people at risk of HIV infection leads to an overall improvement in the health and well-being of those already infected with HIV. This can lead to a reduction in the number of new HIV infections. The lived experience of PLWHIV/AIDS and those at risk for HIV infection has shown that there is a relationship between poor housing and poor health: acknowledging this relationship between social determinants and HIV risk forces us to look at HIV/AIDS as not just a health or moral issue but as issues of human rights and equity. A population health model has the capacity to understand that universal and equitable access to the services and supports is what is needed to help people to maintain a high standard of health and well being. The availability of these services and supports can decrease a person's vulnerability to HIV infection, the speed with which HIV infection will progress to AIDS and enhance a person's ability to manage and live with HIV/AIDS.

The shift to a population health model has promoted the idea of building healthy communities by engaging individuals and communities in becoming responsible for their own health and well being. However, despite this paradigm shift, prevention strategies remain more focused on changing personal behaviour and on encouraging people to adopt lifestyle practices that reduced the risk of infection. This style of prevention messaging has a tendency to blame the victim. Positive prevention on the other hand aims to increase the self-esteem and confidence of HIV positive individuals and to build their capacity to protect their health, to avoid new STIs, to delay HIV/AIDS disease progression, avoid re-infection, to prevent passing their infection on to others and to adopt a wellness lifestyle aimed at prolonging life. Positive prevention interventions with people with HIV

¹² HIV/ AIDS and Health Determinants: Lessons for Coordinating Policy and Action
 Catalogue No. H39-632/ 2002E ISBN 0-662-32560-52 Prepared by Martin Spigelman Research Associates

are deemed likely to have a greater impact on the epidemic, for an equivalent input of cost, time, and resources than primary prevention strategies focused on negative individuals. Because of this positive prevention needs to be encased in a framework that respects and upholds the rights and needs of people living with HIV developed in a supportive legal and policy environment. Positive prevention represents the most basic synergy between prevention, care, treatment, and support.

POSITIVE PREVENTION SECTION 3

TESTING AS PREVENTION

Of ever increasing popularity, especially from a public health perspective is the notion of testing as prevention. This is a strategy based on the assumption that knowing one's sero-status significantly promotes behavioural change, that HIV counselling and testing enables people with HIV to take steps to protect their own health and that of their partners, and helps people who test negative get the information they need to remain HIV-negative. The UNAIDS/WHO Policy Statement on HIV Testing suggests that without effective HIV prevention, there will be an ever increasing number of people who will require HIV treatment. Among the interventions which play a pivotal role both in treatment and in prevention, HIV testing and counselling stands out as paramount.¹³

Understanding that secondary prevention encompasses activities such as HIV testing (particularly offering HIV testing to those who present for STI testing); providing HIV prevention information and support to people already living with HIV; and assisting people who test positive for HIV to contact their sexual and/or needle-sharing partners. The benefits of testing and early diagnosis as a means of secondary prevention are numerous. However, embedded within the benefits of knowing one's sero-status at an early stage are a myriad of issues concerning stigma and discrimination and a less than optimum concept of shared responsibility with regards to HIV transmission. These issues boil down to a matter of trust – trust in confidentiality of information, trust that healthcare providers will not test without consent, and trust that partners are telling the truth about their status.

Since the advent of HIV Testing in 1985 there have been guiding principles with respect to the code of conduct in testing individuals for HIV. The three C's; confidentiality, consent, and counselling remain the bridge between public health strategies and human rights promotion in the debate on testing as a means of positive prevention. The UNAIDS/WHO policy states that such testing of individuals must be:

- **confidential**
- be accompanied by **counselling**
- only be conducted with informed **consent**, meaning that it is both informed and voluntary.

Client-initiated HIV testing to learn HIV status provided through voluntary counselling and testing, remains critical to the effectiveness of HIV prevention.¹⁴

¹³ UNAIDS/WHO Policy Statement on HIV Testing :
http://www.who.int/ethics/topics/en/hivtestingpolicy_who_unaids_en_2004.pdf

¹⁴ Ibid

To fully understand the diverse ramifications of HIV testing as a means of prevention one needs only to see how testing is viewed on a global scale. A prime example is seen when contrasting HIV testing goals between Britain where an HIV test is treated as a diagnostic tool, and where little emphasis is placed on the social, or preventive role of HIV testing and in Sweden where health authorities believe that "one of the most important strategies to stem the spread of HIV is to encourage the screening of all those who are at risk for transmission" because an individual who is aware of his or her diagnosis makes behavioral changes that lessen the risk of transmitting the infection further.¹⁵ This latter view paves the way for debate around the justification of promoting testing where the insistence on identifying HIV positive individuals at all costs reflects a desire to closely watch those with HIV, rather than prevent the spread of the illness. It also falls short of a philosophy of shared responsibility decreasing discrimination against people living with HIV, by seeming to blame them for the spread of the virus.¹⁶

*"The recent hype to treat HIV "infected persons" as pariahs that need to be contained is problematic for many reasons. In the context of positive prevention, the new public health approach is mainly interested in finding those living with HIV and making sure they "behave" so that the virus doesn't get transmitted."*¹⁷

Encouraging more widespread HIV testing is consistent with the traditional public health approach of case identification, treatment, and promotion of strategies to prevent further transmission; however one cannot ignore the effects of ever increasing cases of criminalization of HIV transmission and the supporting role HIV testing plays in criminalization. While little is known about the impacts of criminalizing HIV transmission, many are concerned that it may have a negative impact on the uptake of HIV testing and access to HIV prevention, treatment and care services.

The criminalization of HIV transmission is also a matter of concern in light of the need and trend to increase access to testing and to knowledge of status in order to achieve universal access to HIV

¹⁵ HIV testing and HIV prevention in Sweden
[British Medical Journal, Jan 24, 1998](#) by [Renee Danziger](#)

¹⁶ Ibid

¹⁷ Positive Prevention: "Opportunity or Threat" by Kevin Moody
http://www.healthdev.org/eforums/Editor/assets/accelerating-prevention/Positive%20Prevention%20FINAL_Key_paper_KevinMoody.pdf

prevention, treatment and care and support. People might decline an offer for HIV testing in health settings, be less inclined to seek the services of VCT clinics, and/or be less inclined to discuss their HIV status with sexual and drug-injecting partners - if they fear application of the criminal law.¹⁸

As well, the threat or potential threat of criminal prosecution may cause some people living with HIV to withhold notification and simply make further personal attempts to protect partners without feeling the necessity to disclose their status. Criminalization does not decrease transmissibility of HIV, nor does it necessarily affect a change in behaviours in the same way that knowing the smashing of a window is against the law does not necessarily reduce the number of people who smash windows.

However there are aspects to testing that must be considered as adding to a positive prevention framework. A person aware of their sero-status can then access treatments to decrease viral load making transmission potentially less likely, and can improve their overall health. In a tertiary prevention model, access to treatments, counselling and other support services can assist the person to make healthier choices about their life and their behaviours.

Testing can also assist the person to avoid disease and illness that can complicate HIV. Vaccination against flu, pneumonias, hepatitis A and B and prophylaxis against opportunistic infections may improve the health of the individual.

But when a person receives a positive test result there are a host of issues including how and who to tell about the test results, shame, depression, managing illness, managing work, anger, denial, the fear of others' reactions, increased use of alcohol and/or other substances as self-medication, and so on.

*Negative consequences that may result from people discovering their positive HIV status include psychological disturbance, rejection, stigmatization, and social as well as financial discrimination. Women living with HIV in some settings are at increased risk of domestic violence.[39] Most of the adverse effects of testing result from stigmatization and discrimination, and strong measures to combat these must accompany efforts to normalize HIV/AIDS.*¹⁹

Testing without the concomitant aspects of counselling and referral to relevant support services does not assist the person in dealing with HIV, or how their life might change after the revelation of the test result. HIV is unlike other illness in that it involves stigma specific to the virus, its route of transmission and its outcome: sex and sexual behaviour, drugs and death. Even some 25 years into the pandemic, many continue to view HIV from a moralistic point of view and in a public health

¹⁸ Criminalization of HIV transmission UNAIDS Reference Group on HIV and Human Rights Seventh meeting | 12-14 February 2007

http://data.unaids.org/pub/BaseDocument/2006/070216_HHR_3_Criminalization.pdf

¹⁹ From exceptionalism to normalization: a reappraisal of attitudes and practice around HIV testing British Medical Journal, Jan 24, 1998 by Kevin M. De Cock, Anne M. Johnson

model, little attention is paid to the greater concerns of stigma and discrimination and how these affect the life of the individual. Hence secondary and tertiary prevention campaigns, coupled with targeted public messages designed to alleviate stigma and discrimination and normalization of people living with HIV/AIDS are essential.

If the current trend continues, positive prevention will be seen solely as a mechanism to keep the virus contained within the vessels that carry them. People living with HIV, then will become persons represented by numbers on an epidemiologist's PowerPoint presentation.²⁰

People living with HIV/AIDS also require individualized health promotion strategies. What works for some people will not work for others. What works in one community will not necessarily work in all communities. Developing health promotion strategies from the point of testing through disease progression involves examining the person as a whole and creating supports for personal change: not only in sexual or drug using behaviours, but in the maintenance of physical, mental, emotional and spiritual health. Current practice in testing in Canada rarely includes the intensive support required to achieve the best outcomes for the individual. Building skills in communication, self-preservation, self-esteem and motivation to create and sustain positive alternatives takes time, patience and understanding. Simply providing test results with limited post-test counselling and very little follow-up, while expecting change to take place is an ill-conceived notion.

Testing in and of itself serves only one purpose: to identify those who have tested positive. As a means of prevention, testing is a tool but without significant post-test counselling and ongoing support for the individual tested it is inadequate especially when compared against the population health model and the determinants of health.

²⁰ Positive Prevention: Opportunity or Threat. Kevin Moody
http://www.healthdev.org/eforums/Editor/assets/accelerating-prevention/Positive%20Prevention%20FINAL_Key_paper_KevinMoody.pdf

POSITIVE PREVENTION SECTION 4

LANGUAGE & PREVENTION

Since the beginning of the HIV pandemic over 25 years ago there have been sub-cultural shifts within the population of people living with HIV/AIDS. In the early years of AIDS, people with HIV did not generally live longer than two years after diagnosis. With no treatments, or with AZT mono-therapy, most people living with AIDS were considerably more susceptible to opportunistic infections, succumbing to these at high rates.

However, since those early days and with the advent of more effective treatments, life spans have increased and people who were literally days from dying experienced sudden turnarounds in their health. This has meant a shift in thinking for both the medical community and people living with HIV/AIDS. Along with a lengthened life span and, for some, an improved quality of life, are considerations with respect to personal sexual and drug using choices.

Increased longevity has on the one hand created a more experienced and articulate group of people living with HIV/AIDS, but it has alternately meant the need for increased vigilance in the prevention of HIV transmission and improved health management. For people living with HIV/AIDS, the benefits of treatment have assisted in allowing the individual to consider returning to work, entering long term relationships, healthy sexual relationships, and the need to find community and belonging. Part of that sense of belonging includes how PLWHIV/AIDS perceive themselves within a community and how they describe the elements of the community in which they participate.

Language shapes the way in which one participates in the world and the way one perceives oneself in the world. Technology has provided a new set of terms as well as slang terminology. For example, computers and the Internet, text messaging and other forms of communication have shifted our culture. “Texting” has replaced “text messaging”; “Sexting” is a term used to describe the sending of sexually provocative messages; “Crackberry” refers to the Blackberry and its potentially “addictive” qualities; “snail mail” refers to standard postal service and its slowness in contrast to the immediacy of email. But language and cultural shifts are not restricted to the computer age: people have developed new language and words throughout time as new experiences and inventions arise and are succeeded by yet other new experiences and inventions.

These language shifts are also found in the AIDS movement. New language has emerged through the advancement of both the community-based and medical communities. As treatments progressed the lexicon grew and evolved: “viral load”, “CD4”, “protease inhibitors”, “fusion therapy”, “microbicides” and other words have changed how people living with HIV/AIDS talk about the virus and the medications that affect their lives. In the community-based movement language, terms and acronyms have also evolved: “MSM”, “IDU”, “sero-status”, sero-sorting”, “sero-discordant” all

language that has changed the way in which people living with HIV/AIDS define not only conditions, but relationships as well. Even the term “Positive Prevention” changes the way in which prevention is perceived; there is no adjunctive term “negative prevention.”

With all new shifts in language come psychological shifts as well. In the early days, people with AIDS did not generally differentiate their relationships with terminology. With new words, new delineations arose. Now, when a person with HIV is in relationship with a person who is HIV-negative, their relationship is termed “sero-discordant.” People with HIV who choose to have sexual relationships only with others who are HIV-positive are described as “sero-sorting”. HIV-negative people may also choose only to have sexual relationships with other HIV-negative people; again, they are sero-sorting, although the jargon does not hold the same social significance for people who are HIV-negative.

Jargon, the professional language of a group, may impact positive prevention strategies, in that it separates “them” from “us”. The new terminology can in fact widen the gap between those who are positive and those who are negative. Even between people who are HIV-positive new terms and language can cause division.

“Jargon – the specialized language of a group of people – has its place in the workplace. It can provide useful shorthand to get across specific meaning quickly.

But jargon becomes a problem when it stops people understanding your message. When you start using jargon (perhaps unintentionally) with audiences it is not intended for, people will find you very difficult to understand.

Even within the group the jargon's meant for, meanings evolve and newcomers misunderstand. And soon jargon can create barriers within groups too.’²¹

Language that is not accessible or understood across groups of people separates those that know from those that do not. The term “HIV community” may also create separation. It implies that people with HIV are somehow not integrated into society as a whole. In truth people living with HIV/AIDS are as much a part of every other community as people who are HIV-negative. However, the distinction of a special “community” of people living with HIV/AIDS may psychologically separate the HIV-positive person from the rest of his or her “home” community or subculture. The stigma and marginalization experienced by HIV-positive people is even more deeply internalized where the words used indicate differences rather than similarities.

As specialized terms become normalized, self-identification with the terms can occur and can be potentially hazardous. For example, where HIV-positive people learn the term “sero-sorting” there may increased risk of super-infection or co-infection: people living with HIV/AIDS who choose to engage in sex solely with others who have HIV, may decide that condom use is not an issue because

²¹ <http://www.mindtools.com/CommSkll/JargonBusting.htm>

their sexual partner is positive as well. This way of thinking can prompt risk behaviours that allow for the transmission of drug-resistant strains of HIV, other STI and opportunistic infections, compromising the health of the individual. The same holds true for people who use injection drugs and sero-sort, sharing needles and other equipment may not seem necessary as both people sharing are HIV-positive.

Positive prevention as a multifaceted campaign that incorporates the psychosocial health of the individual as well as the public health need to stem the spread of HIV should strive to be inclusive of the diverse populations of people living with HIV/AIDS. There is diversity in the populations of gay men, straight men, MSM, women, people who use injection drugs, youth, Aboriginal people, immigrants and all must be a part of the process of developing prevention messages that resonate not only with people with HIV and people from different cultures and subcultures, but with those who are not infected as well. Language and terminology must be clear and easily understood by all those participating and must be culturally relevant. A lack of consensus of a definition of positive prevention was a common theme during focus groups held by GNP+/RMP+ in 2008²². This lack of understanding and consensus creates barriers to developing effective messaging and prevention campaigns.

Another common theme emerging from focus groups held in North America by GNP+, the Global Network of People Living With HIV/AIDS, was that HIV prevention initiatives are the responsibility of everyone: prevention campaigns cannot be conducted in an HIV vacuum. People with HIV should be included in all areas of prevention including policy development²³, however HIV-negative people must also share responsibility for messaging that resonates with them.

The fear of stigma associated with HIV also played a role in the discussions at the GNP+ focus groups; that is, positive prevention from a purely public health framework may create environments where people with HIV are further stigmatized²⁴ in that primary prevention is aimed at preventing HIV-positive people from infecting HIV-negative people. HIV-positive people are viewed as the vectors of disease rather than partners in an overall prevention strategy.

Why identify people who are living with HIV if they are not given the treatment needed to stay alive? Another mitigating factor that affects everyone who tests positive for HIV is the increasing criminalization of HIV transmission. More and more, people who know that they are HIV-positive are criminalized for “exposure”; “bodily harm” or “transmission”, after engaging in a normal human activity – sex.²⁵

²² GNP+/RMP+ Focus Group Summary Report 2008

²³ *ibid*

²⁴ *ibid*

²⁵ Positive Prevention: Opportunity or Threat. Kevin Moody

http://www.healthdev.org/eforums/Editor/assets/accelerating-prevention/Positive%20Prevention%20FINAL_Key_paper_KevinMoody.pdf

Internalized stigmatization and shame can be as personally impacting as external stigma. Personal narratives can be debilitating when they are focused solely on the negative aspects of living with HIV rather than the positive aspects of improving overall health and living full and satisfying lives. Consideration must be paid to the potential for increased stigma and discrimination, both external and internalized, as prevention initiatives are developed and implemented and measures should be taken to address these concerns.

With the advent of rapid testing, there is increased need to ensure that newly diagnosed persons are aware of the risks, not only of spreading HIV, but of contracting other STI and infections that can affect their overall health. Attention must also be paid to the mental health of newly diagnosed persons: the risk for depression and suicidal ideation may be greater for a newly diagnosed person than for a person who has been living with HIV for a number of years with some level of improved health. The fear of social segregation accompanied by the fear of illness, disability and death may affect a person for several years after diagnosis. Secondary and tertiary positive prevention campaigns must include aspects that take these realities into consideration.

Another consideration in developing effective prevention campaigns is the importance of understanding and communicating the variables in HIV transmission and prevention. A person with an undetectable viral load may be less able to transmit the virus than a person with a detectable or median viral load although this is still controversial²⁶. There is also a difference in the amount of free virus found in plasma than that which is found in seminal or vaginal fluid. Other factors such as mucosal integrity, age, gender, strain of virus and more affect one's understanding of HIV disease and its complexities. Where the information about these complexities is not clear and easily comprehended people living with HIV/AIDS may be at risk for compromising their personal decisions: a little knowledge is a dangerous thing.

A person with HIV has grounding in the basic facts of HIV, including modes of transmission, levels of possible infectivity and personal impact. Here there is more likely to be a shift in personal behaviours and choices. Where the person lacks that knowledge there may be a higher risk of transmission of HIV and contracting of other STI through simple ignorance. This knowledge base is most effectively shared between people living with HIV/AIDS through peer to peer support and education.²⁷

Medical care and treatment of HIV has, in some instances, created a culture where test results are often given more weight than the personal impact of HIV infection experienced by the individual. In a medical model, HIV is simply a virus that must be stopped, or when contracted to be treated with medication. However, to effectively reach the goal of primary prevention, the secondary and

²⁶ Blood viral load predicts HIV transmission better than semen viral load in small study among MSM. David McLay <http://www.aidsmap.com/en/news/9FB2F33E-A7E4-4033-8933-C39BE61F17E8.asp> August 2008

²⁷ GNP+/RMP+ Focus Group Summary Report 2008

tertiary aspects of positive prevention are crucial to engaging people within the HIV community and its various sub-cultures. Secondary and tertiary efforts are geared toward improved health and well being and as part of an overall prevention strategy they enhance primary efforts to slow the spread of HIV.

The media employed to disseminate messages is as important as the messages themselves. It has been suggested that while there are many barriers to prevention including gender, stigma, age, discrimination, employment, poverty, etc. there are many activities that can assist in promoting positive prevention and health promotion. These activities include: peer-based outreach, discussion groups, sexual health workshops, social groups, workshops for newly diagnosed persons and more.²⁸ Use of available technologies including social networking, social marketing campaigns and simple one-to-one conversation can assist prevention efforts and increase connection between people at risk as well as those living with HIV.

It is clear that without an informed and empowered population of people living with HIV, who are part of all processes and policy development, positive prevention and all that it entails will only have a marginal effect on stopping the transmission of HIV. The greater need remains: to educate people who are HIV-negative to remain HIV negative.

To conclude that positive prevention is the sole responsibility of people living with HIV consigns an individual's decisions and personal responsibility to another. The Living 2008 Statement on positive prevention (PP) reads,

For PP measures to be successful, it will require buy-in from the PLHIV community, peer support, and opportunities for PLHIV involvement in the design and implementation of PP initiatives as well as a coordinated communication mechanism to ensure an informed and knowledgeable PLHIV community. What is crucial in this, is that PP needs to be based on a culture of shared responsibility, which means that the responsibility for avoiding HIV transmission is not only placed on the person living with HIV but on both partners and that there is an environment of open communication and equality in relationships (“we are all responsible for prevention”). The focus of PP should be on people’s well-being as a whole and not on “HIV positive versus HIV negative”; and that PP needs to be an empowering concept, not one associated with blame or shame.²⁹

Where a community of affected people can develop meaningful and engaging messages, terms that describe behaviour without defining the individual, and shared understanding of common experience there is an increased opportunity for successful positive prevention campaigns to emerge. The language chosen to explore, explain and define positive prevention can assist in the development of concepts that positively reinforce the goals prevention seeks to attain.

²⁸ http://www.bcpwa.org/articles/prevention_activites_map.pdf

²⁹ Statement on Positive Prevention. The Positive Leadership Summit 2008

POSITIVE PREVENTION SECTION 5

OPPORTUNITIES & CHALLENGES FOR PLWHIV/AIDS

Since the early days of the pandemic, the full involvement of people living with HIV/AIDS in the shaping of positive prevention strategies either on a local or pan-Canadian level is crucial to their success. There are many opportunities as well as significant challenges for people living with HIV/AIDS in the development of initiatives that address all three levels of positive prevention.

Levels of expertise among people living with HIV/ AIDS vary between groups and across Canada. However, there is room for all people living with HIV/ AIDS to contribute to the process of building a positive prevention strategy. Whether a person is involved in brainstorming or being involved in a focus group regarding issues specific to their community (e.g. IDU, gay men, First Nations, women, etc) or in actually crafting activities and campaigns that address all three arms of positive prevention, each person should be encouraged to contribute to their interest and ability.

The challenges faced by people living with HIV/AIDS being fully engaged in positive prevention are considerable. As previously discussed, people with HIV are responsible to disclose their status to sexual and/or drug using partners. However, this can potentially increase the risk of further stigmatization and discrimination through social isolation and even physical violence. On a continuum of safer sex/drug use practices there are activities that do not pose the risk of transmission of HIV. The question arises then, that if a person *only* practices activities that do not transmit the virus, is that person still responsible to disclose? If a person who injects drugs refuses to share any equipment with a partner does that person need to disclose? Is disclosure required in all instances or only during instances where there may be risk of transmission?

In primary prevention strategies the answer would be yes. The person with HIV is always responsible to disclose status, but regardless of this view unsafe sexual or drug using activities might still occur where both parties accept the risk involved. Primary prevention is pragmatic in its approach to behaviours. Nonetheless, many people dealing with addictions will continue their drug use after diagnosis and most people living with HIV/AIDS continue being sexually active after diagnosis.

Over 70% of people with HIV continue to be sexually active after they learn that they are infected (Office of AIDS, 2003). Although many engage in safer-sex practices, empirical evidence suggests that some people with HIV continue to have risky sex (Collins, Morin, Shriver, & Coates, 2000; De Cock, Mbori-Ngacha, & Marum, 2002; King-Spooner, 1999; Remien, Senterfitt, & Decarlo, 2000).³⁰

³⁰ Glaxo Smith Kline website. <http://www.apositivelife.com/forasos/positive-prevention-target-populations.html>

The challenge for positive prevention initiatives are to acknowledge the realities of life after diagnosis, support the individual in health promotion and health maintenance, recognize and support the sexual and reproductive health rights of the individual and provide enough information from a public health perspective to prevent further transmission.

In secondary prevention efforts, the goal is “to identify and minimize risk behaviours or environments and decrease any further advancement of the virus.”³¹ Both those who are HIV-negative and people who are HIV-positive are encouraged to change behaviours and minimize risk in their personal lives. Part of this strategy may include targeted messaging to reach specific groups (e.g. MSM, IDU), as well as more generic messaging to reduce stigma and discrimination against people living with HIV/AIDS and to promote the personal responsibility of everyone to make informed decisions about their sexual and/or drug using choices.

Regardless of the behaviour changes made by people living with HIV/AIDS, stigma and discrimination remain a reality for this population.

“... HIV-related stigma and discrimination are pervasive at the national and local levels. Judgmental attitudes toward people living with HIV/AIDS persist, making it difficult for people with HIV to disclose their status for fear of hostility or discrimination and of negatively affecting the quality of care they receive. Far too often, health care professionals have refused to care for HIV patients, disclosed clients’ HIV status without consent, provided highly directive counselling on contraceptive methods and pressured women to undergo abortion or sterilization.”³²

These sentiments are echoed within the GIPA principles:

“Ensure psycho-social support for persons living with HIV who, in revealing their status, may experience discrimination against themselves or their dependants.”³³

It’s clear that whatever prevention efforts are developed there must not only be the recognition of potential threat to people living with HIV/AIDS, but also concrete measures to ensure that the threat is reduced. This can be accomplished through campaigns that strive to reduce stigma and discrimination as well as actions that bolster the self-esteem and confidence of people living with HIV/AIDS.

Tertiary prevention efforts are intended to reduce the negative/challenging effects of the illness and maximize quality of life.³⁴ Under this arm of positive prevention, concern remains for the transmission of HIV, but more attention is paid to the individual and his/her lifestyle choices; these

³¹ BCPWA website. http://www.bcpwa.org/section.php?section=empower_yourself&page=positive_prevention

³² Meeting the Sexual and Reproductive Health Needs Of People living with HIV/AIDS. Heather Boonstra, Guttmacher Institute http://www.guttmacher.org/pubs/IB_HIV.pdf

³³ UNAIDS Policy Brief March 2007. http://data.unaids.org/pub/Report/2007/JC1299-PolicyBrief-GIPA_en.pdf

³⁴ BCPWA website. http://www.bcpwa.org/section.php?section=empower_yourself&page=positive_prevention

include physical, emotional, mental and spiritual health and well-being. When a person feels empowered to take control over all aspects of their life they may be more likely to make positive and informed decisions about sexual activities or drug use.

“Positive prevention involves helping people living with HIV/AIDS to protect their sexual and physical health, to avoid new sexually transmitted infections, to delay HIV disease progression and to avoid transmitting HIV. For some, MIPA—the meaningful involvement of people living with HIV/AIDS—is a preferred term to GIPA because of the fact that people living with HIV/AIDS are active and equal agents of change, not passive recipients of services.”³⁵

What is meaningful involvement is determined by the individual. Whether or not a person’s skills and interests are best suited in contributing to the development of positive prevention initiatives is ultimately the decision of the individual. For some, hanging posters or distributing pamphlets can be as meaningful as participating in policy development and working on social marketing campaigns. There is a wide range of possibilities for people living with HIV/AIDS to become active participants in positive prevention; however there may be barriers within an organization’s culture that make it difficult for people living with HIV/AIDS to fully and meaningfully participate. Shifting the paradigm from service consumers to program creators may not be an easy task.

Through the years people living with HIV/AIDS have played key roles in the movement, however there has been a move toward professionalism/institutionalization that has in some instances created environments where people living with HIV/AIDS are viewed simply as service recipients. Programs are delivered through paid staff people who are professionally educated; and while volunteer positions are available for PLWHIV/AIDS the opportunities for greater involvement in an organization may be limited. Many boards of directors have seats designated specifically for people living with HIV/AIDS, but the skill sets required for board work may be beyond the capacity of the some, and many people living with HIV/AIDS are not necessarily interested in participating on boards. Training and orientation are generally available, but may not be sufficient to fully engage HIV-positive people in all aspects of organizational development or the development of positive prevention initiatives.

The development of positive prevention initiatives cannot be seen as the sole responsibility of HIV-positive people. HIV-negative people also have a role to play and are essential in establishing messages and media that reach that group.

Developing prevention programs for, and inclusive of, HIV-positive people must not become an excuse for shifting all responsibility for prevention (or blame for new infections) onto the shoulders of people with HIV.

³⁵ UNAIDS Policy Brief March 2007. http://data.unaids.org/pub/Report/2007/JC1299-PolicyBrief-GIPA_en.pdf

A culture of shared responsibility that encourages communication and equality in relationships should be a goal of HIV prevention programming.³⁶

Increasing the capacity of people living with HIV/AIDS to take leadership and development roles in positive prevention is essential to fully engage a wide range of participants. However, as mentioned previously it must be recognized that the level of involvement in prevention initiatives is the decision of the individual and capacity building should be designed to meet both the needs of the person as well as the prevention measures themselves.

The key to all successful prevention efforts, whether primary, secondary or tertiary lies with accessible information. People with sufficient information may make better decisions than those with inadequate, partial or incorrect information. The most effective information is that which is easy to understand and which is relevant to the individual. Broad moral statements, complex medical dissertations and possibly even sexually explicit messages will not necessarily resonate with a particular person or group of people. As each person is unique, so too are communities and the sub-cultures within those communities. Knowledge translation and transfer of clear, balanced, and relevant information is essential to reducing the barriers experienced by people living with HIV/AIDS in accessing prevention and health promotion messaging. When people who are the target audiences for the receipt of information are encouraged to participate in the creation of the messaging, there is greater chance for the information to be consistent, relevant and applicable.

By involving people living with HIV/AIDS to their level of skill, interest and ability positive prevention initiatives can incorporate the broadest knowledge base possible and meet the goals of primary, secondary and tertiary prevention.

³⁶ Poz Prevention. Toronto Persons With AIDS Foundation. 2008

POSITIVE PREVENTION SECTION 6

STRATEGIES FOR ORGANIZATIONAL POSITIVE PREVENTION PROGRAMMING

The development of any programming aimed at primary, secondary and tertiary positive prevention initiatives requires intentional adherence to the GIPA principles. While the expertise of staff people and researchers is valuable, without the direct involvement of HIV-positive people from diverse backgrounds the development of programming may not reflect the daily reality experienced by people living with HIV/AIDS.

To date, positive prevention discussions have often not included positive people, which has created two problems:

- 1. An overemphasis on HIV testing rather than on the needs of people who already know their status; and*
- 2. A focus on preventing HIV transmission rather than on preventive health services for people living with HIV/AIDS.³⁷*

The development of positive prevention programs will vary across Canada. A pan-Canadian strategy can guide communities, but diversity and available resources will ultimately shape any programming. Initiatives that work in large urban centres may not work in rural and remote communities; programs targeted toward gay men may not be transferrable to programs targeted toward women; and so on.

Responses from the GNP+ focus groups showed that there are different understandings and misunderstandings about what positive prevention is. Many understood the standards of primary prevention efforts and did not consider secondary and tertiary initiatives as part of an overall prevention strategy. There are also differences between groups of people about how to define positive prevention. Some organizations have developed positive prevention strategies to include a wide audience, while others have different strategies for the different arms of positive prevention.

“In Ontario, the Poz Prevention Working Group has defined the term “poz prevention” for gay men living with HIV. In other contexts, HIV prevention initiatives for HIV-positive people are referred to as “prevention for positives,” “prevention with positives” or “positive prevention,” and include all people living with HIV/AIDS.”³⁸

³⁷ GNP+ Positive Prevention by and for people living with HIV/AIDS. 2009

³⁸ Poz Prevention knowledge and practice guidance for providing sexual health services to gay men living with HIV in Ontario. Toronto PWA Foundation 2008

Consequently, the different interpretations and terminology used in developing programming may best be created by the people concerned with the program itself: people living with HIV/AIDS from various backgrounds and with different needs. In this way organizations can be responsive to cultural sensibilities or sensitivities within their communities. However, there needs to be a consensus of positive prevention definitions in order to avoid misinterpretation, partial information or lack of attention to any one of the three levels of positive prevention.

Internally, organizations can benefit from a standard process when developing positive prevention programming. In both the Toronto and the BCPWA models, working groups and committees assist in program development and evolution: BCPWA employs a standing committee that meets monthly to assess new ideas and pose potentials for program initiatives.

Assessing gaps and need will also direct where best to initiate positive prevention programming. Organizations should be free to develop programming particular to their community or culture and aim initiatives where there are gaps, higher rates of HIV among specific populations, accelerated disease progression or other concomitant issues (poverty, mental illness, etc). While some organizations have focused primarily on initiatives that target gay men, others have focused on the newly diagnosed as a group lacking connection with services and programs. These priorities were identified through environmental scans prior to program development. Other communities may identify specific groups and sub-groups where need for prevention initiatives are greatest; a rural communities approach to positive prevention will look much different than an urban setting approach.

Developing a national framework must incorporate common terms, goals and objectives that can be widely understood and accepted by the majority of people living with HIV/AIDS and organizations. From a national perspective both French and English terminology would best accommodate clearly articulated definitions and the broadest possible interpretations of positive prevention and include all three arms: primary, secondary and tertiary as part of any programming recommendations.

Strategically, organizations should develop a series of activities and roles that include people living with HIV/AIDS in all aspects of planning, policy development, activities, implementation and evaluation. Some of these strategic activities might include, but are not restricted to:

- Working groups to develop the overall definitions for positive prevention messages and process
- Focus groups to vet the potential activities, and definitions for relevance to people living with HIV/AIDS
- Targeted message development groups to develop messages that resonate with specific target populations
- Discussion groups that are participatory action groups to explore how positive prevention can be implemented

- Policy advisors to advise the organization's board regarding potential policies and their implementation as it relates to positive prevention on all three levels
- Activity leadership groups to educate and support participants in leading activities that engage people in positive prevention planning and implementation
- Education/Seminar leadership groups to educate and support people living with HIV/AIDS to help provide knowledge exchange for positive prevention

For all initiatives, GIPA principles must be applied to fully and meaningfully involve people living with HIV/AIDS in all aspects of program development and delivery.

Setting standards for a national strategy will be difficult, as the variety of experience and need across the country, as well as variables in resources, will affect the ability of organizations to perform well where standards are based on resource rich areas. This does not mean that standards are not necessary; setting simple, attainable standards in terms of a national positive prevention strategy are crucial to ensuring the best possible services and programs are available to people living with HIV/AIDS.

Possible standards might include:

1. All positive prevention programs must adhere to the GIPA principles.
2. People living with HIV/AIDS are to be involved in all aspects of program development.
3. Wherever possible, people living with HIV/AIDS should be involved in program delivery.
4. Committees and working groups must have a majority of people living with HIV/AIDS as participants.
5. Positive prevention programs must address all three levels of prevention: primary, secondary and tertiary.
6. Positive prevention programs should be holistic in nature encompassing the mental, physical, emotional and spiritual aspects of the individual.

In any case, while no specific national positive prevention strategy exists, local organizations should strive to include both long-term survivors (the holders of corporate memory) and more recently diagnosed (those with immediate memory), to help ensure planning and delivery of programming that is most meaningful in their home community.

As advancements are made in the field of positive prevention, models of best practice will emerge and these will assist in shaping local, regional and national understanding of the ways in which positive prevention can be an effective tool, not only to reduce new infections, but also to ensure that people living with HIV/AIDS are knowledgeable about ways to maintain their health and quality of life. Organizations, as part of this process, will play a crucial role in defining and evaluating positive prevention initiatives and creating innovative ways to promote positive prevention not only as a means of reducing the spread of HIV, but ensuring that people living with HIV/AIDS are supported in quality of life.

POSITIVE PREVENTION

CONCLUSION

A public health model views positive prevention pragmatically in that the end goal is solely the non transmission of HIV, however, from a community perspective, positive prevention is based on a different set of principles. Public health models are inadequate to meet the diverse needs of people living with HIV and the factors that contribute to decisions that may affect the health of the individual as well as the potential for transmission of HIV. A pan-Canadian community based framework would provide a more holistic approach to prevention taking into account the social determinants of health and quality of life issues that affect people living with HIV/AIDS.

Overarching Principles

The following principles should be at the core of a pan-Canadian positive prevention framework.

1. All initiatives must adhere to the Greater Involvement of People with AIDS principles (GIPA).
2. All initiatives should, wherever possible, consider incorporative language that addresses the alternative of Meaningful Involvement of People with AIDS (MIPA).
3. People living with HIV/AIDS must be involved in all planning, policy development and implementation of Positive Prevention initiatives.
4. People who are HIV-negative must be involved in all initiatives that specifically address that population.
5. All initiatives should embrace a human rights and population health model incorporating the determinants of health at their base.

Establishing a pan-Canadian positive prevention strategy will need to bring together a myriad of ideas to arrive at a single definition that can be agreed upon across the country. Defining positive prevention from a community perspective would mean addressing the various ways in which terminology is employed to describe both prevention and target audiences. That is, what is considered positive prevention in one province is not necessarily the same in other provinces or territories. Language that is consistent and easily understood across regions and in different linguistic cultures is crucial to this process.

Primary prevention in and of itself is not adequate in addressing the complex conditions in which people with HIV/AIDS live. Secondary and tertiary prevention initiatives tend to address these social conditions as well as acknowledging and speaking to issues of stigma and discrimination which are, in and of themselves, barriers to prevention. A pan-Canadian framework would incorporate actions and strategies that increase focus on secondary and tertiary aspects of prevention and work to decrease stigma and discrimination experienced by people living with HIV/AIDS. Testing and treatment as a means of prevention, a strategy embraced by primary prevention and public health models, may in fact debilitate secondary and tertiary efforts in that these tend to focus on the person with HIV as the vector of illness and therefore diminish the personal responsibility of all people to make informed decisions regarding their sexual and drug using behaviours. A pan-Canadian framework would encourage the responsible behaviours of all adults whether they are HIV-positive or HIV-negative.

The development of a pan-Canadian framework based upon secondary and tertiary prevention would include the broadest possible audience, unless targeted prevention for a specific group is considered to be of the greatest need at any particular time. Nonetheless, the sexual and reproductive health rights of the individual must be maintained in all prevention initiatives whether they are broad in scope or targeted for a specific population.

This framework should, wherever possible, link with existing local and regional resources to improve access for people living with HIV/AIDS to both gain the information they require to make informed decisions regarding their sexual and drug using behaviours and also to encourage the full participation of people with HIV in all aspects of prevention initiatives. While a national framework would focus on the overall goals of initiatives, it is the local and regional groups that will be the most likely to develop specific activities. Consultation with regional and local groups will assist in the development of a pan-Canadian framework by eliciting innovative and creative strategies to address HIV transmission and prevention.

In developing this framework, messages should be created that resonate with either a specific target audience (eg. gay men, Aboriginal people), or should reflect the broader scope of prevention and health promotion. Diverse forms of media including social networking, can be used to disseminate information widely and will assist in the promotion of healthy decision making for both people living with HIV and those who are HIV-negative.

Criminalization of HIV transmission and the fear of prosecution have become barriers to effective messages regarding HIV. More work needs to be done to alleviate fear for people living with HIV/AIDS and promote responsible decision making on the part of all sexually active adults and adults who choose to use injection drugs. As mentioned previously, decreasing stigma and discrimination is paramount to ameliorating the damaging effects of potential criminalization in that

it demands responsibility from all sexually active and drug using adults regardless of the HIV serostatus.

A pan-Canadian positive prevention framework must acknowledge the challenges experienced by people living with HIV/AIDS, but must equally urge that HIV-positive people become actively involved in the development and delivery of prevention services and programs. Following GIPA principles all initiatives must include the meaningful involvement of people living with HIV/AIDS in as many aspects of development, delivery and evaluation of positive prevention.

Building consensus toward a pan-Canadian framework will take time and effort. Common ground and compromise will be required to respond to the various issues and cultural differences that exist across regions and communities. An effective pan-Canadian positive prevention framework can be achieved where the best possible outcomes for people living with HIV/AIDS are the basis on which initiatives and messages are built. Supporting the health of the individual is the first and primary foundation positive prevention.

POSITIVE PREVENTION DISCUSSION PAPER

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