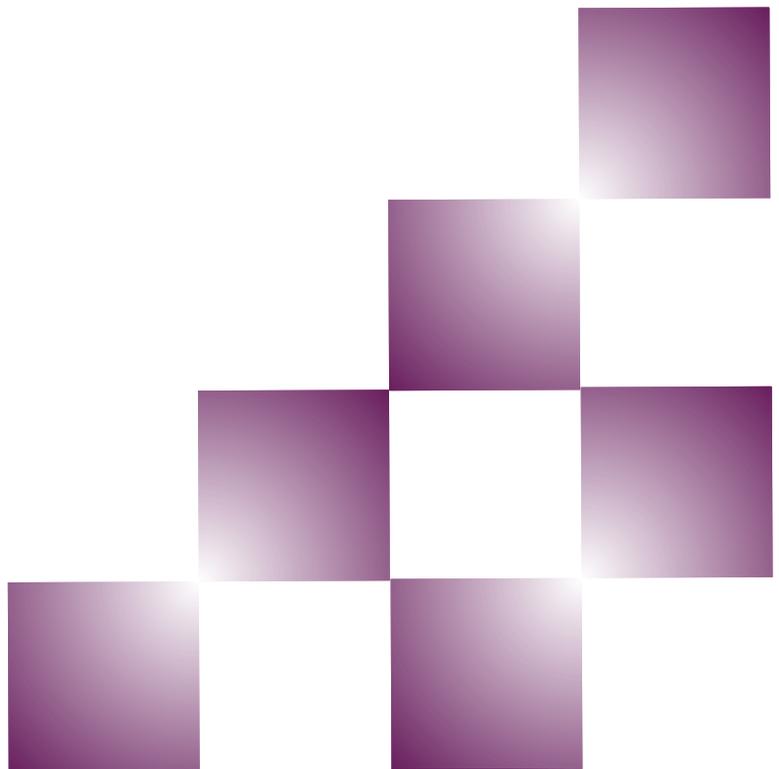


HIV/AIDS and Health Determinants: Lessons for Coordinating Policy and Action

**A Discussion Paper for the
Ministerial Council on HIV/AIDS**



Please note that the views presented in this document do not necessarily represent the views of Health Canada, the Federal/Provincial/Territorial Advisory Committee on AIDS or of any government represented in those groups.

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HIV/AIDS and Health Determinants: Lessons for Coordinating Policy and Action

**A Discussion Paper for the
Ministerial Council on AIDS**

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***E*xecutive Summary**

Today in Canada, the HIV/AIDS epidemic is settling ever more resolutely in the most vulnerable of communities. The inability to control its spread has made clear how illusory is the belief – once confidently held – that advanced industrial societies are somehow immune to infectious disease and that medical science and medical care can address every biological threat and health condition.

Canada, therefore, needs to pursue other approaches if it is to prevent HIV/AIDS and manage the HIV/AIDS epidemic. The *population health* model offers one such strategy. It builds on a holistic view of health that recognizes the many factors that influence population health and well being. These *social determinants* include, for example, poverty, income inequality, racism and discrimination, and early childhood experiences.

Health Canada initiated this literature review in order to consider HIV/AIDS in a population health context, to identify those social determinants most closely associated with HIV/AIDS, and to consider policy directions that will strengthen the Canadian response to the epidemic.

Reflections on the Literature

There is a strong body of literature that considers the population health concept. There is very little literature, however, that places HIV/AIDS in this broad context. This may be due to researchers being more interested in encouraging behavioural change in the short term than in societal shifts that require a longer period of time and sustained effort across sectors.

It may be due also to the researchers having to confront a number of very fundamental methodological challenges. These include, for example, the epidemic's diversity, the need to construct appropriate control or comparison groups, and the need for longitudinal studies that require more patience than the epidemic allows and more resources than are usually available. Analysts invariably have to struggle with the need not to equate the "absence of evidence" with "evidence of absence."

Findings

The literature presents compelling evidence of the relationship between the social determinants of health and HIV/AIDS. The different social determinants influence a person's vulnerability to HIV infection, the speed with which HIV infection will progress to AIDS and a person's ability to manage and live with HIV/AIDS.

The most important of these determinants include emotional, physical and sexual abuse during childhood as well as inequities based on income, race and gender. Importantly, racism and discrimination – not race, culture or gender themselves – leave groups of people particularly vulnerable to HIV infection by excluding them from the social and economic mainstream and by denying them the social supports needed to enhance and preserve life.

These health determinants act at the level of the individual, for example when child abuse and adult homelessness increase the likelihood of a person engaging in high-risk behaviours. They act also at the societal level, for example when economic inequities create short-term needs – the need for food and shelter, and even the need for drugs – that make long-term health prospects an academic concern.

Making Progress on Population Health

The literature frequently offers recommendations for influencing individual and community behaviour. Distributing condoms and clean needles figures prominently as do special efforts targeted to specific at-risk groups. These are vitally important for managing the epidemic.

However, leaving prevention to behavioural change – to condoms – reinforces the notion that HIV transmission is narrowly the result of personal shortcomings and group dynamics. Such efforts, while essential in the short term, are not the answer for the long term. Building a population health framework for HIV/AIDS requires strong, committed, non-partisan leadership at the highest levels in the community and in governments across the country. This leadership must embed the population health concept within a social justice agenda encompassing efforts:

- ◆ to reduce the income and other inequities in Canada;
- ◆ to invest in the country's children and youth; and
- ◆ to ensure that people are not relegated to the margins of society because of mental or other illnesses, disability, sexual orientation, race, culture or gender.

Progress on this social justice agenda will require research and education, cooperation and coordination across agencies and jurisdictions, and efforts to apply the lessons of population health to current strategies for managing the HIV/AIDS epidemic.

The Canadian Strategy on HIV/AIDS and the various Ministerial Councils and federal/provincial/territorial committees constitute a strong foundation for building a social justice agenda for Canada. What is needed are efforts to build partnerships with those departments that already understand population health, and efforts to reach out to those other government and community agencies that do not. Given the importance of leadership, these efforts should be directed initially at Ministers, Deputy Ministers and senior staff in the hope that their commitment will then permeate their respective organizations.

Building leadership, commitment and a public consensus will require efforts to place epidemiology more clearly into a social justice context. Research is needed to associate the social determinants with longer-term health outcomes and to articulate the potential cost savings and public health benefits that will flow from this approach. There would be value also in reaching out to those governments and commissions currently endeavouring to analyze and reform their health care systems.

Furthermore Health Canada and the Canadian Strategy on HIV/AIDS could endeavour to enhance the ability of health sector researchers to share their knowledge with a broader and more general audience. These researchers need to communicate their findings and knowledge in ways that are compelling and effective, and through vehicles other than technical journals.

The effort to manage the HIV/AIDS epidemic cannot stand still while pursuing the social justice agenda. It is important, therefore, to move certain HIV/AIDS-related activities in directions that reflect the current understanding of population health. This could include, for example, efforts:

- ◆ to engage leaders from other policy sectors in the HIV/AIDS-related committees;
- ◆ to address the underlying factors that place people at risk of HIV infection when testing for HIV or when providing support in health clinics and homeless shelters;
- ◆ to integrate sexual abuse counselling with HIV prevention efforts and to link the Canadian Strategy on HIV/AIDS with the National Children's Strategy, the Social Union and other early childhood development efforts;
- ◆ to expand harm minimization programs and place addictions in a social and health context rather than in the criminal justice system;
- ◆ to provide supports to the children of parents living with HIV/AIDS so as to ensure that their life chances are not compromised;
- ◆ to develop protocols to assist hospitals and health professionals meet the particular needs of marginalized groups; and
- ◆ to re-orient thinking and reporting so as to focus on racism and discrimination rather than on race and on those groups who are particularly vulnerable to HIV infection.

Given the nature, threat and potential impact of HIV/AIDS, there are no practical alternatives to the population health model and a social justice agenda. Governments and society need to regard the HIV/AIDS epidemic not as a health issue alone – and certainly not as a moral issue – but as a legal issue, a human rights issue and an equity issue. A nation's health must be treated as a barometer of its commitment to social justice and human rights. Common sense, practical experience and a wealth of research from around the world suggest that societies are investing wisely when they broaden their vision to include a population health and social justice framework.

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I. Introduction

HIV/AIDS is the most devastating infectious disease since the Black Death killed one-third of Europe's population in the 14th century. Globally, 36 million people are today living with HIV/AIDS while 22 million have already died as a result of the epidemic. HIV/AIDS has orphaned over 13 million children under the age of 15 years, a number that is expected to double in the next decade.¹ The epidemic has certainly not spared Canada where 50,000 people are now living with HIV/AIDS. It is the leading cause of premature death among men in Montreal and Toronto, while in Vancouver, it has reduced average life expectancy by up to twenty years among young gay and bisexual men.²

The medical world and scientific community have responded vigorously to HIV/AIDS. People today are living longer and better with HIV/AIDS and AZT, for example, can practically eliminate mother-to-infant transmission. In spite of this progress, "HIV remains a deadly infection for which there is no vaccine, no cure, and for which there is an expanding, but still limited, inventory of available treatments."³ Significantly, in both Canada and around the world, HIV/AIDS has settled resolutely in the most vulnerable of communities. It "has become woven, like some kind of invisible thread, into the lives of those infected, altering their existence in ways mostly quiet and unseen."⁴

The inability to control the epidemic has made clear how illusory is the belief – once confidently held – that advanced industrial societies are somehow immune to infectious disease and that medical science and medical care can address every biological threat. Medical means for preventing HIV infection and for curing HIV/AIDS remain a hope for the future.

Societies, therefore, need to pursue other strategies if they are to prevent HIV/AIDS and manage its impact. The *population health* concept offers one such strategy. It builds on a holistic view of health that recognizes the many environmental factors – i.e., the *social determinants* – that contribute to good health. Population health is defined as an approach "that aims to improve the health of the entire population and to reduce health inequities among population groups. In order to reach these objectives, it looks at and acts upon the broad range of factors and conditions that have a strong influence on our health."⁵ It envisions initiatives in the full range of public policy areas.

1 See UNAIDS, An overview of the AIDS epidemic and Orphans and children in a world of AIDS, 2001. (http://www.unaids.org/fact_sheets/ungass/index.html)

2 Strathdee, 2000.

3 United States, 1997.

4 New York Times, 3 June 2001, "The AIDS War – New Weapons and New Victims."

5 See Canada, Health Canada, 1998, Taking Action on Population Health. See also Anderson and Garmaise, 2001:21; Hayes and Glouberman, 1999.

Population Health in Practice

The Boston Medical Centre – a hospital that treats more poor people than any other in Massachusetts – has hired a team of lawyers to fight the legal and administrative battles that the doctors deem necessary to improve children's health in ways that pills and surgery cannot. The hospital's Chief of Pediatrics says they are trying to think "outside the box since you cannot separate out a child's organ functions from the rest of his body and the context of his environment." These lawyers, therefore, pressure landlords, help families apply for food stamps and persuade insurance companies to pay for baby formula.

"Traditional medicine can treat the effects of poverty. This program hopes to intervene so that poverty won't have the effects it has on children's health."

Goldberg, 2001

1.1 Purpose and Objectives

Literature reviews identify and weave together the themes presented in the research findings of different people in different countries. The purpose of this literature review is:

- ◆ to consider HIV/AIDS in a population health context;
- ◆ to identify and consider those social determinants that are most closely associated with HIV/AIDS in Canada; and
- ◆ to identify policy directions that will strengthen the Canadian response to the HIV/AIDS epidemic through a population health approach.

1.2 Methodology

The research took place between August and November 2001. A Steering Committee with representatives from Health Canada, the Federal/Provincial/Territorial Advisory Committee on HIV/AIDS, and the Ministerial Council on HIV/AIDS provided valuable guidance and advice, and commented on the draft report.

The project illustrated the power and utility of the Internet. A letter posted on a number of HIV/AIDS-related list servers generated responses from around the world. The Internet also gave the project immediate access to materials that had just recently been published and to research appearing in a variety of journals. It also provided access, in a way unthinkable even ten years ago, to a broad range of resources. A simple mouse click opened the door to UNAIDS in New York, the World Health Organization in Geneva, the Centre

for Health Promotion in Toronto, the National Centre in HIV Social Research in Australia, the Terrance Higgins Trust in the United Kingdom and the AIDS Housing Project in New York City. **Appendix A** identifies the Internet sites consulted.

The methodology included developing a comprehensive bibliography of materials – from Canadian and international sources – on the relationship between the social determinants of health and HIV/AIDS. Importantly, the focus was on HIV/AIDS itself rather than on the full range of health outcomes influenced by the social determinants of health.

InfoAction at the Vancouver Public Library used a variety of delimiters to explore search engines such as the European Database on AIDS and HIV, the OCLC (including PAIS, Social Sciences Abstracts, SIRS, ECO, Proceedings and WilsonSelectPlus), Microlog, the Canadian Research Index, Ebsco (Health Source Academic, Academic Source Elite and Masterfile databases) and Medline for North America, Europe and Australia. **Appendix A** presents these search engines. The project team also hand searched the bibliographies of most of the reports, papers and monographs consulted. The **References** section lists all the sources and identifies certain of these as being particularly useful.

The project team analyzed the literature from the perspective of the project's objectives and research issues. The discussion presented in this report, however, was limited by certain factors.

- ◆ First, this literature review – like most – was often unable to fully assess the methodological rigour that underlay many of the publications.
- ◆ Second, the literature does not provide research-based evidence associating certain of the epidemic's aspects with certain of the social determinants, for example quality of life and disease progression.
- ◆ Third, most of those undertaking HIV/AIDS-related research were not working from a population health perspective. Their approach was more narrowly focused and rarely considered the broad range of factors that individually and together influence HIV/AIDS.

The report, therefore, focuses on only certain of the social determinants. Furthermore, it relies upon only those sources which appear to have employed rigorous research methodologies and which have been published in reputable journals or by reputable sources.

1.3 Report Organization

Following this Introduction, Section 2 briefly provides some background on the evolution of the population health concept. Section 3 begins by reflecting on the literature and then presents findings from that literature. It also identifies the policy and program implications that flow from these findings. Section 4 analyzes the association between HIV/AIDS and population health and offers both conclusions and policy directions.

2. From Medical Care to Social Care

The concept of health has evolved very considerably through the past decades. Whereas historically health in Canada was associated with medical care and treatment, more recently there has been a much fuller appreciation of how social and economic factors influence the health of individuals and communities.

2.1 Health Promotion

In Canada, the literature often identifies the Lalonde Report⁶(1974) as a watershed in terms of shifting the public policy debate on health:

- ◆ away from a reliance upon medical treatment and the health care system; and
- ◆ toward an emphasis on building healthy communities and on individual and community responsibility for their own health and well being.

This concept was promoted in the *Achieving Health for All* report and the *Ottawa Charter for Health Promotion* (1986). The latter was internationally recognized as both a standard and a foundation for health promotion efforts. It suggested that governments could improve public health by building healthy public policy, creating supportive environments, strengthening community action, developing personal skills and redirecting health services so as to place less emphasis on residual care and more on preventing disease.⁷ Some sources suggest that the Ottawa Charter included peace, shelter, education, food, income, a stable eco-system, sustainable resources, social justice and equity as important health prerequisites.⁸

Health promotion combined this broad perspective with a behavioural approach that focused on individuals and groups. It is described as “**the science and art of helping people change their lifestyle to move toward a state of optimal health.**”⁹ Lifestyle change, it suggests, can be facilitated through a combination of efforts to enhance awareness, influence behaviour and create environments that support good health practices. The concept emphasizes “*the active role of the individual as an agent of change.*”¹⁰

The health promotion concept dominated early efforts to address the HIV/AIDS epidemic. However while government and community agencies understood the importance of broad societal change, prevention strategies were more narrowly focused. Roy Anderson and his colleagues, for example, suggest that the risk of HIV infection in this period

6 Health and Welfare Canada, *A New Perspective on the Health of Canadians*, 1974.

7 Hayes and Glouberman, 1999:6.

8 *AIDS Vancouver*, 1997:1-2.

9 *American Journal of Health Promotion*, 1989.

10 *Canadian Public Health Association*, 1997:8.

... was defined according to mode of transmission. As a result, public health funding, prevention programmes and surveillance activities targeted specific risk groups or categories, such as injection drug users, men who have sex with men, and haemophiliacs, and focused on specific behaviours.¹¹

Prevention efforts focused on changing personal behaviour and on encouraging people, often through a community development approach, to adopt lifestyle practices that reduced their risk of infection. The HIV/AIDS experience illustrated not only the potential impact of this approach but also its shortcomings:

- ◆ first, the “focus on mode of transmission ignored the needs of those who do not fit neatly – or identify themselves as fitting – into these transmission categories or who are vulnerable to HIV because of wider socio-economic, cultural and political factors;”¹²and
- ◆ second, the “exaggerated emphasis on lifestyle as a determinant of health ... [had an] implicit tendency to blame the victim.”¹³

Critics suggested that the health promotion approach conceived of individual lifestyles as existing in a vacuum. They also suggested that its popularity derived “from its congruence with the traditional medical model, wherein causal biologic pathways can be hypothesized and high-risk people individually managed by health providers.”¹⁴ Society, seemingly, had little responsibility for the “choices” made by individuals.

2.2 Population Health

In the 1990s, the research and government communities endeavoured to re-affirm the broader roots of the health promotion concept. While certainly not neglecting individual behaviour and vulnerable groups, they began to emphasize the larger social system within which people lived and worked. This approach offered “considerably more promise for ... beneficial change”¹⁵by emphasizing that “social environments have a far stronger impact on health than [does] individual behaviour.”¹⁶ This approach was well suited to the changes evident in the HIV/AIDS epidemic during that decade, namely its proliferation among widely diverse populations.

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

11 Anderson, 1999:8.

12 *Ibid.*,8.

13 Hayes and Glouberman, 1999:4-5.

14 McKinlay, 1993:109.

15 *Ibid.*,110.

16 Glouberman, 2001:22.

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).

These reports represented an important commitment to the population health model and to research and monitoring.¹⁷ This emphasis reflected government concern with ever-increasing costs within the health care system and reflected also the need to promote health rather than treat illness.

The goals of the population health model were:

- ◆ to maintain and improve the health of the entire population; and
- ◆ to reduce inequities in health between population groups.

The decline in mortality since 1900 was the result more of improvements in the social and physical environment than of advances in medical care. In fact, most new interventions, including therapeutic drugs, immunizations and surgical procedures were introduced several decades after a marked decline in mortality from those diseases had already taken place.

Auerbach, 2001:3

This concept takes into account the entire range of factors and conditions that influence health as well as the interactions among them. It acknowledges that many of these factors – and the most important of these factors – lie outside the health care system.¹⁸

Initially community-based HIV/AIDS organizations were uneasy with the population health concept suggesting that it:

- ◆ did little to recognize the importance of individual and community-based initiatives designed to prevent the epidemic's spread and to care for those living with the virus;
- ◆ did not recognize the tremendous diversity that existed within both the general and the at-risk populations; and
- ◆ was a “largely top down approach” that relied upon social and economic policy initiatives that did not adequately consider the “personal, group and community development [activities that] often come from the affected communities themselves.”¹⁹

17 Health Canada, Population and Public Health Branch, 2001, *The Population Health Template*.

18 Guildford, 2000:5. See also Canada, Health Canada, 1998, *Taking Action on Population Health*.

19 Canadian Public Health Association, 1997:7.

Additionally, many groups believed that the population health approach offered little for the short term or for actual field practice. Furthermore, its goals required consistent, coordinated and sustained efforts involving a broad range of governments, agencies and sectors. This requirement presented a formidable barrier to progress.

In the first decade of the HIV epidemic, researchers focused on sexual and drug using behaviours which directly related to the risk of HIV infection. Now that we are well into the second decade, our attentions have turned to the reasons for these behaviours

Strathdee, *Social determinants related ...*, 1997:2

2.3 The Social Determinants

The population health approach emphasizes those “social determinants” that influence individual and community health.

There has been very considerable discussion around which determinants – or which groups of determinants – contribute to population health. In 1994, for example, the Federal/Provincial/Territorial Advisory Committee identified “social, economic and physical environments, personal health practices, individual capacity and coping skills, human biology, early childhood development and health services.”²⁰ The *Second Report on the Health of Canadians* identified income, education and working conditions.²¹ Elsewhere Health Canada added social status, social support networks, employment, physical environments, social environments, biology and genetic endowment, personal health practices and coping skills, healthy child development, health services, gender and culture.²² Hayes and Glouberman, meanwhile, emphasized early childhood experiences, social and economic gradients, work and working conditions, and social networks and supports.²³

The list of determinants is broad and comprehensive, and can be summarized as follows:

- ◆ *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;

20 Canada, Health Canada, *The Population Health Template*, 2001.

21 Federal/Provincial/Territorial Advisory Committee on Population Health, 1999.

22 Canada, Health Canada, *Taking Action on Population Health*, 1998. See also, Guildford, 2000:5.

23 Hayes and Glouberman, 1999:7-8.

- ◆ *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 behaviours, 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.

This list of potential determinants reflects not only the reality and complexity of life but also the effort to explore every possibility. This has several consequences:

- ◆ first, everything – every experience and every factor at every time throughout one’s life – is described as having an impact on health. The literature rarely endeavours to determine the relative importance of each and only infrequently notes the association among the different social determinants.
- ◆ second, the concept remains poorly understood and different individuals and organizations use the language of population health while having very different concepts of what it means for public policy and programs. Thus it is difficult for organizations to communicate with each other and to agree on priorities.

There is not at present a clear understanding that, very simply, individual and population health are determined by a wide variety of factors acting singly and together. And that a diverse array of efforts are required to improve health and well being.

3. The Social Determinants and HIV/AIDS

Section 3 begins by offering reflections on the research literature and identifies the methodological challenges inherent in conducting that research. The Section then explores in more detail the relationship between HIV/AIDS and those social determinants for which there is adequate research, and presents findings related to each of these determinants. The criteria for selecting these findings included the author's reputation and professional associations, and the project's funding source and the report's publisher. Only those findings supported by compelling research-based evidence and having a sound methodological base are presented in the following.

Although this review presents findings on each determinant separately, the population health model affirms their inter-dependence. Poverty, early childhood experience, discrimination and the other determinants are inextricably linked and together contribute to the epidemic's spread and impact. Section 3 also offers some consideration of the policy implications that flow from the findings associated with each determinant. The more specific initiatives required to address these policy implications are presented within a broader context in Section 4, as part of the report's conclusions.

3.1 Reflections on the Literature

There is a strong body of literature that considers the population health concept and provides evidence of the social determinants' impact on the health and well being of individuals and communities. There is very little literature, however, that places HIV/AIDS in this broad population health context. Instead the literature most often explores the association between a particular social determinant and the behaviour that places a person at risk of HIV infection.

This pattern may be due to the researchers – most often epidemiologists or health professionals – working from a health promotion perspective that aims to influence individual and group behaviour. Given the importance of their work and the immediacy of the HIV/AIDS threat, these researchers may be more interested in their work having an impact in the short term than in societal shifts that require a longer period of time and sustained effort across sectors.

The researchers have to confront a number of very fundamental methodological challenges. One is the need to accommodate the complex, ever-changing nature of HIV/AIDS, the characteristics of the different at-risk groups, and the epidemic's entrenchment in the most marginalized of communities. Accessing these communities for research purposes can itself be a formidable challenge.

Another challenge is to distinguish between cause and effect. Researchers have to determine whether poverty, for example:

- ◆ is responsible for HIV/AIDS by placing people in situations where they are at higher risk of contracting the virus; or
- ◆ a consequence of having HIV/AIDS by obliging them to leave the paid labour force in order to live with the condition.

Similarly the literature must ask whether the depressive symptoms often exhibited by those living with HIV/AIDS contribute to the disease's progression or are an early manifestation of the disease's progression. In these and other examples, cause and effect are not always clear and distinguishable.

Another challenge is to distinguish between the impact of the different determinants. If a particular community is vulnerable to HIV infection, for example, is it because of their poverty, their social circumstances, their housing, their working conditions, their ethnicity or their gender? While the population health model acknowledges the relationship among these, the ability to influence public policy requires some distinguishing among them. Furthermore in exploring relationships, the research has to take three steps rather than one:

- ◆ first from social determinant to risk behaviour;
- ◆ then from risk behaviour to HIV infection; and
- ◆ finally, from HIV infection to AIDS.

Another challenge is to identify associations and causal or predictive relationships between health outcomes today and life situations from perhaps five, ten or twenty years ago. In this regard, researchers invariably struggle with the need not to equate the "absence of evidence" with "evidence of absence."

Identifying these associations in a scientifically rigorous manner depends upon conducting the research through an extended period of time and having an appropriate control or comparison group. Neither the urgency of the epidemic itself nor the traditional perspective of funders allows for such a long-term approach. Adequate funding is rarely available and, indeed, the financial commitment to HIV/AIDS-related research in Canada lags behind that of other developed countries such as Australia, Switzerland and the United States. The Canadian Strategy's funding commitment to research, for example, declined by 26% between 1994 and the present.²⁴

24 Spigelman, *Taking Stock*, 2001a:25-27.

Furthermore, drawing conclusions from the literature is compromised by social and epidemiological researchers most often focusing on behavioural issues. Researchers have associated HIV/AIDS with intravenous drug use. Only rarely, however, have the researchers taken the next step backward and associated it with the emotional pain and poverty that often contributed to this drug use. The researchers' orientation is likely a consequence of their effort to identify practical prevention strategies for the short term.

Addictions always originate in unhappiness, even if hidden. They are emotional anesthetics; they numb pain. The first question – always – is not 'Why the addiction?' but 'Why the pain?' The methadone I prescribe for their opiate dependence does little for the emotional anguish compressed in every heartbeat of these driven souls.

Mate, 2001: A9

Additionally, the literature and the researchers invariably begin with an adult population that is currently living with HIV/AIDS and are obliged to use a retrospective approach when exploring the root causes of their current situation. As such, the researchers cannot speak to the very many people who, for example, have not contracted HIV/AIDS in spite of their poverty or their early childhood experiences. The validity of their conclusions, in terms of association or causality, again very much depends on the appropriateness of their control groups, an appropriateness that is exceedingly difficult to achieve when addressing socio-economic conditions.

All in all, the literature relating HIV/AIDS to population health – and to the social determinants that underlie that concept – was surprisingly sparse. It is narrowly focused on behaviour and on specific at-risk groups rather than more broadly on the social and economic roots of the epidemic. Nevertheless there are patterns evident in the research findings and these are compelling even if one can quibble about the methodology behind them. These findings lend support to the intuitive logic of the population health approach. It simply makes sense that a healthy social and economic environment leads to better health outcomes. It simply makes sense that a person who grew up in an abusive environment is more likely than one who did not to engage in behaviours that place them at risk of HIV infection.

The basic human need for shelter makes the relation between poor housing and poor health seem self evident. Despite, or perhaps because of, this intuitive relation, good research evidence is lacking on the health gains that result from investment in housing.

Thomson, 2001:189

3.2 Wealth and Health: Income, Equity and Social Status

The literature provides compelling evidence, unrelated to HIV/AIDS, associating wealth with health. This pattern is evident throughout the income distribution ladder²⁵ and implies that a nation's economic structure and commitment to income equity may be the most important determinant of health.²⁶

That wealthy people live longer and have lower morbidity, on average, than do poor people has been well documented across countries, within countries at a point in time, and over time with economic growth.

Case, 2001:1

Consequently the United States, in spite of its wealth, scores lower in terms of health outcomes than do many other, seemingly less wealthy countries.²⁷ According to a study undertaken for the Rockefeller Foundation and the Swedish International Cooperation Agency, even within the United States, people living in the most affluent counties can expect to live 16 years longer than those in the poorest counties. Similarly Hogg et al. have calculated that after adjusting for age, lower income men experienced a mortality risk about 60% higher than that of higher income men.²⁸

In other words, regardless of overall wealth, those countries with smaller gaps between rich and poor are healthier than those in which the gap is larger.²⁹

Importantly, income inequities serve as proxy measures for other socio-economic inequities. In general, those with lower incomes are also those with lower educational attainment levels, higher rates of unemployment and fewer social supports. In the United Kingdom, the Terrance Higgins Trust – the country's largest HIV/AIDS-related organization – emphasizes the impact of social exclusion on health and well-being, with “social exclusion [being] ... a shorthand term for what can happen when people suffer from a combination of linked problems, such as unemployment, poor skills, low incomes, poor housing, high crime environments, bad health and family breakdown.”³⁰

The concept of social exclusion provides an entrée into the discussion of health, wealth and HIV/AIDS. Numerous research projects, dating back to the early 1980s, have identified an association among poverty, disadvantage, social exclusion, drug use and other factors that place people at higher risk of HIV infection.³¹ Using monitoring data from community-based agencies in London, for example, O'Brian and Tierney conclude that those living with HIV/AIDS as a result of injection drug use are most commonly poor, early

25 Case, 2001:1; see also Evans, 2001:3.

26 Bezruchka, 2001:1701

27 OECD, 2001.

28 Hogg, 1994.

29 Case, 2001:1. See also Bezruchka, 2001:1701-03; OECD, 2001:81-83.

30 Terrance Higgins Trust, 2001:1.

31 See O'Brian, 1998.

school leavers, unemployed and powerless.³² Their vulnerability to HIV infection is determined by “the degree of control [they] ... have over life circumstances and, hence, their capacity to take action.”³³

AIDS is a disease of low socio-economic status ... a disease of poverty.
Toronto Star, 1991:A13

Research Findings

The literature suggests that people with low incomes are more likely than those with higher incomes to be at risk of HIV infection, to have HIV/AIDS, to progress from HIV to AIDS and to succumb to AIDS more quickly. The following are drawn from research undertaken by respected researchers, for example Martin Schechter and Steffanie Strathdee in Vancouver, and/or published by credible sources such as the Centers for Disease Control and Prevention in the United States or Health Canada. The examples generally reflect the larger body of research.

- ◆ Women from five low-income neighbourhoods in California had an HIV prevalence rate that was more than four times that of all women in the state. The California study was “a one-stage, cluster-sample, population-based, door-to-door, cross-sectional survey of the prevalence of HIV infection, sexually transmitted diseases, hepatitis A, B and C, and related risk behavior.”³⁴ The research team contacted almost 20,000 dwellings and interviewed over 2,500 participants. Similar outcomes were evident in a Quebec study indicating that HIV-infected mothers were more likely to reside in regions with incomes below the provincial median.
- ◆ An Australian study published in *AIDS Care* found that 32% of people living with HIV/AIDS had incomes that left them below the poverty line. It also noted some association between poverty and progression from HIV to AIDS. The author linked poverty and unemployment, and noted that two-thirds of people living with HIV/AIDS reported they had left work for reasons related to their condition, and only one-third subsequently returned to work.³⁵
- ◆ A Vancouver study published by the BC Centre for Excellence in HIV/AIDS – part of a decade-long examination of people living with HIV/AIDS – also found socio-economic status prior to infection to be associated with both disease progression and the chances of survival even after adjusting for CD4 count, age at infection, year of infection and use of HIV therapies and prophylaxis.³⁶ An article

32 Ibid.

33 Ryan, 2000:48.

34 Ruiz, 2000:368-371.

35 Ezzy, 1999.

36 Schechter, 1994; Hogg, 1994.

published in the *Journal of Acquired Immune Deficiency Syndromes* associated the nutritional deficiencies resulting from poverty with disease progression and survival among HIV-infected women.³⁷

- ◆ A further study from the BC Centre for Excellence in HIV/AIDS also associated poverty and HIV/AIDS. It indicated that HIV-positive gay men with annual incomes less than \$10,000 experience illness-related weight loss at a significantly faster rate than do those with higher incomes.³⁸ Meanwhile an American study indicated that gay men generally have lower mean personal incomes, lower mean household incomes and experience greater poverty than do heterosexual men.³⁹ A Health Canada-funded study of some 2000 people identifies the impact of this economic disadvantage: gay men with incomes less than the poverty line were twice as likely as more affluent gay men to die within ten years of contracting HIV.⁴⁰ Other BC Centre for Excellence studies indicate that those engaging in high-risk behaviours had lower incomes and were younger than non-risk takers.⁴¹ Young gay men with less than a high school education were nearly twice as likely to be risk takers.⁴²

Conclusions and Policy Implications

The research findings suggest an important association between poverty, behaviours that place people at risk of HIV infection and both disease progression and life expectancy once infected. The reason very likely is that poverty, and the educational and other consequences of poverty, limit the choices available to people and compromise their ability to avoid high-risk situations. Some low-income people, for example, cannot afford even condoms while others may have to engage in commercial sex as a survival strategy. Furthermore:

HIV disease is a disease of the vulnerable, especially in the presence of marginalization and poverty. To be vulnerable in the context of HIV and AIDS means to have little or no control over one's risk of infection or acquiring HIV, or, for those infected or affected by HIV, having little or no access to appropriate treatment, care and support.

Canada, House of Commons, 1996:1/32

37 Baum, 1997:272. See also Canadian AIDS Society, 1996:4.

38 Voight, 1994.

39 Canada, National Reference Group, 2001:27; See also Ryan, 2000.

40 Strathdee, 1997.

41 Hogg, 1994.

42 Strathdee, 1997.

the links between poverty and HIV/AIDS are bi-directional. On the one hand, poverty contributes to vulnerability to HIV and exacerbates the impact of HIV/AIDS. On the other hand, the experience of HIV/AIDS by individuals, households and communities that are poor readily leads to an intensification of poverty. Thus, HIV/AIDS frequently impoverishes people in such a way as to intensify the epidemic itself.”⁴³

Very simply, HIV/AIDS is both the result and a cause of poverty in Canada.⁴⁴

Poverty creates an environment that assists the spread of HIV, while the increase in illness and death associated with AIDS increases levels of poverty.

European Commission, 1999:1

This pattern does not bode well for future efforts to prevent the spread of HIV/AIDS given that Canadians became poorer in the 1990s as average and real incomes declined and as income disparities between rich and poor widened.⁴⁵ Compounding the situation are the “cutbacks in the social safety net [that] have pushed more people to the margins of society. In general there are fewer social buffers and the bridges to a better life are lacking for many.”⁴⁶

The policy directions required to address this situation are simple to conceive but difficult to achieve. The effort to prevent HIV/AIDS and to ameliorate the consequences of living with HIV/AIDS requires policies that will:

- ◆ reduce both absolute and relative poverty, and ensure a more equitable distribution of Canada’s wealth;
- ◆ promote community development efforts that prevent children, youth and adults from being relegated to the social and economic margins of society;
- ◆ enable those already marginalized by poverty to return to the mainstream;⁴⁷ and
- ◆ acknowledge and offset the economic burdens associated with HIV/AIDS and other disabilities.

43 UNAIDS and World Health Organization, 2001:7.

44 European Commission, 1999; See also Canadian AIDS society, 1996.

45 See Centre for Social Justice, 2001. See also Guildford, 2000:5. During the 1980s the real income (i.e., income adjusted to reflect inflation) of most Canadians decreased. By 1996, the poverty rate in Canada had risen to 18% and the child poverty rate reached a 17-year peak of 21%.

46 Albert and Williams,1998:97.

47 Terrance Higgins Trust, 2001:1.

3.3 Early Childhood Experience

Poverty clearly has an impact on the life-long health and well being of children. Children who grow up in poverty have a powerful strike against them when it comes time to live in an adult world. Children from low-income families are more likely than others to be living in inadequate housing and less likely to complete their high school education. They are less likely to obtain the post-secondary education and training that increasingly is the key to a stable future, and more likely as adults to be unemployed and receiving social assistance. They are less likely to enjoy good health both as children and as adults. Indeed the literature presents evidence that a “family’s long-term average income is a powerful determinant of children’s health status ... The health of children from families with lower incomes erodes faster with age, and these children enter adulthood with both lower socioeconomic status and poorer health.”⁴⁸

Conversely the literature indicates that a safe, secure and nurturing environment can compensate for family poverty and that broadly based developmental efforts can prevent many of the social and economic outcomes associated with poverty. Most commonly cited in this literature is the precursor of the Head Start program in the United States, the High/Scope Perry Pre-school Program in Ypsilanti, Michigan. Established in 1962, the program “has become the cornerstone of a body of longitudinal research that permits definitive statements about the value of early childhood education for children from low-income families.”⁴⁹

Intuitively it makes sense that children who are well nourished – both physically and emotionally – will grow into healthier adults. Conversely, “children who are in emotional turmoil, neglected, rejected and poorly supervised are easily manipulated and abused.”⁵⁰ Ultimately these children are at higher risk of living in poverty and on the street, and of engaging in the drug and sexual behaviours that place them at higher risk of contracting HIV.

Findings

The HIV/AIDS-related literature devotes some attention to the early childhood experiences of those who are at higher risk of contracting HIV or who are living with HIV/AIDS. It devotes particular attention to sexual abuse and its clear association with risk-taking behaviours. The literature’s methodology, however, often relies upon participant surveys and often is not supported by entirely appropriate control or comparison groups.

48 Case, 2001:29.

49 Berrueta-Clement, 1984:2. See also Sweinhart, 1993; Healthy People 2010, 2000:8/16; Spigelman, 1996:20.

50 Canada, House of Commons Standing Committee on Health, 1996:2/32.

- ◆ A number of studies associate a history of physical abuse, sexual abuse or rape with engaging in a variety of HIV risk behaviours and to a continuation or increase in the total number of these behaviours between adolescence and young adulthood. One study undertaken at the George Warren Brown School of Social Work at Washington University involved a random sample of 602 youths drawn from a group of almost 2,800 patients seen at public health clinics in ten cities. It included structured in-person interviews conducted through a period of ten years.⁵¹
- ◆ Of the 327 homosexual and bisexual men participating in an ongoing study pertaining to risk factors for HIV infection, 35.5% reported being sexually abused as children. Those with a legacy of abuse reported having more lifetime male partners and a greater incidence of having engaged in unprotected, receptive anal intercourse.⁵² These findings are consistent with an older study in which over 1000 homosexual or bisexual men were interviewed. That study also found a significant association between sexual abuse and HIV risk behaviour including unprotected intercourse and injection drug use.⁵³ Peer-reviewed articles in the *American Journal of Orthopsychiatry* and the *American Journal of Preventive Medicine* serve to affirm these findings. They associated early sexual abuse with a higher incidence of sexual and physical assault as an adult, with high-risk behaviours such as alcohol and cocaine abuse, anal intercourse, prostitution and with not using condoms.⁵⁴
- ◆ Reinforcing the importance of early childhood experiences is a host of studies conducted by leading researchers with the BC Centre for Excellence and presented to a variety of local, national and international audiences or published in major journals. In some of these studies, sexual abuse was independently associated with a two-fold increase in sexual risk-taking among young men who have sex with men. It was also one of the strongest predictors of needle sharing among injection drug users in Vancouver.⁵⁵ Indeed drug addicts with a history of abuse were three times more likely to share needles than were those who had not been abused.⁵⁶ Young gay men with a history of sexual abuse were twice as likely to be risk takers while both male and female injection drug users with a history of sexual abuse were three times more likely to share needles than were those without such a history.⁵⁷ “Of particular importance was the finding that sexual abuse was an independent predictor of [needle] borrowing among both male and female IDUs.”⁵⁸

51 Cunningham, 1994.

52 Lenderking, 1997.

53 Bartholow, 1994.

54 Goodman, 1998; see also Wingood, 1997.

55 Strathdee, Presentation to XI International Conference, 1996; see also Strathdee, *Social Determinants predict ...*, 1996.

56 Vancouver Sun, 1996.

57 Strathdee, 1997.

58 Strathdee, *Social Determinants predict ...*, 1996:3/5.

Those sharing needles reported their abuse having occurred at all ages and for 53% of the respondents, this experience preceded their first experience with drugs.

... the lingering effects of sexual abuse, incest and rape are helping to drive the spread of HIV among both drug addicts and young homosexual men.
Vancouver Sun, 1996

Conclusions and Policy Implications

According to Steffanie Strathdee, one of the most active and prolific researchers exploring the early experiences of those people engaging in high-risk behaviours, "... a history of sexual abuse is one of the many missing pieces of the puzzle that may help to account for the inability to adopt or negotiate safer sex practices."⁵⁹ An earlier study published in the Australian *AIDS Care* journal complemented this conclusion by suggesting that among youth, sex – on any terms – was motivated by their search for the love, caring, affection and protection denied them during their earlier years.⁶⁰

These findings serve to highlight the policy directions required as part of the effort to address the HIV/AIDS epidemic in Canada. None of these directions, however, are new to the policy table.

- ◆ Ensure the physical and emotional security of children and youth during their formative years. Health Canada has noted, for example, that "many behaviour patterns are established that will affect a young person's risk of HIV infection, both within this time span and throughout his/her adult years. Early intervention is an important step in helping youth to adopt and to maintain protective behaviours."⁶¹
- ◆ Provide sexual abuse counselling as an integral part of HIV prevention and treatment efforts, and HIV/AIDS risk-reduction counselling as an integral part of efforts directed at sexual abuse.
- ◆ Develop a partnership between the National Children's Strategy and the Canadian Strategy on HIV/AIDS, in recognition of the former's ability to contribute to the latter. Early childhood development efforts will reduce the number of people contracting the HIV virus in the future.
- ◆ Consider the health outcomes and costs associated with HIV/AIDS treatment and care when determining the cost/benefit associated the National Child Benefit and its impact on family poverty.

59 Strathdee, 1997:3.

60 Rosenthal, 1994.

61 Canada, Health Canada, HIV and AIDS among youth, 2001.

3.4 Social Support, Social Cohesion and Discrimination

The literature suggests an important association between social support, social inclusion and social cohesion on the one hand and positive health outcomes on the other. Social supports enable people to negotiate life's crises. Social cohesion helps to stabilize health-threatening situations by including and accepting people, and by enabling them to "participate fully within our families, our communities and our society."⁶²

In the nineteenth century, school promoters often argued that schools were cheaper than jails. In the twenty-first century, we might develop a similar argument, that social and economic inclusion is cheaper than hospitals.

Guildford, 2000:16

As such, these are particularly important to those marginalized groups who are at highest risk of contracting HIV and to those who are living with HIV/AIDS. Like other vulnerable populations, the well being of people living with HIV/AIDS depends upon the presence of a network of formal and informal supports and services. For many, a supportive environment can enhance their quality of life and extend their very survival. Yet for people forced to the margin of society because of their sexual orientation, ethnicity, culture or addictions, these supports are often inadequate or inaccessible.⁶³

HIV/AIDS is a behaviour-based disease. However it is not spread only by the behaviour of those engaging in high-risk activities. It is spread also by the discriminatory behaviour of people and governments. In the United States for example, gay and lesbian lovemaking is a criminal act in twenty-three states. Openly gay and lesbian people are considered unfit for military service and their issues are considered inappropriate for discussion in the public school system. In both Canada and the United States, "we condemn gay promiscuity, but then tell gay and lesbian couples who desire to make their commitment to each other that they are somehow a threat to the family."⁶⁴

Discrimination is a health care concern....

Canada, House of Commons, 1996:4/32

"Prejudice, discrimination and stigma have played a central and defining role" in the history of HIV/AIDS in Canada and "[h]istorically, where discrimination exists, the virus is more likely to proliferate."⁶⁵ Discrimination occurs when "particular aspects of some people with HIV/AIDS, such as sexual orientation or drug use, are magnified to the exclusion of the

62 Guildford, 2000.

63 Chernesky, 2000.

64 Canada, House of Commons Standing Committee on Health, 1996:5/32

65 Canada, Health Canada, Legacy Discussion Paper ..., 2000:1.

individual humanity of each person with HIV/AIDS and the diversity of all people with HIV/AIDS.”⁶⁶ Discrimination and stigma are reinforced when even professionals describe injection drug users or sex workers not as people but rather as “vectors of disease.”⁶⁷ And discrimination and stigma can manifest themselves as violence. Studies undertaken in both the United Kingdom and Vancouver document the high level of violence directed toward gay men.⁶⁸

The stigma and discrimination are reinforced by the too-common perception of those groups most at risk – gay men, commercial sex workers, Aboriginal people and injection drug users – and continue in spite of two decades of public education. As late as 1997, 17% of the American public endorsed the idea of quarantining people with HIV/AIDS while 19% thought the names of those who are infected should be publicized. Twenty-nine percent agreed that people who acquired AIDS through sex or drug use “got what they deserved.”⁶⁹

The initial identification of HIV among these marginalized groups has had a lasting impact on the way in which the disease is perceived

Ruiz, 2000:77

Findings

The literature provides evidence associating HIV/AIDS and the absence of those social supports that enable people to negotiate life’s crises.

- ◆ A study conducted by the University of Pennsylvania concluded that interventions with parents that improve social cohesion in the family constitute effective strategies for discouraging adolescents from engaging in high-risk behaviours. The conclusions were based upon surveys of a stratified cross-section of over 350 African-American children living in public housing.⁷⁰

Other Health Canada funded research indicated that HIV-positive gay men with strong family support were less likely to engage in high-risk behaviours.⁷¹ Based upon a literature review and endeavouring to place gay men’s health into a population health context, the report concluded that a person’s ability to incorporate safer sex practices is closely associated with high self-esteem, solid social supports, positive sexual identity and belonging to a peer group. Young gay men, it suggests, are often lacking all of these.⁷² Similarly an Australian study published in *AIDS Care* associated social support with a reduction in high-risk

66 de Bruyn, 1998:11.

67 *Ibid.*, 41.

68 See Trussler, 2000:7; Terrance Higgins Trust, 2001:6.

69 Ruiz, 2000:78.

70 Romer, 1999.

71 Ryan, 2000:64.

72 *Ibid.*, 66.

behaviours among those using injection drugs.⁷³ That particular study investigated the structural and functional nature of the social support networks available to 100 injection drug users in Sydney, 60% of whom were male and 40% female.

- ◆ A study published in the *International Journal of STD & AIDS* indicated that those people living with HIV who had adequate social support adapted more fully to the illness crisis, demonstrated less anxiety and depression and had fewer somatic complaints than those without such support. This longitudinal study tracked almost 140 patients associated with the University of Nebraska Medical Center and with Veterans Affairs medical centers in California and Pennsylvania. It endeavoured to associate perceived Quality of Life (QOL) with satisfaction with social supports, employment, education, marital status, race and a variety of other potential factors.⁷⁴

A similar longitudinal study, tracking 82 HIV-infected gay men through a period of almost six years, associated more rapid disease progression with heightened stress and fewer social supports. At 66 months, those above the median in terms of social support had a 40% higher probability of being free of AIDS compared with those below the median.⁷⁵

- ◆ Work undertaken by the BC Centre for Excellence and both published in *The Clarion* and presented to the XIth International Conference on AIDS, indicated that female injection drug users with greater symptoms of depression were more likely to share needles. “Psychological distress, rather than access to clean needles, was strongly associated with needle sharing.”⁷⁶
- ◆ Studies undertaken in 1991 for the United Nations HIV and Development Programme and in 1998 at Macquarie University in Australia provide further insights into the importance of social support. Both indicate that sexually confident, well-educated gay men who are socially engaged with the gay community are more likely to have changed their sexual behaviour than gay men who are not attached to the gay community. They have the informed social support necessary to modify their behaviour while men who are isolated from others like themselves are least likely to change.⁷⁷ The importance of gay community attachment was affirmed in a later Australian study.⁷⁸

Conclusions and Policy Implications

Discrimination and stigma compromise efforts to prevent HIV/AIDS, to control its spread and to provide treatment and care. They severely compromise the ability of people to manage their condition by creating stress, increasing social isolation and discouraging efforts to access health care services. The National Academy of Sciences in the United States further notes that:

73 Stowe, 1993:2/15.

74 Swindells, 1999:384.

75 Lesserman, 1999:397, 401.

76 Strathdee, Social determinants predict ...,1996; see also Strathdee, Social Determinants related ..., 1997.

The protection of the human rights of vulnerable groups is a key aspect of reducing transmission, as social exclusion can increase transmission and impact of HIV/AIDS.

All Party Parliamentary Group, 2001:1

fear of discrimination is a major constraint to the wide acceptance of many potentially effective public health measures. Public health measures will be most effective if they are accompanied by clear, strict sanctions to prevent unwarranted discrimination against those who are HIV-infected or at risk for infection.⁷⁹

This implies a need for policy efforts, at both the national and the community level, designed to enhance social cohesion and social inclusion. “In this AIDS crisis, the number one factor in helping any person – young or old, gay, lesbian, bisexual or heterosexual – take the necessary steps to avoid HIV ... is to give that person a sense that they have the potential for a bright and productive future. If they are not told that, how can they be persuaded to put on a condom, stop drinking or stop abusing substances.”⁸⁰

Significantly, the success of various HIV/AIDS interventions has been shown to be directly proportional to the degree to which human rights are promoted and protected These realities, demonstrated time and again over the course of the HIV/AIDS epidemic, make clear that the protection and promotion of human rights must be an integral component of all responses to the epidemic.

All Party Parliamentary Group, 2001

Further policy directions will require effort from a spectrum of people in the country.

- ◆ Health professionals bear a significant responsibility for efforts to reduce discrimination and promote social cohesion. They must understand that promoting and protecting human rights are essential for promoting and protecting health since “discrimination (and other human rights issues) were found not only to be tragic results of the pandemic but to be root societal causes of vulnerability to HIV.”⁸¹

Many of the addicts [in Vancouver’s downtown east side] simply don’t seem to care that they are spreading AIDS.

77 Carr, 1991:3/13.

Cernetig, 1997:A2

78 Chapple, 1998.

79 de Bruyn, 1998:3.

80 Canada, House of Commons Standing Committee on Health, 1996:6/32

81 Mann, 1996:924.

- ◆ Improve the social supports available to and the coping skills of men and women who inject drugs in the expectation that such could reduce their needle-sharing behaviours.⁸² Address addictions, in the community and in correctional institutions, as a health and social problem rather than as a criminal justice issue.
- ◆ HIV treatment must address not only the physical needs of patients but their emotional and social needs as well since progression to AIDS is delayed among

Leaders at all levels, from politicians to religious leaders to local heroes, need to challenge HIV-discrimination, spearhead public campaigns, and speak out against the multiple discriminations that poor people, women, ethnic minorities and gay men face in relation to HIV/AIDS.

Peter Piot, 2001

those who have an adequate social support system in place.

3.5 Race and Gender

Increasingly the HIV/AIDS epidemic is turning toward minority populations. In the United States in 1995 for example, African Americans represented approximately 12% of the population and 40% of newly reported HIV infections while Hispanics represented 9% of the population and 19% of new cases.⁸³ In Brazil, HIV/AIDS now rages in the favelas of Rio de Janeiro and Sao Paulo while in Ethiopia, it is devastatingly embedded among the poor

Health equity is best thought of not as a social goal in and of itself, but as inherently embedded in the pursuit of social justice.

Evans, 2001

and dispossessed. In Canada, meanwhile, the epidemic increasingly is striking at Aboriginal people and their communities. The pattern is clear:

[In every society] those people who were marginalized, stigmatized and discriminated against – before HIV/AIDS arrived – have become over time those at highest risk of HIV infection. Regardless of where and among whom it may start within a community or country, the brunt of the epidemic gradually and inexorably turns towards those who bear this societal burden.⁸⁴

While less than 3% of the Canadian population is Aboriginal, the proportion of AIDS cases attributed to this community increased from 1% before 1990 to 15% in 1999. In 1999, Aboriginal people were five times more likely to have AIDS than other Canadians.⁸⁵

82 Strathdee, Social determinants predict ..., 1996.

83 United States, 1997:n.p.

84 de Bruyn, 1998:18; see also the presentation by Jonathan Mann to the (U.K.) All-Parliamentary Group, 2001:11.

Meanwhile in British Columbia, Aboriginal people make up about 5% of the population but 19% of those newly testing positive for HIV⁸⁶ and in Saskatchewan, they comprise 15% of the population but almost 48% of new cases (1997).⁸⁷

Although the literature often implies Aboriginal ethnicity as a risk factor – and routinely reports numbers specific to this population – it is difficult to conceive of their vulnerability being associated with race. Indeed to imply such is offensive in the extreme since “[r]ace and ethnicity ... are risk markers that correlate with other more fundamental determinants of health status such as poverty....”⁸⁸ The population health literature suggests their vulnerability is associated with the many difficult social, economic and behavioural factors too often evident in their communities.

Findings

The extent of the epidemic’s incursion into Aboriginal society and communities speaks to the social and human rights problems evident in this country. The incarceration, suicide, drug and alcohol use and poverty rates are all very significantly higher among Aboriginal people in Canada than among the non-Aboriginal population.⁸⁹

One could add to this potent prescription for infection, the lower levels of education, the greater social stress and the greater emotional distress evident in Aboriginal communities. One could add also the living and housing conditions, both on and off reserve, that exacerbate the problems confronting Aboriginal people living with HIV/AIDS. People without sufficient income and living in substandard housing cannot maintain – and often do not care about maintaining – the level of good physical health that is required to manage the infection.

In other words, Aboriginal people are at increased risk of HIV infection not because they

Aboriginal people with HIV/AIDS live with many layers of stigma and discrimination.

de Bruyn, 1998:58

are Aboriginal but because of the social determinants associated with risk of infection.⁹⁰

Furthermore, the conditions associated with race influence the health outcomes following infection. In the United States, for example, the literature speaks of African American cynicism with the medical system. Authors suggest the Tuskegee Syphilis Study has been a

85 AIDS Weekly Plus, HIV/AIDS an epidemic ..., 2000; see also Canada, Health Canada, HIV and AIDS among ..., 2000.

86 Canada, Health Canada, HIV and AIDS among ..., 2000:2-3.

87 Entwisle, n.d.

88 CDC, 1997.

89 AIDS Weekly Plus, HIV/AIDS an epidemic ..., 2000.

90 Heath, 1999.

powerful symbol of “racism in medicine, misconduct in human research, the arrogance of physicians and government abuse of black people.”⁹¹ The consequence of this cynicism and symbol is that African Americans are more reluctant to participate in clinical trials and to benefit from such efforts.⁹²

At times, different vulnerabilities combine with consequences that are even more devastating. In North America this is glaringly evident when race and gender intersect. Although African American and Hispanic women comprise less than 25% of all women in the United States, they account for more than 75% of AIDS cases among women.⁹³

The literature presents a parallel between gender and race in terms of HIV/AIDS vulnerability. There are gender-based differences certainly. Women are more vulnerable than men to HIV infection for biological reasons and studies suggest that male-to-female transmission of HIV is twenty-four times as efficient as female-to-male transmission.⁹⁴ However, women’s biological susceptibility to HIV/AIDS is certainly exacerbated by their social and economic circumstances. For example the literature speaks:

- ◆ about how a “lack of economic resources can force women into survival sex where condom use is difficult to negotiate.”⁹⁵ A good deal of the literature suggests that many women have to depend on sexual relationships for economic survival, again reducing their bargaining power. Over Mead gives voice to a common theme when she suggests that both poverty and income inequality facilitate and speed the spread of HIV/AIDS.⁹⁶
- ◆ of the association between abuse, violence and HIV vulnerability. Elizabeth Whynot, writing in the *Canadian Medical Association Journal*, states that “[f]or women, previous sexual or physical victimization may be a predisposing factor in

The bleak reality is that the sexual and economic subordination of women fuels the HIV/AIDS epidemic.

UNAIDS, Agenda for Action, n.d.

[the] drug abuse” that places them at higher risk of HIV infection.⁹⁷ Meanwhile findings from a survey of 110 HIV-infected women, also presented in the *Canadian Medical Association Journal*, indicated that 53% had been sexually assaulted as an adult, 43% had been sexually abused as a child and 27% had been sexually abused or assaulted as both a child and an adult. Women who were so abused were almost seven times more likely than those who were not to have injection drug use as a risk

91 Gamble, 2000.

92 Auerbach, 2001:v.

93 CDC, 1997.

94 UNAIDS, Agenda for ..., n.d.:6/13.

95 arkin, 2000:4/10.

96 Mead, 2001:47-49.

97 Whynot, 1998.

All their life experiences teach them that they have very little control over their futures.

Sack, 2001

factor. Fifty-four percent of those with a history of sexual abuse during childhood had injection drug use as a risk factor compared to 8% of those without such abuse.⁹⁸

The literature is overwhelming in this regard. Using data gathered from 1100 women at risk of HIV infection, Health Canada indicates that over 67% reported sexual or physical violence by a current or past partner, while 33% had been victims of childhood sexual abuse and 15% of childhood physical violence.⁹⁹ Similarly a presentation to the XIth International Conference on AIDS documented the high prevalence of domestic violence and childhood abuse among women with HIV and among women at high risk of infection.¹⁰⁰ Other research indicated that abused women were four times more likely than others to engage in high-risk sex.¹⁰¹

Women in Canada are at increasing risk for HIV infection and illness progression for the same reason as women and other marginalized groups around the world are: we share a position on the bottom rung of the social ladder in inegalitarian societies.

Kellington, 2000

98 Kirkham, 1998.

99 Deamant, 1996.

100 Deamant, 1996.

101 El-Bassel, 1998.

Conclusions and Policy Implications

Peter Piot, Executive Director of UNAIDS, leaves little doubt about the source of women's vulnerability to HIV/AIDS. It derives "from contexts in which they have little control over sex, whether as a consequence of the predominating power relations between men and women or as a function of the economic and life choices available to them." In turn the impact of the epidemic further increases their vulnerability as women and girls from families whose economic well being has been weakened by AIDS may have to resort to the sex trade for their livelihoods. In this context "planning for the future becomes a more distant goal in the face of current devastation."¹⁰²

It is the grotesque, world-wide inequality, powerlessness, poverty and violation of women and girls that is fuelling the rapid-fire spread of the AIDS epidemic.

Landsberg, 2001:A2

HIV/AIDS, in other words, is caused in part by the poverty and powerlessness of women, and in turn – at the same time – increases their poverty and powerlessness by imposing either health or caregiving obligations. "The social framework of gender encircles and affects women's capacity and health."¹⁰³

The policy implications of these findings are clear.

- ◆ It is important not to confuse race with racism or attribute HIV vulnerability to race and gender rather than to the discrimination so often associated with these characteristics.
- ◆ Ensure that women, Aboriginal people and other stigmatized and marginalized groups are free of discrimination and can share equitably in the opportunities available in this country.
- ◆ Develop innovative activities targeting boys and girls that will promote more equitable and mutually respectful attitudes and behaviour. Develop coherent national policies, strategies and plans directed to this purpose.
- ◆ Incorporate efforts to address domestic violence in HIV/AIDS risk reduction and care strategies.

There is a direct correlation between women's low status, the violation of their human rights and HIV transmission. This is not simply a matter of social justice. Gender inequality is fatal.

Noeleen Heyzer, Executive Director, UNIFEM (Gender-AIDS, 21/1/001)

102 Piot, 2001:2/5.

103 Nagy-Agren, n.d.

3.6 Housing and Homelessness

Inadequate housing has long been used both as an indicator of poverty and as an intervention designed to improve public health. As early as 1944, the London Association for Education in Citizenship identified the “three evils” associated with inadequate housing:

There is diminished personal cleanliness and physique leading to debility, fatigue, unfitness and reduced powers of resistance. A second result of bad housing is that the sickness rates are relatively high, particularly for infectious, contagious and respiratory diseases. Thirdly, the general death rates are higher and the expectation of life is lower. The evidence is overwhelming and it comes from all parts of the world – the worse people are housed, the higher will be the death rate.¹⁰⁴

The basic human need for shelter makes the relationship between poor housing and poor health appear self-evident. Thomson and Petticrew, writing in the *British Medical Journal*, suggest that despite this intuitive relationship – or perhaps because of it – good research evidence is lacking on the positive health outcomes that may result from an investment in housing. They attribute this to the methodological obstacles inherent in exploring that relationship with the most formidable of these being that poor housing invariably exists alongside of other key health determinants. Similarly, housing improvements usually occur in tandem with other efforts to address social and economic needs.¹⁰⁵

Generally, however, the literature acknowledges the relationship between poor housing and poor health. Stephen Hwang, for example, notes in the *Canadian Medical Association Journal* that “Homeless people are at increased risk of dying prematurely and suffer from a wide range of health problems.... Homeless people also face significant barriers that impair their access to health care.”¹⁰⁶

Meanwhile homelessness is increasingly problematic in Canada. The number of homeless people in Canada doubled between 1992 and 1998 and now, each night, perhaps 8000 people in the country’s nine largest cities are sleeping in shelters. As many as 40,000 people – families, single men, single women and youth – use these shelters at least once through the course of a year. Aboriginal people are especially prominent in the shelters, accounting for 35% of the homeless population in Edmonton and 11% in Vancouver.¹⁰⁷ Until the very recent (2001) federal/provincial/territorial agreement, only the Government of Quebec appeared committed to enhancing its stock of social housing.

104 Starfield, 2001. Quoting J.N. Morris, Health Handbooks for Discussion Groups, Number 6. London: Association for Education in Citizenship, 1944.

105 Thomson, 2001:187.

106 Hwang, 2001.

107 Ibid.

Findings

The HIV/AIDS-related literature focuses largely on the issue of homelessness. It emphasizes that people living with HIV/AIDS require housing that is adequate, accessible and affordable, particularly in the inner cities where most people with HIV/AIDS live in order to access services.¹⁰⁸

The crises of homelessness and HIV are two of our country's greatest challenges. Rather than existing independent of each other, they are inextricably interwoven.

Adams, n.d.

- ◆ Over a decade ago, the Australian National HIV/AIDS Strategy (1989) identified the homeless as a group at particular risk of contracting HIV. A series of studies confirmed the alarm. A 1990 study of 40 homeless youth in Brisbane, published in the *Medical Journal of Australia*, indicated that the homeless had significantly less knowledge than a control group about HIV transmission and prevention. The homeless group were also more often involved with prostitutes, used condoms only infrequently and shared needles.¹⁰⁹ Interviews conducted in 1989 with 200 homeless young people in Melbourne found that 75% of the females and 62% of the males described themselves as drug or alcohol dependent. In Sydney, a survey of 92 young homeless people found that 36% of females and 64% of males reported sharing needles at least occasionally.¹¹⁰

A comparative study of Anglo-Australian and Greek-Australian youth, published in *AIDS Care*, suggested that the homeless were at considerably higher risk of HIV infection than were their home-based peers as a result of both their sexual and drug activities. Homeless adolescents not only engaged more frequently in risky sexual practices but did so with a comparatively large number of partners. This study's design included qualitative interviews and questionnaires with a total of 163 young people divided into participant and comparison groups.¹¹¹

Australia has also been particularly sensitive to the risk of HIV infection among homeless people with mental health problems. Interviewer-administered questionnaires completed by 145 patients with chronic mental illnesses in Australia showed alarming patterns. Sixteen percent of respondents reported injection drug use, a figure approximately 10 times that found in the general population. Almost 13% of male respondents reported sex with another male, including 9% who engaged in anal sex, while 19% of females reported sex with a bisexual male. Nearly half of the males reported sex with a prostitute, 2.5 times the rate evident in a

108 de Bruyn, 1998:28.

109 Matthews, 1990.

110 Rogers, 1992:1/8.

111 Rosenthal, 1994:1/17.

comparison group. Meanwhile only 16% of this population reported ever receiving information on HIV even though one-third reported having been tested for the virus.¹¹²

One can speculate that Australia's early awareness of the risks associated with homelessness has contributed to it now having one of the lowest infection rates in the developed world.

- ◆ In the United States, a comprehensive study prepared for the federal Department of Health and Human Services has estimated that between one-third and one-half of all people with AIDS are either homeless or at imminent risk of homelessness. Conversely, 15% of homeless Americans are infected with HIV. The study also found that homeless psychiatric patients at a New York shelter for men had an HIV prevalence rate double that of similarly aged men in the same inner-city community.¹¹³

Also in the United States, the American Civil Liberties AIDS Project tracked the spread of HIV in sixteen American cities during the 1980s and early 1990s. It identified a median HIV seroprevalence of 3.4% for homeless adults compared to less than 1% among the general population. More recent studies have found HIV infection rates of 8.5% among homeless adults in San Francisco and 19.4% among homeless, mentally ill men in New York City. A survey of homeless adults found that 69% were at risk of HIV infection because of their sexual or drug use practices, with 45% reporting at least two risk factors combined and 26% reporting three or more risk factors.¹¹⁴

Similarly the *Journal of Epidemiology and Community Health*, reporting on the situation in Philadelphia, found that people in public shelters had a three-year rate of subsequent AIDS diagnosis that was nine times that among the general population. A history of substance abuse, male gender and a history of serious mental disorder were significantly associated with the risk for AIDS diagnosis. The authors, associated with the University of Pennsylvania and the City of Philadelphia Health Department, used multiple decrement life tables analyses and logistic regression analyses to identify risk factors associated with AIDS among the homeless.¹¹⁵

- ◆ The Canadian literature is much more sparse with regard to homelessness although it has indicated that gay adolescents and youth are disproportionately represented among the homeless in Canada.¹¹⁶ Researchers with the BC Centre for Excellence found that injection drug users with unstable housing were twice as likely to

112 Thompson, 1997.

113 Goldfinger, n.d.:2.

114 Adams, n.d.

115 Culhane, 2001:515.

116 Ryan, 2000:52.

become infected with HIV¹¹⁷ and significantly more likely to report emergency department and hospital use, likely a reflection of their disorganized lifestyle or poorer health status.¹¹⁸

Conclusions and Policy Implications

HIV/AIDS and homelessness each represent a social crisis. Combining the two creates a level of social marginalization that has profound implications for both public health and the HIV/AIDS epidemic.

Access to safe, affordable housing helps people living with HIV/AIDS and marginalized people to follow medical and drug treatments. Housing is essential to their long-term stability.

BC, Minister's HIV/AIDS Advisory Committee, 2000:6

Homelessness and by implication poor housing clearly place people at higher risk of contracting HIV. Homelessness obliges people to engage in hasty sexual encounters in which condoms are rarely considered let alone used. It compromises their ability to insist upon safe sexual practices particularly if they must trade sex for shelter and penetration for protection. Homelessness leaves young people – already hurting – even more vulnerable to exploitation and abuse. It may oblige them to share needles since they do not have a private and safe place to keep their own injection equipment. The country's criminal code response to drug use only exacerbates this situation.

Homelessness and inadequate housing also make it more difficult for people to manage and live with their HIV/AIDS. Without secure housing, people do not have the stability required to maintain their treatments or their pharmacological regimens. Indeed their housing situation will make long-term health issues pale in comparison to their immediate distress and may well compromise even their interest in changing behaviours and pursuing, receiving and sustaining treatment. Furthermore, homelessness compromises community efforts to provide information and to prevent infection.

The literature carries important implications for policy and programming.

- ◆ Stabilize people's lives through safe and secure shelter and in that way prevent harm and reduce the likelihood of HIV infection. These efforts must enable the homeless – including those with mental illnesses – to escape the street and to address the issues that relegated them to the street in the first place.

117 Strathdee, Social determinants related ..., 1997.

118 Palepu, 1999.

- ◆ Target people at risk of HIV infection in efforts to prevent homelessness and to provide social housing. Conversely HIV prevention programmes should target homeless people and particularly those with mental illness issues. These are often one and the same populations.¹¹⁹
- ◆ Ensure that staff in shelters for the homeless are better informed on HIV/AIDS issues and are prepared both to identify the signs of HIV/AIDS-related illness and to encourage safer sexual and drug practices. Staff must be prepared for the significant challenge of forming trusting relationships and making consistent contact over time to help improve clients' situations and promote behaviour change.¹²⁰

3.7 Health Services

Most consider the health care system as being one of the important contributors to population health although Hobbs and Jamrozik, in the *Oxford Textbook of Public Health*, suggest there are few studies demonstrating the impact of medical services on the health of populations as opposed to that of individuals.¹²¹ Indeed one study presented in the *Journal of the American Medical Association* argues that the acute health care system itself inflicts significant harm.¹²² Other studies describe health care services as the ambulance waiting at the bottom of the cliff to rescue those cast off by society's social structures.¹²³

Medicine usually fails marginalized people.

Smith, 1999:1/5

Nevertheless it can be assumed that most people have considerable faith in the health care system and seek its services.¹²⁴ That assumption may not hold, however, for many of those at risk of HIV infection or living with HIV/AIDS. Indeed the health system itself is in part responsible for the poor health outcomes evident in these populations. For many women and others in marginalized groups, there are significant barriers blocking their access to treatment. A Health Canada and UNAIDS study suggests that the lack of "provider-client trust and of women-centred research, and general mistrust of confidentiality laws continue to exacerbate the fatalism of women, people of colour and marginalized groups regarding the manageability of living with HIV or AIDS."¹²⁵

Very simply, access to care and appropriate treatment are not available to many in those very populations that require the best of medical care.

119 Culhane, 2001:515.

120 Center for AIDS Prevention Studies, n.d.

121 Hobbs, 1997:232.

122 Starfield, 2000: 483.

123 Gilligan, 1996.

124 Armstrong, 2001. See also Bezruchka, 2001.

125 Anderson, 1999:13

Findings

- ◆ A study undertaken by the Centers for Disease Control and Prevention in the United States indicated that the majority of those with HIV/AIDS as a result of injecting drugs are not receiving optimal drug therapy. Similarly a Baltimore study employing cross-sectional survey techniques and reported upon in the *Journal of the American Medical Association* concluded that only one in seven HIV-infected IDU patients received the most currently recommended therapy. In fact, only half of HIV-infected injection drug users being treated at Johns Hopkins and the University of Maryland – “cutting edge AIDS care providers” – received anti-retroviral treatments.

The Baltimore study also indicated that even those who no longer used drugs were denied optimum treatment, often because of their physicians’ concern that they would not, or could not, comply with the treatment regimen. The Director of the Brown University AIDS program offered another reason, namely that “doctors discriminate against HIV-infected IDUs” and often believe that “once a user, always a user.”¹²⁶

- ◆ This pattern appears in Canada also even though access to health care and treatment is largely guaranteed and free. *AIDS Alert* reported on a Steffanie Strathdee study indicating that only 40% of 177 patients received any antiretroviral therapy.¹²⁷ Similarly an article published in the *Canadian Medical Association Journal* indicated that 17% of HIV-positive women reported having had doctors refuse to see them because of their status.¹²⁸ The results were drawn from a 75-item questionnaire distributed through community AIDS organizations and physicians’ offices. A total of 110 HIV-positive women responded to this survey.

This pattern is evident also in the results from a survey of dentists practising in Canada. The survey was mailed to a random sample of all licensed dentists in Canada (n=6444) and enjoyed a response rate of 66%. The data were weighted to allow for probability of selection and non-response and analyzed using various econometric techniques.

The data revealed that 16% of dentists would refuse to treat HIV-infected patients. Eighteen percent were unwilling to treat homosexual and bisexual persons or patients with a history of sexually transmitted diseases while 10% were unwilling to treat recipients of blood and blood products. At the same time, 87% said they were perfectly capable of safely treating a person with HIV.¹²⁹

- ◆ A Health Canada and UNAIDS study suggested that those using injection drugs and sharing needles “have the least access to care for two reasons. Socially isolated and often living with a mental health problem, they seldom seek any kind of health

126 AIDS Alert. 1998.

127 Ibid.

128 Kirkham, 1998:7/13.

129 McCarthy, 1999:541.

care.” Additionally Canada – and many other countries – has a “drug policy” that is more likely to imprison drug users than provide health care or the range of other social supports that could allow them to address their drug and other problems.¹³⁰

Conclusions and Policy Implications

It is more than a quarter century since Julian Hart published his famous paper on “the inverse care law” which suggests that those who most need medical care are the least likely to receive it.¹³¹ The application of this law is most obvious on a global level where the highest rates of sickness and premature death are in the developing world while high quality medical care is concentrated in the developed world.

John Mann has used this “law” to argue that when HIV is introduced into a society it will eventually be concentrated among those whose rights are most neglected – the babies of women too poor to have their HIV infection diagnosed or treated, prostitutes whose clients refuse to wear condoms, and addicted prisoners who are denied access to clean needles and pure drugs.

Most doctors will encounter patients struggling with their addictions and some will be reluctant to accept them into their practice. The perception is that this group is likely to create more difficulties and to have more demanding medical needs than other patients. In essence, because the health care system “is designed for compliant groups, HIV infected injection drug users are discriminated against when attempting to access this care.”¹³² The literature suggests this applies as well to other groups on the margin, including homeless people, those who are mentally ill, refugees and many youth.

With all marginalized groups the poorer standard of care seems to stem from a combination of ignorance, fear and prejudice plus a feeling that they should adapt to the services rather than the other way around.

Smith, 1999

The policy directions to be pursued, therefore, are numerous.

- ◆ Ensure quality treatment is accessible to people living on the margins of mainstream society, and that the medical care system can reach out to these groups. The health care system needs to find innovative ways to build trust and to provide service that is flexible and appropriate to a wide range of clients including those who cannot readily comply with standard regimens.¹³³

130 Canada, 2000:9.

131 See J.T. Hart, The inverse care law. In Lancet, 1971, i:405-12.

132 Canadian Centre on Substance Abuse, 1994:33.

133 Anderson, 1999:13; see also Canadian Centre on Substance Abuse, 1994:33.

- ◆ Access to timely and adequate health care for persons with HIV must be considered as an ethical issue given the success of newer HIV treatments, especially when health care and HIV medications are generally available and free.¹³⁴
- ◆ The health care system must be prepared to treat the whole person, both their immediate HIV/AIDS-related problems and their underlying mental health and socio-economic issues.
- ◆ Educate both the public and governments so they recognize that injection drug users have a personal health problem with major public health implications. Incarceration is not an answer and apathy is not a solution.

134 Schilder, 2001:1643.

4. Conclusions: Making Sense and Making Progress

The literature presents compelling evidence of the relationship between the social determinants of health and HIV/AIDS. It does so in spite of the significant methodological challenges inherent in such work. Researchers, for example, often have not been able to construct the control or comparison groups that would solidify their findings. Often they have not had the funding necessary for following participants through an extended period of time. Often the threat posed by the epidemic has obliged researchers to focus their attention on practical short-term prevention and treatment issues rather than on the broader and longer-term implications of their findings.

These challenges – and the questions that remain unanswered – should not be used as a rationale for dismissing the literature’s underlying themes and conclusions, particularly since these are consistent both with the literature in other policy realms and with common sense itself. Governments and policy makers “need to be aware that in many fields there are no unequivocal answers.”¹³⁵

The following integrates the findings from the previous sections and endeavours to assess the body of literature that places HIV/AIDS in a population health context. It is followed by a consideration of the most appropriate strategy for building a population health approach to the HIV/AIDS epidemic.

4.1 Making Sense

The research strongly suggests that the social determinants of health influence a person’s risk of HIV infection, the speed with which HIV infection will progress to AIDS and a person’s ability to manage and live with HIV/AIDS.¹³⁶

The microbe is nothing, the terrain is everything

Louis Pasteur

These determinants include emotional, physical and sexual abuse during childhood as well as inequities based on income, race and gender. Importantly, racism and discrimination – not race, culture or gender themselves – leave groups of people particularly vulnerable to HIV infection by excluding them from the social and economic mainstream and by denying them the social supports needed to enhance and preserve life. These inequities are compounded by a health care system that periodically insists upon compliance. The system is

135 MacIntyre, 2001:224.

136 House of Commons Standing Committee on Health, 1996:8/32.

not always willing to adjust to the cultural and social needs of its patients. This reticence creates barriers that compromise access and, for some people, the Canadian commitment to universal access is more a principle than a reality.

These social inequities and health determinants act at the level of the individual, for example, when child abuse and adult homelessness increase the likelihood of a person engaging in high-risk behaviours. They act also at the societal level, for example when economic inequalities between men and women affect the latter's ability to negotiate safe sex practices or when short-term life necessities – the need for food and shelter, and even the need for drugs – make one's long-term health prospects an academic concern. Economic survival in the short term will invariably be a more pressing necessity than good health in the long term.

It is no coincidence that Canada's metropolitan centres are struggling to manage the HIV/AIDS epidemic and its spread. Here poverty, homelessness and social isolation are increasing in intensity and are leaving people at risk of infection.

AIDS is a disease that holds a magnifying glass to some of America's ugliest social problems such as homophobia, drug use, poverty and racism.
AIDS Weekly Plus, Conference Coverage, 1996.

Among the determinants, poverty and income inequity are certainly at the very core of the relationship between HIV/AIDS and population health. Angus Deaton, writing for the National Bureau of Economic Research in the United States, emphasizes that

“equal societies have more social cohesion, more solidarity, and less stress; they offer their citizens more social support and more social capital; and they satisfy humans' evolved preference for fairness. Equal societies are healthier.”¹³⁷

Abuse, violence and early childhood experiences are also at the core of this relationship. Importantly, however, the population health literature indicates how the many different determinants are so fully interwoven.

- ◆ those living in poverty are very often those who are visible minorities or Aboriginal, and those who have a limited education;
- ◆ those with a limited education are very often those who endured abuse as children or who grew up in emotionally impoverished households;
- ◆ those who were emotionally or economically impoverished as children are very often those with limited job security and no control over their working conditions, or those who are homeless and at high risk of infection, or those who are searching for companionship and security through sharing needles and taking sex at any risk; and

137 Deaton, 2001:1.

- ◆ those who are poor, or homeless, or injection drug users, or mentally ill or discriminated against are very often those whose access to the health care system is most limited regardless of their heightened need.

Groundbreaking Canadian studies dating from the early 1980s – the Vancouver Lymphadenopathy AIDS Study for example or the more recent Vanguard and Point projects – and the high infection rates among people who are homeless and have serious mental illnesses speak to this interconnectedness.¹³⁸

The most powerful determinant ... is not race or gender or sexual orientation. It is class. In that respect, there are just two AIDS epidemics: the one among people who, by virtue of their education and income, lead stable lives and the one among people who do not.

Stolberg, 2001

4.2 Making Progress on Population Health

The literature frequently offers recommendations for influencing individual and community behaviour. Distributing condoms and clean needles, and encouraging less risky sexual behaviour all figure prominently as do special efforts targeted to specific at-risk groups, for example prisoners, homeless youth and those who inject drugs. Behavioural change and targeted efforts are vitally important for managing the epidemic. Indeed more such efforts are required if Canada is to prevent the spread of AIDS and provide appropriate treatment and care to those living with HIV/AIDS.

... logic would suggest that it takes more than information, leaflets and condoms to combat the forces in a person's life that might make them likely to engage in risky sexual behaviour. What is required is action that acknowledges the many and varied influences on an individual, including childhood experiences, employment, immigration and partnership rights.

Worrall, 2001:1

However, leaving prevention to behavioural change – to condoms – reinforces the notion that HIV transmission is narrowly the result of personal shortcomings and group dynamics. As the tobacco industry knows so well, people do not change their behaviour on the basis of an intellectual awareness that they are putting themselves at risk. This is particularly true for those most vulnerable to HIV infection. Such efforts, while essential in the short term, are not the answer for the long term.

138 See Strathdee, Social determinants related ..., 1997:2; see also Goldfinger, n.d.:3.

Similarly Canadians will not prevent the spread of HIV/AIDS by committing more resources to the health care system alone. The United States, for example, spends more on health care than any other nation yet has an adult HIV rate many times that of other industrialized nations.¹³⁹ Indeed relying too heavily on the health care system to address HIV/AIDS and other health problems could diminish population health by consuming resources that could otherwise be committed to those efforts that will make a lasting difference.

Canada needs a better approach to HIV/AIDS and to health. In this regard, policy makers must recognize that behaviour change is less a process of individuals deciding to change than “a process of communities changing their standards of behaviour and values.”¹⁴⁰

The effects of the usual do's and don'ts that we all preach pale in comparison with the effect of society's structural factors on population health.

Bezruchka, 2001:1701

Governments and policy makers need to build fences at the top of the cliff – providing income and personal security, stability, self-esteem and social support – if they want to dramatically reduce the need for ambulances at the bottom.

Consciousness does not automatically lead to commitment.

Landsberg, 2001:A2

It is not clear why Canada and other countries have not built more fences. Given the research and the advice of those undertaking the research, given the experience of those living with HIV/AIDS, and given the intuitive logic of the population health approach, it is perplexing that “so much evidence apparently generate[s] so little action....”¹⁴¹ Perhaps governments and society have been reticent to act in this vein because:

“... poverty as a root cause of ill health is both evident and paralysing to further thought or action.

Mann, 1996

- ◆ the results of preventive social programming are inherently invisible since their success is measured by the absence of problems and since their outcomes are separated in time from the effort;

139 Spigelman, Taking Stock, 2001a:22. See also Auerbach, 2001:1.

140 Carr, 1991:12/13.

141 McInnis, 2001:391.

- ◆ the rescue is much more dramatic than prevention, and prevention often requires an investment based as much on faith and conviction as on documented evidence; and
- ◆ prevention must address multiple causes whereas medical care focuses only on the visible manifestation of a disease or injury.

Furthermore society appears to place a premium on the technological fix – a new vaccine or a new MRI. These are more tangible than low-profile efforts that distribute wealth more equitably or that ensure children are physically and emotionally well nourished.

Leadership and a Social Justice Agenda

First and foremost, building fences rather than buying ambulances requires strong, committed, non-partisan leadership at the highest levels in the community and in governments across the country. This leadership must embed the population health concept within their vision of Canada. And, most importantly, their vision has to incorporate a social justice agenda encompassing efforts:

- ◆ to reduce the income and other inequalities evident in Canada. This may well require reversing the trend of the past decade through adjustments within the tax system and by improving the employment potential of all Canadians. It may require new employment initiatives, higher minimum wage rates, improved income security programs and enhanced access to health care.
- ◆ to invest in the country's children and youth by preventing violence and abuse and by ensuring gender equity. It may require expansion of the National Child Benefit as well as early childhood education initiatives, new Head Start programs in low-income neighbourhoods, special efforts to retain youth in the school system and to prevent illiteracy, and an increased public commitment to social housing.
- ◆ to ensure that discrimination is not a factor in Canadian society, and that those who are socially isolated and living on the margin – because of mental or other illnesses, disability, sexual orientation, race, culture or gender – are able to participate fully in the mainstream of Canadian economic and social life.

In essence, the social justice vision and agenda has to strengthen Canadian communities by building social cohesion.

Social goals such as these can be practical objectives if commitment and leadership are present. The challenge of enlisting leaders to champion the effort and of building the commitment necessary is formidable and daunting. It is important to recognize, however, that “[d]isparities in health between social groups ... are not inevitable – it is possible to challenge health inequities with purposeful public policy. And such a challenge is long overdue. We need not and must not tolerate such inequities.”¹⁴²

142 Evans, 2001:15.

Society creates these social determinants and has both an opportunity and a responsibility to change them.

Canada, House of Commons, 1996:8/32

It is also important to recognize that some decades ago, seniors and senior women in particular were among the poorest in Canada. Political leadership and commitment, community support and sustained effort have ensured they no longer inhabit that bottom rung of the economic ladder. Fundamental social change is possible when there is leadership, commitment and community consensus.

Importantly a social justice agenda would address the full range of social problems – including the HIV/AIDS epidemic – that are so painfully evident today. And it would do so in a manner that the health care system alone cannot. This agenda would also give Canadians the tools they require to address new challenges as they emerge in the future.

Progress toward this social justice agenda, toward a population health model and toward a more lasting strategy for addressing the HIV/AIDS epidemic will require what Trussler and Marchand refer to as “Action Steps.”¹⁴³ Cooperation and coordination, research and education, and applying the lessons of population health must all be among these action steps.

Knowing is not enough; we must apply. Willing is not enough; we must do.

Goethe

Co-operation and coordination across agencies and jurisdictions

There currently exists a strong foundation for cooperation and coordination across agencies and jurisdictions. The Canadian Strategy on HIV/AIDS brings together federal departments as diverse as Health Canada, Correctional Service Canada, the Canadian International Development Agency and the Department of Justice. There is a national Ministerial Council on HIV/AIDS and a Federal/Provincial Territorial Advisory Committee on HIV/AIDS. Some provinces have their own interdepartmental committees and there is the social union framework and the many other federal/provincial/territorial forums at the political and bureaucratic levels.

Partnerships must be built across levels [sic] of government and between institutions, departments and sectors if resources for health are to be unlocked.”

Zollner, 1998:8

143 Trussler and Marchand, 1997.

These can be used to broaden the understanding of population health and to build a consensus around the need for a social justice agenda that incorporates the population health model.

In building this commitment and consensus, it will be important for Health Canada, its provincial and territorial counterparts, and the various HIV/AIDS-related committees to build partnerships with other agencies that already understand population health, for example with every governments' human resource development, education, housing and Aboriginal affairs departments. It will be equally important, however, to reach out to those departments and non-governmental agencies that are not consistently involved in developing social policy, for example the Departments of Finance and Treasury Boards in each jurisdiction and lobby groups such as the Business Council on National Issues. Progress toward a social justice agenda will require that they too understand the issues.

Given the importance of leadership in this endeavour, these efforts should be directed initially at Ministers, Deputy Ministers and senior staff in the hope that their understanding and commitment will then permeate their respective organizations.

Research and Education

Building leadership, commitment and a public consensus will require efforts that place epidemiology more clearly into a population health and social justice context. Research is needed to associate the social determinants with longer-term health outcomes. Research is needed to identify opportunities for promoting population health within the different public policy sectors that can contribute to the social justice agenda. Research is needed to articulate the potential cost savings and public health benefits associated with a social justice agenda. And this research has to have sufficient resources to build appropriate comparison groups and to follow people through an extended period of time. In this regard, governments' current efforts to report on the social indicators associated with population health are an important beginning. Similarly there may be potential for further incorporating social justice and population health issues in the National Longitudinal Survey of Children.

Efforts are also required to help Canadian communities understand how population health can be transformed from a theoretical model into a practical reality. A "best practices" inventory of community initiatives that have incorporated this perspective into their daily activities may be a good beginning.

There would be value also in reaching out to those governments and commissions currently endeavouring to analyze or reform the Canadian health care system. Such efforts would provide the population health model with a broad public forum and HIV/AIDS can be a vehicle for encouraging people to expand their vision. Indeed the current commitment to universal and public health care can be sustained only if the Canadian vision is broadened in this way.

Furthermore, Health Canada, the Canadian Strategy on HIV/AIDS and the Canadian Institutes for Health Research could provide support to researchers and research entities such as the BC Centre for Excellence to enhance their ability to share their knowledge with a broader and more general audience. Importantly, these audiences are interested less in control groups and regression analysis than in what population health means for them and their community. These researchers need to communicate their findings and conclusions in ways that are compelling and effective, and through vehicles other than technical and medical journals. Much of the population health and epidemiological evidence available today is not available to the communities from which support is required for pursuing a population health model.

Applying Population Health Lessons to HIV/AIDS

The effort to manage the HIV/AIDS epidemic cannot stand still while building community understanding of and support for a population health model, and while enlisting leaders and champions for a social justice agenda. It is important, therefore, to move certain HIV/AIDS-related activities in directions that reflect the current understanding of population health. These more narrowly focused efforts could include, for example, measures:

- ◆ to expand the commitment to addressing in a holistic way the needs of people vulnerable to HIV infection or living with HIV/AIDS, by engaging leaders from other policy sectors in the work of the Federal/Provincial/Territorial Advisory Committee on AIDS.
- ◆ to explore with Statistics Canada the potential for further incorporating issues relating to HIV/AIDS and population health in the National Longitudinal Survey of Children.
- ◆ to use the opportunity presented when testing pregnant women for HIV to offer interventions addressing the underlying factors that have placed them at risk of HIV infection.
- ◆ to provide training to staff in shelters for the homeless so they are prepared to address the relationship between HIV/AIDS and homelessness, and the HIV risks associated with homelessness especially among youth and those with mental health issues.
- ◆ to provide training to those working with people with mental illnesses, in recognition of their particular vulnerability to HIV infection.
- ◆ to integrate sexual abuse counselling with HIV prevention efforts and to link the Canadian Strategy on HIV/AIDS with the Social Union, the National Children's Strategy and other early childhood development efforts.
- ◆ to expand the harm minimization programs currently in place, particularly in relation to those injecting drugs, and to address addictions in a social and health context rather than as a criminal justice issue.

- ◆ to build a range of supports for the children of parents living with HIV/AIDS so as to ensure that their life chances are not compromised.
- ◆ to develop protocols to assist hospitals and health professionals meet the particular needs of marginalized groups and to provide care and support to people living with HIV/AIDS in ways that are sensitive to their individual and cultural requirements.
- ◆ to re-orient thinking and reporting so as to focus on racism and discrimination rather than race and those groups who are particularly vulnerable to HIV infection.

Governments and researchers often “know more about what needs to be done than ... about how to do it.”¹⁴⁴ The first action step toward “what needs to be done” may well be for Health Canada, the Ministerial Council on HIV/AIDS and the Federal/Provincial/Territorial Advisory Committee on AIDS to cooperatively develop a strategic plan for progressing in each of the directions outlined above. The Health Canada Direction-Setting Meeting scheduled for April 2002 would be an appropriate forum for discussing this plan and for enlisting the support of HIV/AIDS-related organizations working at both the national and community levels. This Meeting could certainly advise on priorities and on building the strategic partnerships that are vital to a population health model for HIV/AIDS.

Given the nature, threat and impact of HIV/AIDS, there are no practical alternatives to the population health model and a social justice agenda. Governments and society need to regard the HIV/AIDS epidemic not as a health issue alone – and certainly not as a moral issue – but as a legal issue, a human rights issue and an equity issue. A nation’s health must be treated as a barometer of its commitment to social justice and human rights. Common sense, practical experience and a wealth of research from around the world indicate that societies are investing wisely when they endeavour to build a population health fence at the top of the cliff.

Doing so will require leadership, commitment and sustained effort to build social cohesion by addressing poverty, unemployment, illiteracy, inadequate housing, social isolation, violence, abuse and discrimination. Without efforts to fundamentally improve community health and well being, Canadians will continue to struggle with the manifestations rather than the root causes of the HIV/AIDS epidemic. And the severity of the epidemic will continue to surpass even the most pessimistic predictions.¹⁴⁵

144 99, UNAIDS, *Gender and HIV/AIDS*, 1999:4

145 Piot, 2001.

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Appendix A – Information Sources

Literature Data Bases

InfoAction (The Information & Research Centre, infoact@vpl.vancouver.bc.ca) at the Vancouver Public Library searched the following sources for relevant literature:

- ◆ OCLC including PAIS, Social Sciences Abstracts, SIRS, ECO, Proceedings and WilsonSelectPlus
- ◆ All Canadian HIV/AIDS-related associations from the Associations Canada List
- ◆ Canadian Business and Current Affairs (including scholarly journals)
- ◆ Dow Jones Health and Medical (The Lancet, Women and Environments, AIDS Weekly, AIDS Alert)
- ◆ Applied Science and Technology Index
- ◆ Health Canada, Bureau of HIV/AIDS, STD and TB website
- ◆ BC Centre for Excellence in HIV/AIDS
- ◆ Canadian Bureau of HIV/AIDS
- ◆ BC Ministry of Health
- ◆ Vanguard Project
- ◆ Canadian Foundation for Drug Policy
- ◆ National Resource Centre on Homelessness and Mental Illness
- ◆ Microlog and the Canadian Research Index (government/consultants' reports)
- ◆ Canadian News Disc (Canadian newspapers)
- ◆ Ebsco including Health Source Academic, Academic Source Elite and Masterfile databases
- ◆ Medline for North America, Europe and Australia
- ◆ European Database on AIDS and HIV (www.edoa.org)
- ◆ National AIDS Trust (United Kingdom)
- ◆ Sigma Research (United Kingdom)
- ◆ U.K. Department of Health
- ◆ European Commission
- ◆ E-Library

- ◆ British HIV Association/Foundation for AIDS
- ◆ HIV Outreach Research Project
- ◆ Community HIV and AIDS Promotion Strategy
- ◆ UNAIDS
- ◆ World Health Organization
- ◆ University of British Columbia Library Catalogue
- ◆ Electric Library
- ◆ Vancouver Public Library Catalogue
- ◆ Government and institutional websites from Canada, the United States, the United Kingdom, Australia and elsewhere
- ◆ Australian National HIV/AIDS Strategy site
- ◆ National Centre in HIV Social Research
- ◆ Australian Research Centre in Health and Society

List Serves

The following list serves produced over 30 responses from Canada, the United States, Bolivia, UNAIDS, the United Kingdom, Italy, India, Saudi Arabia, Gambia, South Africa and elsewhere.

- ◆ Health Promotion on the Internet, York University – Click4HP@YorkU.ca;
- ◆ Community Health List – Community-health-L@MAIL.MSH.Org; and
- ◆ PWHANet (gender, community research, PWHANet, Human Rights, sea-AIDS, INTAIDS, Treatment-Access).
 - INTAIDS – www.hivnet.ch:8000/global/intaids/
 - Community Research – www.hivnet.ch:8000/global/community-research/
 - Gender AIDS – www.hivnet.ch:8000/global/gender-aids/
 - Human Rights – www.hivnet.ch:8000/global/human-rights/
 - PWHANET – www.hivnet.ch:8000/global/pwha-net/
 - Treatment-Access – www.hivnet.ch:8000/global/treatment-access/

Internet-Based Sites Consulted

- ◆ The American Foundation for AIDS Research (amfAR):
<http://www.amfar.org/cgi-bin/iowa/index.html>
- ◆ Center for AIDS Intervention Research (CAIR), Medical College of Wisconsin:
<http://www.mcw.edu/psych/cair.html>; <http://www.cair.mcw.edu/>
- ◆ National Library of Medicine, PubMed: <http://www.ncbi.nlm.nih.gov/PubMed/>
- ◆ New England Journal of Epidemiology and Community Health:
<http://jech.bmjournals.com/>
- ◆ British Medical Journal: <http://bmj.com/>
- ◆ BMJ links to articles relating to the social determinants of health:
http://bmj.com/cgi/collection/socioeconomic_determinants_of_health?notjournal=bmj&page=12
- ◆ American Review of Public Health: <http://www.apha.org/>
- ◆ American Public Health Association, AIDS Research:
http://www.apha.org/public_health/aids.htm
- ◆ American Public Health Association, Selected Internet Resources for Health Education and Health Promotion: http://www.apha.org/public_health/hphe.htm
- ◆ Centre for Health Promotion, University of Toronto: <http://www.utoronto.ca/chp/>
- ◆ AIDS and Public Policy Journal: <http://www.upgbooks.com/page24.html>
- ◆ Journal of Epidemiology and Community Health: <http://jech.bmjournals.com>
- ◆ National Centre in HIV Social Research: <http://www.arts.unsw.edu.au/nchsr/>
- ◆ Social Policy Research Centre (Australia): <http://www.sprc.unsw.edu.au/>
- ◆ Australian Centre for Health Promotion: <http://www.achp.health.usyd.edu.au/>
- ◆ National Centre for Epidemiology and Population Health (Australia):
<http://nceph.anu.edu.au/>
- ◆ Health Transition Review (Australia): <http://nceph.anu.edu.au/>
- ◆ Martin T. Schechter, publications as identified at www.google.com
- ◆ Steffanie Strathdee, publications as identified at www.google.com
- ◆ Community Health and Epidemiology, Dalhousie University:
www.medicine.dal.ca/che/papers.asp? and <http://www.medicine.dal.ca/che/research/>
- ◆ Centre for Health Evaluation and Outcome Sciences.
<http://www.cheos.ubc.ca/cheospubl.html>

- ◆ Health Services Utilization and Research Commission, Saskatchewan:
<http://www.hsurc.sk.ca/>
- ◆ Centre for Health Economics and Policy Analysis, McMaster University:
<http://www.chepa.org/>
- ◆ Canadian Health Services Research Foundation: <http://www.chsrf.ca>
- ◆ New York City AIDS Housing Network: <http://www.nycahn.org/>
- ◆ AIDS Prevention and Research:
<http://www.guilford.com/cartsript.cgi?page=periodicals>
- ◆ Boston Review: <http://bostonreview.mit.edu/>
- ◆ WHO Statistical Information System: <http://www.who.int/whosis/>
- ◆ The Lancet: <http://www.thelancet.com/journal>
- ◆ The National Academies, Institute of Medicine: <http://www.iom.edu/>
- ◆ The Body: An AIDS and HIV Information Resource:
<http://www.thebody.com/index.shtml>
- ◆ American Medical Women's Association:
<http://www.amwa-doc.org/publications/amwapub.html>
- ◆ Applied Research Branch, Strategic Policy, HRDC:
<http://www.hrdc-drhc.gc.ca/arb/publications/research/>
- ◆ CDC National Prevention Information Network: <http://www.cdcnpin.org/>
- ◆ Canadian Health Network:
http://www.canadian-health-network.ca/1AIDS_HIV.html
- ◆ Terrence Higgins Trust, U.K.: <http://www.tht.org.uk/>
- ◆ The AIDS Reader:
<http://id.medscape.com/SCP/TAR/public/archive/2001/toc-1105.html>
- ◆ U.K., All Party Parliamentary Group on AIDS: <http://www.appg-aids.org.uk>
- ◆ World Bank PovertyNet: <http://www.worldbank.org/poverty/strategies/index.htm>
- ◆ Canadian HIV/AIDS Legal Network: <http://www.aidslaw.ca/home.htm>
- ◆ Canadian AIDS Society: www.cdnaids.ca/
- ◆ BC Centre of Excellence in HIV/AIDS: www.cfeweb.hivnet.ubc.ca
- ◆ The Vanguard Project: <http://cfeweb.hivnet.ubc.ca/vanguard/homeframe.html>
- ◆ National Resource Center on Homelessness and Mental Health:
<http://64.226.226.10/nrc/>

- ◆ American Civil Liberties Union: <http://www.aclu.org/issues/aids/hmaids.html>
- ◆ Canadian HIV/AIDS Clearinghouse:
http://www.clearinghouse.cpha.ca/english/index_e.htm
- ◆ UNAIDS publications by topic: www.unaids.org/aidspub/publication_all.asp?
- ◆ Australian Research Centre in Sex, Health and Society:
<http://www.latrobe.edu.au/arcs/shs/frontpage.html>
- ◆ Interagency Coalition on AIDS and Development:
<http://www.icad-cisd.com/content/home.cfm?lang=e>
- ◆ Australian Federation of AIDS Organisations: www.afao.org.au
- ◆ UK Gay Men's Health Network:
http://communities.msn.co.uk/GayMensHealthNetwork/_whatsnew.msnw
- ◆ U.S. Department of Health and Human Services: <http://www.hhs.gov/>
- ◆ Institute of Health Promotion Research, UBC: <http://www.ihpr.ubc.ca/>
- ◆ Housing Works, New York: <http://www.housingworks.org/about.htm>
- ◆ National AIDS Trust, UK: <http://www.nat.org.uk>
- ◆ AIDS Links (Australia): <http://www.arts.unsw.edu.au/nchsr/>
- ◆ International Journal of STD and AIDS: <http://www.rsm.ac.uk/pub/std.htm>
- ◆ CDC national Prevention and Information Network:
<http://www.cdcnpin.org/hiv/start.htm>
- ◆ European Union, HIV/AIDS Programme in Developing Countries:
<http://europa.eu.int/comm/development/aids/index.htm>
- ◆ Health and Development Networks: <http://www.hdnet.org/home2.htm>
- ◆ AIDS Education and Prevention, An Interdisciplinary Journal:
http://www.guilford.com/cartscript.cgi?page=periodicals/jnai.htm&cart_id=
- ◆ The Rockefeller Foundation:
<http://www.rockfound.org/display.asp?Context=1&Collection=1&Preview=0&ARCurrent=1>
- ◆ Laboratory Centre for Disease Control, Canada:
http://www.hc-sc.gc.ca/pphb-dgspsp/new_e.html