Healthy Public Policy

Assessing the Impact of Law and Policy on Human Rights and HIV Prevention and Care

Phase One

Synthesis Report of the Literature Review and Environmental Scan

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Executive Summary

Why is research on the impact of laws and policies important?

Many people intuitively understand that factors such as income, employment, education, and social support systems affect physical and mental health, and there is a body of literature illustrating these relationships, both generally and in specific relation to HIV prevention, care, treatment and support. A "population health" approach, the conceptual basis of the Canadian Strategy on HIV/AIDS (CSHA), acts upon this broad range of "determinants of health" to promote health.

Laws and policies also affect the health of individuals, communities and populations, but are not often included among the determinants of health. In some cases the impact on health is direct and easily observed – for example, a law denying health insurance to a certain group of people will negatively affect the health of that group and individuals within it. In other cases, it may be more indirect or diffuse, requiring more careful scrutiny and research to determine whether it is sound from the point of view of protecting and promoting health – for example, what is the health impact of a law requiring that the names of all people testing HIV-positive be reported to government health authorities? Laws and policies are "structural" determinants, in that they often determine the other, more widely recognized determinants of health. Yet the impact of laws and policies on health has not attracted the same attention from researchers as other determinants, although there is increasingly a call for "evidence-based policy" in many areas, including in the area of health-related policy.

At the same time, as a matter of law and of ethical obligation, human rights standards should guide national and local policy-makers in making HIV-related policy.[1] Therefore, "healthy public policy" is characterized by explicit concern for both health and human rights, and by accountability for the impact on both. But what is the relationship between the health and human rights? As the World Health Organization has explained:

There are complex linkages between health and human rights:

- Violations or lack of attention to human rights can have serious health consequences;
- Health policies and programmes can promote or violate human rights in the ways they are designed or implemented;
- Taking steps to respect, protect and fulfil human rights can reduce vulnerability and the impact of ill health.[2]

[1] E.g., Joint United Nations Programme on HIV/AIDS and the Office of High Commissioner for Human Rights. *HIV/AIDS and Human Rights: International Guidelines*. Second International Consultation on HIV/AIDS and Human Rights, Geneva, 23-25 September 1996. New York, Geneva: United Nations, 1998. Available at: http://www.unaids.org/humanrights/

[2] World Health Organization. *25 Questions and Answers on Health and Human Rights*. Health and Human Rights Publication Series, Issue No. 1, July 2002. Available on-line at: www.who.int

The mere assertion that health and human rights are interdependent - and that policy that respects and promotes the human rights of people living with HIV/AIDS and vulnerable groups is therefore sound public health policy - is often insufficient to guide the response of policy-makers to HIV/AIDS and related issues. "If they are to be effective", it is essential to base legal and policy responses upon a good empirical understanding: "AIDS laws must not be based upon ignorance, fear, political expediency and pandering to the demand of the citizenry for 'tough' measures. Good laws, like good ethics, will be founded in good data".[3]

What is required is research data analyzing the connections between particular legal/policy options and their impact on both human rights and the health of individuals, communities and populations infected and affected by HIV/AIDS. With this evidence, decision-makers can avoid enacting laws, making legal judgments, or creating policies that infringe human rights and that damage the health of individuals and the public more generally. Such research will help in responding to HIV/AIDS by creating a legal/policy environment that supports, rather than undermines, HIV prevention efforts or promotes, rather than impedes, HIV/AIDS care, treatment and support. Most importantly, research on the impact of laws and policies will assist people living with HIV/AIDS by informing their own advocacy and build communities' capacities to improve health for all. Unfortunately, the empirical data on laws and policies as structural determinants of health is under-developed. Similarly, in the specific context of HIV/AIDS, there is limited empirical data illustrating the positive health outcomes of laws and policies that respect and promote human rights.

What does assessing the impact of laws and policies entail?

In June 2001, the Canadian HIV/AIDS Legal Network obtained "project formulation" funding under the Canadian Strategy on HIV/AIDS to design a community-based research project assessing the impact of law or policy on the human rights of people living with and affected by HIV/AIDS, and how this affects their health and public health. Community-based research is research conducted by and for communities. The project formulation is divided into two phases.

- The first phase of this project, completed in June 2002, reviewed the literature and did an environmental scan of what research has already been done, and what research still needs to be done, on the impact of different laws/policies on HIV prevention and on HIV/AIDS-related care, treatment and support.
- Based on this information, in the second phase, the Canadian HIV/AIDS Legal Network will design, in partnership with another community-based organisation and an experienced researcher, a community-based research project proposal to gather data on one key, under-researched issue. That proposal will then be submitted for funding and will be implemented if funding is received.

[3] Kirby M. *A Paradoxical Relationship of Mutual Interest*. Paper presented at IUVDT World STD/AIDS Congress, Singapore, 22 March 1995 [emphasis added]. Available on-line at: www.fl.asn.au/resources/kirby/papers/

What does this report contain?

This report summarises the results of the literature review and environmental scan (Phase 1), and in so doing offers a basis for developing the community-based research proposal (Phase 2). Different types of information on the impact of laws/policies are synthesised, including:

- Literature that outlines the theoretical impact of various laws/policies related to HIV/AIDS.
- Empirical data from quantitative and qualitative studies that make the connections between structural factors associated with HIV/AIDS and the health of individuals and populations.
- The views of key respondents working directly or indirectly with communities affected by HIV/AIDS, collected during the environmental scan, on which priority research areas should be the focus of further study and on how this should be researched.

Section I of the report describes the methodology used for the literature review, the environmental scan, and the selection of the research area for phase two of this project, as well as the limitations of the methodology.

Section II summarizes general research on law/policy as structural determinants of health. This is a rapidly emerging research area in response to the fact that structural factors have been understudied and underutilized. Much research has emphasized individual-level behavioural approaches to health rather than call attention to broader structural approaches. Laws/policies, health-related or otherwise, operate as structural determinants of health by: (1) constituting the physical and social context in which individuals and populations behave, defining options and influencing choices; and (2) interacting with other known determinants of health. We also know that the impact of laws and policies may be indirectly related to health (e.g., through discrimination and stigmatisation) or have more direct effects (e.g., facilitating or hindering access to prevention materials) or may act simultaneously at both direct and indirect levels (e.g., directly affecting the behaviour of a segment of society while having a more indirect effect on the general population). Current research strongly suggests that laws and policies 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. These HIV/AIDS-related health outcomes are the result of the complex interaction of various structural determinants of health. Obtaining sound evidence of the impact of laws/policies demands new research methodologies, such as Health Impact Assessment methods.

Section III summarizes literature in four specific research areas of HIV/AIDS-related laws/policies: (1) HIV testing, reporting and follow-up; (2) drug use, (3) sex work and (4) criminalizing HIV transmission/exposure. For each research area, the literature reviewed is twofold. First, theoretical literature on the impact of various structural legal/policy factors associated with HIV/AIDS is mostly argumentative and provides a useful basis upon which future research questions can be formulated. Second, empirical data reviewed make the connections between structural factors and their impact on health and other human rights.

This is the kind of scientific data that can be used to guide elected legislators, government policy-makers, judges, and individuals and organizations that run programs or provide services to people living with HIV/AIDS in making choices between different laws or policies.

- Literature on the impact of laws/policies on HIV testing, reporting and partner notification raises individual and public health concerns (e.g., regarding various testing options, the debate over epidemiological data collection). We know, for example, that the impact of name-based surveillance on partner notification programs and on access to HIV testing may have been exaggerated. We also know that HIV/AIDS continue to raise many issues that relate to stigmatisation. However, we do not fully understand whether these laws/policies affect people's willingness to test for HIV, particularly with respect to specific populations that may be at different levels of risk and/or be drawn from different socio-economic strata.
- Literature on the impact of drug laws/policies reveals the negative effects criminalization of drug use has on harm reduction and access to HIV prevention and care for people who use injection drugs, as well as the positive effects of harm reduction programmes and policies, such as needle-exchange. Empirical research confirms that many of the serious health problems associated with illegal drug use are caused directly or indirectly not by drug use itself but by drug prohibition. We also know that drug laws/policies can increase vulnerability to HIV or can enable contact with the most marginalized drug users and act as gateways to other systems of care and treatment. There is still the need for a stronger empirical base demonstrating how police enforcement of prohibitions on possession of controlled substances specifically impacts on HIV prevention and care.
- Literature on the impact of laws/policies that regulate sex work raises the issue that, like IDUs, sex workers are uniquely vulnerable to HIV, as they routinely lack the materials, the information or authority to protect themselves and their clients. We know that criminalization of sex work means that sex workers are subject to abuse, discrimination and stigmatisation, and forced to work in high risk conditions that compromise HIV prevention efforts. We also know that vulnerability to HIV is best dealt with through prevention efforts emphasizing peer education, rather than through regulating prostitution. But how do local codes and municipal by-laws across Canada impact on HIV prevention and care in people who work in the sex industry? Some research has emerged to examine the impact of laws and public policies on the health of sex workers and research data should be available soon.
- There is a dearth of empirical literature documenting the impacts associated with using criminal law to prosecute people for transmitting HIV or engage in activities that risk transmission. Theoretically, measures available under public health legislation could offer a preferable alternative to using the criminal law in cases where a person risks transmitting HIV without disclosing their status to their partner. There are many outstanding questions, including: does a law requiring people to disclose their HIV-positive status to sexual partners upon pain of criminal prosecution affect willingness to test for HIV, preference for anonymous or nominal testing, or to whom they disclose, how and in what circumstances? The lack of research data makes it difficult to adequately address the impact of such laws on HIV prevention or access to HIV/AIDS-related care, treatment and support.

Section IV summarizes key respondents' views collected during the environmental scan. Almost one quarter (22%) of those interviewed reported that research into the general area of law/policy as a structural determinant of health is a priority. These respondents considered that more research is needed regarding the direct or indirect impact of law/policy on access to HIV prevention, care, treatment and support, and on locating responsibility and accountability for such impact. Another quarter (26%) of the key respondents reported that research on the link between

laws/policies and (other) determinants of health is a priority. These respondents readily made connections between law/policy and "income"; "employment and working conditions"; "physical environments"; "education"; and "social environment" and discrimination. Finally, half (52%) of the key respondents reported that research on the impact of specific HIV/AIDS-related laws/policies is a priority. They generally understood the connections between health and laws/policies as directly and indirectly facilitating or inhibiting vulnerability to HIV in specific populations. In addition, key respondents raised methodological questions as to how the Canadian HIV/AIDS Legal Network should or may participate in the design of a research project assessing the impact of laws/policies on human rights and HIV prevention and care.

A summary version of the report is also available. It provides a shorter, more accessible version of sections I to III of the report, and is available at http://www.aidslaw.ca/Maincontent/reports.htm#dpafr.

What does this report conclude?

Section V recommends key issues for further research and priorities. Although each research area or issue reviewed is worthy of further empirical assessment, only one specific area of law/policy impact was selected for in-depth research as it ranked highest in terms of the selection criteria used. The project report concludes that the area of criminalizing HIV transmission/exposure is a key under-researched area in which the Canadian HIV/AIDS Legal Network, in partnership with another community-based organisation and an experienced researcher, should design a community-based research project proposal to gather empirical data. This issue is one for which: (1) Canadian research data is non-existent; (2) a rationale for empirical assessment can be based on available theoretical literature; (3) the Legal Network has done pre-existing analysis that would assist in identifying research questions; (4) enhancing the potential of law/policy in responding to HIV/AIDS in Canada is most relevant and timely; and (5) guiding community-based research principles can be enacted.

It is recommended that the design of a research proposal focus on assessing the impacts of applying the criminal law to conduct that risks transmitting HIV on both the lives of people living with HIV/AIDS and on population health generally in Canada. In short the research initiative should address ways in which this use of the law directly and indirectly affects HIV prevention and care, including whether it:

- Reinforces AIDS-related stigma against people who are HIV-positive;
- Creates a false sense of security among those who are HIV-negative;
- Deters HIV testing in persons most vulnerable to HIV and in the general population;
- Hinders access to counselling and support services for people living with HIV/AIDS or affects their willingness to seek treatment; and
- Facilitates or hinders disclosure of HIV-positive status.

Introduction

One important objective of assessing the impact of laws/policies on HIV prevention and care is to build community capacities that will provide knowledge with which to improve community conditions. Community-based research (CBR) is informed by the following guiding research principles:[4]

- The research promotes and develops the inquiry skills of all participants. The aim is to build sustainable capacities within communities for self-informed, self-inspired transformation.
- The community's experience belongs to the community. As such, research initiatives should invite community participation as early as possible in their formation, to shape cooperative agreements about ethical issues, the treatment of data and the dissemination of findings.
- In order to ensure respect, dignity and empowerment, relations between those conducting research and those participating must be negotiated in a collaborative spirit of equity.
- The research is inclusive of community members in all its phases: the review of proposals, construction of protocols, collection of data, interpretation of results and dissemination of findings.
- The research uses language and methods that are broadly accessible to its diverse range of participants, because their research skills form the basis of community transformation.
- The research data generated and the results produced are tools of the community's empowerment and are be honoured as such in all transactions.

The Canadian HIV/AIDS Legal Network is committed to these guiding principles. Results from the assessment of how law/policy impact affects HIV prevention and care will benefit a wide number of individuals and organizations.

- Most importantly, the research will assist people living with and those vulnerable to HIV/AIDS by ensuring that law/policy makers are better informed about the health and human rights consequences of such decisions.
- The research data generated will build communities' capacities to improve the health and well being of people living with HIV/AIDS by informing their own advocacy and the development of community-based organizations' policies and programs.
- The information gathered will assist all those who make laws or policies affecting people living with HIV/AIDS and our efforts to respond to the epidemic, as well as all those who advocate on behalf of the human rights of people living with and those vulnerable to HIV/AIDS or provide services to them.

This report summarises the results of the literature review and environmental scan undertaken in the first phase of formulating a CBR project, and in so doing offers a basis for developing a research proposal. The report is divided into five sections.

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[4] International Network for Community-Based Research on HIV/AIDS. *Communities Creating Knowledge. A Consensus Statement on Community-Based Research*. Vancouver: The Community-Based Research Centre, 2000.

- Section I describes the methodology of the literature review and the environmental scan, and its limitations.
- Section II summarizes general literature reviewed on law and policy as structural determinants of health; outlines how structural factors associated with HIV may have direct and/or indirect effects on health and human rights; and how these impacts can be measured.
- Section III summarizes specific theoretical and empirical literature reviewed in four research areas of HIV/AIDS-related laws and policies: (1) HIV testing, reporting and follow-up; (2) drug use; (3) sex work; and (4) criminal law. Conclusions regarding different legal and policy options are presented and areas where the impact of policies is unknown or under-researched are identified.
- Section IV summarizes the views of key respondents interviewed during the environmental scan on these same general and specific research areas as well as on other additional issues.
- Section V recommends key issues for further research and priorities in those areas where research data is limited or non-existent. It identifies the issue of criminalizing HIV transmission/exposure as a key under-researched area in which the Canadian HIV/AIDS Legal Network, in partnership with another community-based organisation and an experienced researcher, should design a community-based research project proposal to gather empirical data.

Section I - Methodology

1.1 Literature Review

The review focused on literature found in medical, legal, social sciences, public health or other journals and publications that significantly advance our understanding of the connections between people's health (specifically in relation to HIV/AIDS) and the adoption or implementation of laws or policies that respect or violate human rights standards. Due to the sheer volume of existing literature on law/policy in the context of HIV/AIDS and human rights and the short duration of the project, the attempt was not made to provide a comprehensive literature review. The literature review further narrows its focus on areas of research identified by the individuals and organizations consulted throughout the project. These are:

- Law and policy as structural determinants of health; and
- Specific issues of health and human rights raised by:
    - Laws and policies regarding HIV testing, reporting and follow-up;
    - Drug laws and policies;
    - Laws and policies that regulate sex work; and
    - Applying criminal law to conduct that risks transmitting HIV.

In addition, to be included in the review, the results of the research had to have been published recently, for the most part in 1995 or later, and readily made available for inclusion into the Legal Network's Resource Centre. Emphasis was put on reviewing recent and timely theoretical and empirical literature.

Literature was gathered between September 2001 and June 2002. Information was primarily obtained from:

- The Resource Centre of the Canadian HIV/AIDS Legal Network;
- Library and database searches undertaken in universities and other policy and research centres in Canada;
- Materials produced by Health Canada and other governmental agencies;
- Individuals and organizations with expertise or likely to have useful suggestions in law/policy impact research, including the Legal Network's membership;
- Notices posted on several e-mail discussion forums (listservs); and
- A search of the Internet.

As a result, information was received from these varied sources and additional leads were generated and pursued. Because these sources for data collection were multiple, materials gathered yielded literature that is both theoretical and empirical. Therefore, the methodology for compiling research data involved: (1) noting the theoretical impact of laws and policies on health and human rights, and (2) identifying research data that assesses the impact of specific laws/policies on HIV prevention and care.

1.2 Environmental Scan

In conjunction with the literature review, an environmental scan was undertaken between November 2001 and January 2002, to identify important issues where the possible link between a law/policy and an effect on human rights and health should be investigated. Interviews were conducted with several key respondents about what they see as the key areas where it is important for us to better understand the role the law plays in affecting HIV prevention or care.

Key respondents were identified and recruited through notices posted on several e-mail discussion forums, and personal communication with individuals and organizations likely to have expertise or useful suggestions in law/policy impact research, including the Canadian HIV/AIDS Legal Network's membership. Key respondents were asked to sign a *Subject Consent Form* (see Appendix A) detailing the nature of their participation and of the research project.

The final sample included 20 individuals based in Canada. These key respondents are involved in key decision- or policy-making processes in government, as well as in community-based and other organizations working directly or indirectly with (or as) people and communities living with and affected by HIV/AIDS (see Appendix B). Key respondents provided input based on their experiences. Together, these experiences represent regional, national and international perspectives on law/policy impact. Key respondents were particularly familiar with those laws and policies directly affecting, or relevant to, their specific area of work or interest. They also provided suggestions as to how the impact of law/policy on HIV prevention and care should be researched. In order to preserve confidentiality of respondent information, interviewees are quoted in italics and key respondent views are quoted as such.

The interview scheme was designed as open-ended given the subject matter and the goal of the scan (See Appendix C). Interviews were conducted face-to-face in Montreal and over the telephone elsewhere. The average length of an interview was 90 minutes and the majority of interviews were scheduled over multiple contacts. Information provided was recorded in field notes and summaries of the interviews were prepared.

All key respondents interviewed identified several areas where further research may be required. The majority of individuals interviewed identified three priority areas whereas three respondents noted only one major priority research area. Overall, fifty specific priority research areas were identified. Key respondents generally understood that laws/policies directly, and indirectly through other determinants of health, facilitate or inhibit vulnerability to HIV/AIDS in specific populations. In order to harmonize the presentation of the results from the environmental scan with that of the literature review, key respondents' views were grouped together under (1) broad categories of research and (2) priority research areas. The frequency of responses is illustrated in Figure A. Earlier drafts of the report were circulated to key respondents in order to validate the information it contained. Following the input received, this final report was prepared.

Figure A: Key Respondents' Views on Research Areas Requiring Further Study

Broad category for research	Priority research area
General impact of law and policy as structural determinants of health: 22%	• Access to care, treatment and support (16%) • Responsibility and accountability for impact (6%)
Links between law/policy and (other) determinants of health: 26%	• Income; employment and working conditions; physical environment (14%) • Education (8%) • Social environment and discrimination (4%)
Research into impact of specific laws and policies: 52%	• Drug laws and policies (16%) • Laws and policies that regulate sex work (14%) • Laws and policies regarding HIV testing, reporting and follow-up (10%) • Criminalization of HIV transmission/exposure (8%) • Other (4%)[5]

1.3 Criteria for Selecting the Research Area for Phase 2

Based on the information gathered from the literature review and environmental scan this report makes recommendations for future research questions and priorities. Only one of these research areas or issues identified can be retained for the second phase of this project — the development of a community-based research project proposal.

Several criteria were used to select which specific law/policy impact area would be the focus of further study. These included:

- Research data regarding the empirical impact of law/policy is limited or non-existent;
- The existence of theoretical literature on the potential or real impact of law/policy on health and human rights, both in terms of HIV prevention and care;
- The Canadian HIV/AIDS Legal Network is already familiar with the issue, through theoretical or practical work;
- Evidence related to the issue can be used to inform the development of law/policy to promote HIV prevention, care, treatment and support in Canada;
- A project to research the issue is amenable to community-based research's guiding research principles, including the availability of resources and the presence and interest of community-based organizations that are well suited to collaborate in the research initiative.

[5] A small portion of key respondents identified other areas of research into the impact of specific laws and policies than those addressed in the literature review. Namely, these included: immigration laws and policies, HIV/AIDS policies in prisons and correctional settings, as well as privacy and confidentiality policies and standards.

1.4 Limitations

The following limitations of this project are acknowledged:

- To keep the project manageable, and to focus on the most recent data, research initiatives prior to 1995 were generally not included in the literature review.
- In the time allowed, it was not possible to identify all research into the impact of law/policy undertaken since 1995.
- A majority of materials on the theoretical and empirical assessments of the impact of law/policy found were written and published in the US. While much of the literature reviewed from the US or from other countries is of interest to Canadians, the need for Canadian resources is clear.
- The literature review cannot address both the impact of law/policy on health as well as on other human rights (besides health) as this expanded discussion is beyond the scope of this project. The specific connections between law/policy and health, however, are discussed in light of how law/policy affects other health determinants associated with HIV/AIDS prevention and care.
- Individuals and organizations from the Atlantic region did not respond to the call for input in the environmental scan. Their particular views may not be addressed in this report.
- Key respondent input reflects the role of the Canadian HIV/AIDS Legal Network's work in generating legal and policy analyses known to community-based organizations. Respondents were more knowledgeable of research areas where the Legal Network has already undertaken much work and less familiar with research areas where the Legal Network has not yet done so.
- The criteria used to select which specific law/policy impact area would be the focus of further study necessarily imply limitations in the types of recommendations and conclusions made in this report. Other research areas or issues not identified here as warranting further empirical assessment may be taken up by other individuals or organizations as priority research areas.
- Finally, the conclusions and recommendations in terms of designing a research proposal will no doubt need to be tailored to the specific needs of the other community-based organization and the experienced researcher involved in the design and, if funded, implementing the research proposal.

Section II - Literature Review on Impact of Law/Policy in General

2.1 Law and Policy As Structural Determinants of Health

Many people intuitively understand that factors such as income, employment, education, gender and social support systems affect physical and mental health, and there is a body of literature to support these contentions,[6, 7, 8, 9, 10, 11] and particularly as it relates to HIV/AIDS.[12] Health Canada, for instance, recognizes this by making the "population health approach" the basis for its Canadian Strategy on HIV/AIDS.[13] 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."[14]

The population health approach thus identifies individual and collective factors, and their interactions, as "determinants of health".[15] These include:

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[6] Lalonde M. *A New Perspective on the Health of Canadians*. Ottawa: Ministry of Supply and Services, 1974.

[7] Health and Welfare Canada. *Achieving Health for All: A Framework for Health Promotion*, 1986.

[8] Labonté R. *Health Promotion and Empowerment: Practice Frameworks*. Toronto: Centre for Health Promotion, University of Toronto and ParticipAction, 1993.

[9] Federal/Provincial/Territorial Advisory Committee on Population Health. *Report on the health of Canadians*. Ottawa: Minister of public Works and Government Services Canada, 1996.

[10] Federal/Provincial/Territorial Advisory Committee on Population Health. *Toward a healthy future: Second report on the health of Canadians*. Ottawa: Minister of Public Works and Government Services Canada, 1999.

[11] Health Canada, Population and Public Health Branch, Strategic Policy Directorate. *The Population Health Template: Key Elements and Actions That Define A Population Health Approach*. Ottawa: Minister of Public Works and Government Services Canada, 2001. Available at: http://www.hc-sc.gc.ca/hppb/phdd/pdf/discussion_paper.pdf

[12] For example, see: Spigelman M et al. *HIV/AIDS and Health Determinants: Lessons for Coordinating Policy and Action - A Discussion Paper for the Ministerial Council on HIV/AIDS*. Ottawa: Health Canada, 2002. This paper reviewed Canadian literature on HIV/AIDS and social determinants of health. It suggests that 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.

[13] Health Canada. *Current Realities: Strengthening the Response - Canada's Report on HIV/AIDS 2001*. Ottawa: Minister of Public Works and Government Services Canada, 2001. Available at: http://www.hc-sc.gc.ca/hppb/hiv_aids/can_strat/pdf/wad01/aids_e.pdf

[14] Information available at: www.hc-sc.gc.ca/hppb/phdd/approach/index.html

[15] Federal/Provincial/Territorial Advisory Committee on Population Health. *Report on the Health of Canadians*, Report prepared for the Ministry of Health, Health Canada, 1998. Available at: http://www.hc-sc.gc.ca/iacb-dgiac/nhrdp/healthofcanadians/index-e.htm

- Income and social status
- Social support networks
- Education
- Employment and working conditions
- Social environments
- Physical environments
- Personal health practices and coping skills
- Child development
- Biology and genetic endowment
- Health services
- Gender[16]
- Culture.

This list may not be exhaustive and the categories are not discrete,[17] but a determinants of health model recognizes that lifestyle, social and physical environment, genetics and quality and availability of health care contribute to a person's health in complex, interacting ways.[18] Determinants of health are believed to interact and overlap as they affect the health status of individuals and populations. It is often not possible to draw a direct causal relationship between a single determinant, or group of determinants, and health status. Rather, the relationships are associative. Specific determinants may not always produce the same outcome.[19]

The effects of "income and social status", for example, may be manifest in a series of outcomes, just as the influence of smoking may result in heart disease, cancer, or asphyxiation through fire. A child raised in poverty may have poorer health because he or she lives in an older slum area where house paint contains lead. The same child may have poor health due to poor nutrition, or he or she may be at risk because of more likely exposure to violent crime. He or she may also grow up to face unemployment due to low educational level, and this unemployment may cause depression and further deterioration of well being. How health determinants exactly affect the health of an individual or group, then, is a complex question. The very word "determinants" may create a false impression of a cluster of single factors acting alone. However, it is the way the

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[16] "Gender" and "culture" were not included as determinants of health in the 1998 FPT report. They were subsequently added by Health Canada. See: Bhatti T Hamilton N. Health Promotion: What is it? *Health Policy Research Bulletin* 2002; 1(3): 5-7 (www.hc-sc.gc.ca/iacb-dgiac/arad-draa/english/rmdd/bulletin/issue3_1.html) at note 1, which references Health Canada. *Towards a Common Understanding: Clarifying Core Concepts of Population Health*. A Discussion Paper Developed by the Conceptual Framework Subgroup of the Working Group on Population Health Strategy. Ottawa: Health Canada, 1996 (www.hc-sc.gc.ca/hppb/phdd/docs/common/index.html).

[17] For example, one might ask why the determinant of health called "gender" is listed separately. If "gender" means specific physiological features of people that can affect health status (e.g., women's greater physiological susceptibility to HIV infection than men's through penetrative vaginal sex), then what is referred to are aspects of "biology and genetic endowment", another of the listed determinants of health. If "gender" refers to the ways in which discrimination against women as a social category can affect health, then this is an issue not limited to gender; rather, the issue is how discrimination (based on gender but also other factors, such as race, sexual orientation, etc) is a determinant of health, and this is an aspect of "social environment". Yet discrimination is not just an aspect of social environment; it is also a legal concept and the treatment of discrimination in/by the law affects other determinants of health (e.g., income, employment, education, etc). These considerations are raised here as an example indicating the need for improving our current understandings of determinants of health, and the relationship between them.

[18] Mustard JF, Frank JW. The Determinants of Health from a Historical Perspective. *Daedalus: Journal of the American Academy of Arts and Sciences* 1994; 123(4): 1-19

[19] Howard D et al. (eds) *Primary Health Care: Six Dimensions of Inquiry*. Edmonton: Howard Research and Instructional Systems Inc., 2000: at 53-65. Available at: http://www.health.gov.ab.ca/key/phc/resource/

factors interact which is most important, and key patterns may emerge and vary over time, place, population, and stage of life.

Although most people intuitively recognise that laws/policies can affect people's health, current lists of the determinants of health do not mention laws/policies *per se* as health determinants for individuals and populations, and consequently their impact is often overlooked. Rarely are health-related laws/policies themselves directly included in understanding the conditions that influence health. Nevertheless literature describing law/policy as a structural determinant of health does exist. This literature points to ways laws/policies, health-related or otherwise, are structural factors that can determine health status (1) by constituting the physical and social context or environment in which individuals and populations behave, defining options and influencing choices; and (2) by interacting with known determinants of health

2.1.1 Constituting the context in which individuals and populations behave

The *Ottawa Charter for Health Promotion* is internationally recognized as both a standard and a foundation for health promotion efforts.[20] The Charter includes social justice and equity as important health prerequisites and it suggests 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 more emphasis on preventing disease.

> Health promotion focuses on achieving equity in health. Health promotion action aims at reducing differences in current health status and ensuring equal opportunities and resources to enable all people to achieve their fullest health potential. This includes a secure foundation in a supportive environment, access to information, life skills and opportunities for making healthy choices. People cannot achieve their fullest health potential unless they are able to take control of those things which determine their health. This must apply equally to women and men. [21]

The Charter recognizes the potential for law/policy to shape the physical and social context or environment that determines health status. It states that: "It is coordinated action that leads to health, income and social policies that foster greater equity. Joint action contributes to ensuring safer and healthier goods and services, healthier public services, and cleaner, more enjoyable environments." Inversely, these environments define health-related options and influence choices available; they structure the ways in which the health of individuals and populations is produced and reproduced.[22]

Structural determinants of health can take a variety of forms, including the economic, cultural, legal and political environments of a given society, which themselves are related and affect each

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[20] Hayes M, Glouberman S. *Population health, sustainable development and policy futures*. Ottawa: Canadian Policy Research Networks, 1999: 6.

[21] Canadian Public Health Association, Health and Welfare Canada, World Health Organization. *Ottawa Charter for Health Promotion*. Copenhagen: World Health Organization Regional Office for Europe, 1986. Available at: http://www.who.int/hpr/archive/docs/ottawa.html

[22] Hancock T. Beyond Health Care: From Public Health Policy to Healthy Public Policy. *Canadian Journal of Public Health* 1985; 76 (Suppl 1): 9-11.

other. Elements of the legal and policy environment can also take different forms, including: laws and legal institutions or actors; policy implementation — broadly defined to include litigation, regulation, law enforcement, and the setting of administrative, organizational, and product standards; and community engagement in legal/policy debate.[23]

The reason for identifying law/policy as a *structural* determinant of health, that facilitates or inhibits HIV prevention and care, is that it forms part of the context or environment surrounding individuals, but outside their direct control; their context is always already defined by law, policy or administration. Health is structurally determined in that individuals or groups may not make healthy choices because contextual legal and political factors may prevent them from doing so.

Structural interventions then, will "locate the source of public health problems in factors in the social, economic and political environments that shape and constrain individual, community and societal health outcomes" and "recognize that health improvements can require change in or challenges to the normal functioning of organizations, institutions, or whole social or economic systems".[24] Healthy public policy in this sense indeed means "policy enacted by the various levels of government that is characterized by explicit concern for health and equity, and by accountability for health impact".[25]

Social epidemiologists have carried out many investigations to search for socio-structural characteristics that promote (or inhibit) health outside the traditional biomedical model, towards factors that are more rooted in features of the economy, culture, politics, and the law.[26] Few however have specifically examined whether and how law/policy may be operating to create or promote (un)healthy social conditions, or as a means through which social conditions are translated into patterns in the level and distribution of health. One such analytic framework posits that by shaping what kinds of environments people live and work in, law/policy is both an *explanatory* variable determining population health, as well as a potential *means* for improving it.[27]

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[23] Burris S. "Law as a Structural Factor in Health: Introduction and Conceptual Framework." In conference materials from *Health, Law and Human Rights: Exploring the Connections, An International Cross-Disciplinary Conference Honoring Jonathan M. Mann* Philadelphia, 2001; at 818.

[24] Blankenship KM et al. Structural Interventions in Public Health. *AIDS* 2000; 14 (Suppl 1): at S11.

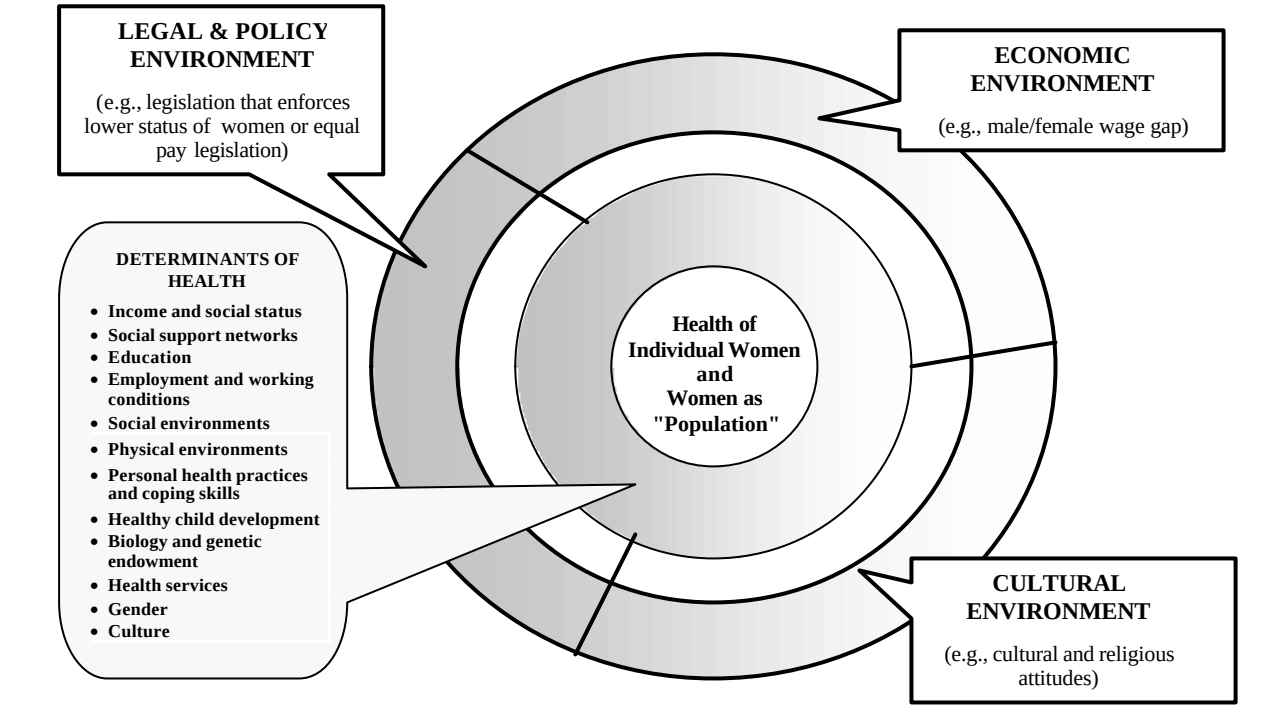
[25] Office of Health Promotion B.C. Ministry of Health. Healthy Public Policy. *Health Promotion in Action*, Fall 1991; 7.

[26] For example, the NiHonSan study [cited in: Marmot, MG et al. Lessons From the Study of Immigrant Mortality. *Lancet*, 1984; i: 1003-1006] demonstrated that heart attack rates increased dramatically among Japanese immigrants as they moved from their homeland to the US. The closer they moved to the US mainland, the higher was their risk of heart attack. Heart attack rates were highest among Japanese who settled in San Francisco, intermediate among those who settled in Hawaii, and remained the lowest among those who stayed behind. Obviously, genes had little to do with these trends, but neither could lifestyle factors, such as diet, account for much of the differences. In other words, one is forced to look towards societal and cultural factors to explain why the Japanese maintain the highest longevity in the world, despite having among the highest smoking rates in the world (among men), and spending roughly half of what the US does on medical care.

[27] Kawachi I et al. Law as a Social Determinant of Health. In conference materials from *Health, Law and Human Rights: Exploring the Connections, An International Cross-Disciplinary Conference Honoring Jonathan M. Mann*. Philadelphia, September 2001.

Figure B takes the example of the structural environment of female individual and population health to illustrate how consideration of the legal and policy environment can contribute to a deeper understanding of the complex mechanisms underlying women's health. The figure illustrates that law/policy are one part of the structural environment that affects health and shows that they interact with economic and cultural environments in determining health and as a means of creating or remedying inequalities in health distribution.

Figure B. The Structural Environment of Female Individual and Population Health



Notes: The circles illustrate the health of women as individuals and as a "population" as affected by a variety of factors. The outer circles refer to structural factors of social organization and include (1) economic, (2) cultural, and (3) legal and policy environments that impact the health of individual women and of populations. The inner circles refer to (other) determinants of health, which are structured by political economy, culture, and laws/policies, and, in turn, determine the conditions under which people live, work, and stay healthy (or get sick). All the circles are interconnected in such a way that they can often not be isolated from each other.

For example, cultural and religious attitudes towards women are a major determinant of women's health achievement at the national level. Based on imbalances in the population sex ratio between women and men, it has been estimated that there are perhaps 100 million "missing women" in the world [see: Sen AK. *Development as freedom,* New York: Alfred A. Knopf, 1999]. Countries such as China, Pakistan, and India have far fewer women in their population than men, because of practices such as sex-selective abortion, female infanticide, and the preferential treatment of boys — e.g., better nutrition, better access to health care. The unequal treatment of women is by no means confined to the less developed countries of the world. Closer to home in the US, it has been demonstrated that the level of women's autonomy (as gauged by the male/female wage gap, the feminization of poverty, and the representation of women in politics) is an important determinant of women's health achievement [see: Kawachi I et al. Women's Status and the Health of Women and Men: A View from the States. *Social Science & Medicine* 1999; 48: 21-32].

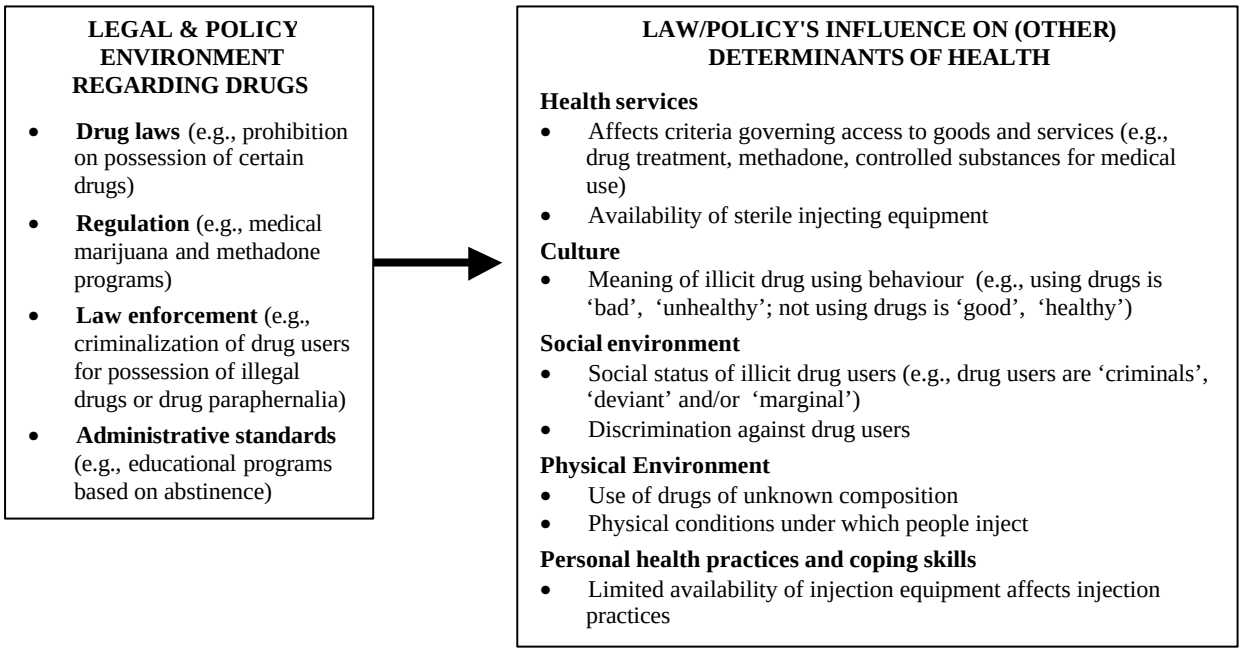
In this example, laws/policies are both an explanatory variable determining women's health (as in its role in rationalizing lower status for women, or more immediately in the form of legislation that enforces lower status), as well as a means of remedying gender inequality (as in equal pay legislation). [For more detail, see: Kawachi et al. 2001, *op. cit.*]

2.1.2 Affecting other determinants of health

Moreover, these interconnected structural environments shape the determinants of health with consequent inter-related impacts on health. For example, laws/policies structure individual and population health by determining our physical environments (e.g., access to shelter, denial of residence in Canada), our development as children (e.g., family poverty, access to child care), our health practices (e.g., use condoms or sterile injection equipment), and our use of health services (e.g., insurance coverage for medications, drug pricing laws, equitable access to medical procedures, safety and efficacy of drugs consumed). Laws/policies may also affect how we experience our biological endowment (e.g., protection against discrimination in employment or housing based on disability, sex, or race/ethnicity).

Figure C takes the example of the legal and policy environment regarding illegal drugs to illustrate how structural determinants affect other determinants of health. Laws and legal institutions or actors, regulation, law enforcement, and the setting of administrative standards, structure known determinants of health such as provision of health services, culture, social and physical environment, and personal health practices. As we shall discuss in more detail below, the contribution of laws/policies on illegal drugs, particularly in terms of syringe access and possession, to the spread of blood borne disease is an excellent example of this complex interaction.

Figure C. The Legal and Policy Environment Affects Determinants of Health



2.1.3 Implications on health as a human right

Finally, because health is defined as a "state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity",[28] health is also a human right. This definition has important conceptual and practical implications: it illustrates the indivisibility and interdependence of human rights as they relate to health,[29] and it points to the far-reaching effects of the law/policy environment on the human rights of individuals and populations.

While the right to health has been set out in a number of international legal instruments, health and government responsibility for health are codified in legal/policy documents in several ways. The "right to the highest attainable standard of health" appears in one form or another in most every one of them and, even more importantly, nearly every article of every document can be understood to have clear implications for health.[30] Therefore, laws/policies that comply with or infringe on a specific human right affect not only that particular right in isolation, but impact on health status as well. In other words, rights relating to discrimination, autonomy, information, education and participation are an integral and indivisible part of the achievement of the highest attainable standard of health, just as the enjoyment of health is inseparable from that of other rights, whether categorized as civil and political, economic, social or cultural.[31]

2.2 Structural Factors Associated With HIV Prevention and Care

Communities that are affected by the HIV/AIDS epidemic have long identified ways in which structural factors affect their health. For example, those who use illegal drugs recognize that drug laws/policies affect their capacity for effectively reducing drug-related harm.[32] Some literature now exists on law/policy as structural factors implicated in health and other human rights, in terms of both HIV prevention and care. This is a rapidly emerging research area in response to the fact that structural factors have been understudied and underutilized — much of health research has emphasized individual-level behavioural and biomedical prevention and care, and even "population health" social science research focussing on various population-level determinants of health has not tended to incorporate much analysis of the impact that law/policy can have on health and its determinants.

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[28] World Health Organization. *Constitution of the World Health Organization*, adopted by the International Health Conference, New York, 19 June–22 July 1946, and signed on 22 July 1946 by the representatives of 61 States.

[29] Kirby M. The Right to Health Fifty Years On: Still Skeptical? *Health and Human Rights* 1999; 4: 7–24.

[30] Mann JM et al. Health and Human Rights. *Health and Human Rights* 1994; 1: 6–23. This article discusses how public health policies and practices affect human rights. For the authors, this is true not just in the familiar sense that public health measures sometimes entail infringements of individual autonomy or privacy, but also in more subtle ways: for example, in setting policy priorities or allocating resources, public health agencies may discriminate against segments of the community in impermissible ways.

[31] Gruskin S, Tarantola, D. "Health and Human Rights". In Detels R et al (eds). *The Oxford Textbook of Public Health*, 4th edition. Oxford University Press, 2002; at: 311-355. Available at: http://www.oup.co.uk/pdf/0-19-263041-5_04-1.pdf

[32] E.g., see the analysis by the Vancouver Area Network of Drug Users, a non-profit organization based in downtown Vancouver, British Columbia that works to improve the lives of people who use illicit drugs. Information at: http://www.vandu.org/

Structural factors associated with HIV prevention and care are broadly defined to include physical, social, cultural, organizational, community, economic, legal or policy aspects of the environment that impede or facilitate persons' efforts to avoid HIV infection. These factors have different names in the literature — environmental, structural, societal, super-structural, policy, contextual and others — often reflecting the disciplines and experiences of the writers. Experts in HIV policy, research and service implementation are beginning to describe the ways that structural barriers create vulnerable populations and sustain high-risk behaviours, and the ways that structural facilitators support safe or healthy behaviours.[33, 34, 35, 36, 37]

In June 2000, the journal *AIDS* dedicated a special issue to the topic of structural factors and determinants in HIV prevention. This supplement publication provides useful definitions and frameworks for understanding structural factors associated with HIV and points to several broad conclusions.

- Structural barriers or facilitators may be put in place by a myriad of interveners including governments, service organizations, businesses, workers organizations, faith communities, justice systems, media organizations, educational systems and healthcare systems.[38]
- Initiatives to prevent health risks other than HIV have focused on structural supports or constraints that influence the availability, acceptability, and accessibility of the materials or environments needed by individuals to maintain safe behaviours.[39]
- Political and economic factors that help foster the spread of HIV and progression to AIDS in developing countries are equally pertinent among disadvantaged populations in developed countries.[40]
- Structural barriers to HIV prevention and care particularly affect those populations at highest risk for HIV: gay men and other men who have sex with men, specific ethno-racial communities, injection drug users, vulnerable women and youth.[41]

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[33] Merson MH. "International Perspective on AIDS Prevention Research", In *NIH Consensus Development Conference. Interventions to Prevent HIV Risk Behaviors: Program and Abstracts.* Washington DC: National Institutes of Health, 1997: at 101-106.

[34] Aggleton P. Global Priorities for HIV/AIDS Intervention Research. *International Journal of STD AIDS* 1996; 7: 13-16.

[35] Dowsett G. The Indeterminate Macro-Social: New Traps For Old Players in HIV/AIDS Social Research. *Culture Health and Sexuality* 1999; 1:95-102.

[36] Marks G et al. Reducing Sexual Transmission of HIV In Those Who Know They Are Infected: The Need For Personal and Collective Responses. *AIDS* 1999; 13: 297-306.

[37] International Council of AIDS Service Organizations. *Inventory of Human Rights Research and HIV/AIDS*, 2000.

[38] Sumatojo E. Structural and Environmental Factors in HIV Prevention: Concepts, Examples, and Implications for Research. *AIDS* 2000; 14 (Suppl 1): S3-S10.

[39] Blankenship KM et al. Structural Interventions in Public Health. *AIDS* 2000; 14 (Suppl 1): S11-21.

[40] Parker RG et al. Structural Barriers and Facilitators in HIV Prevention: A Review of International Research. *AIDS* 2000; 14 (Suppl 1): S22-32.

[41] In particular see *AIDS* 2000; 14 (Suppl 1): Fullilove RE et al. The Family Program: A Structural Intervention With Implications for the Prevention of HIV/AIDS and Other Community Epidemics: at S63-67; O'Leary A, Martins P. Structural Factors Affecting Women's HIV Risk: A Life-Course Example: at S68-72; Shriver MD et al. Structural Interventions to Encourage Primary HIV Prevention Among People Living With HIV: at S57-62;

Research that demonstrates the relationship between structural factors and HIV is still rare. Yet where available, this research can inform the development of healthy public policy. For example:

- Following the implementation of a comprehensive national HIV/AIDS prevention policy in Switzerland, researchers were able to attest to an increase in reports of condom use between steady partners by up to 24% and between casual partners by up to 48% in the Swiss general population.[42] These findings suggest that a general-population approach to AIDS prevention policy has a positive impact on condom-based protection against HIV infection.
- One study of the Canadian experiences of living with HIV/AIDS since the introduction of protease inhibitors and the widespread adoption of various forms of combination therapy found that US immigration policies have a negative impact of the health and human rights of Canadians living with HIV.[43] Qualitative data revealed that the US maintains an overtly discriminatory policy regarding the entry of seropositive people. Since border guards are unable to discern who is seropositive, on-the-ground effect of the policy is enforcement against those who carry medication for HIV disease. The authors conclude that the policy works, then, not as a barrier against the virus, but "as a barrier to adherence to medication, to support networks, and to the ability to earn a living".[44]

As part of the emerging effort to assess the relationship between structural factors and HIV, interdisciplinary meetings of researchers and policy-makers have identified the impact (positive or negative) of structural factors associated with HIV on two levels.[45, 46, 47] Law/policy impact may

1) be indirectly related to health (distal effects);
2) have more direct (proximal) effects; or
3) may act simultaneously at both direct and indirect levels.

Wohlfeiler D. Structural and Environmental HIV Prevention For Gay and Bisexual Men: at S52-S56; and Rotheram-Borus MJ. Expanding The Range of Interventions to Reduce HIV Among Adolescents: at S33-S40.

[42] Dubois-Arber F et al. Increased Condom Use Without Other Major Changes in Sexual Behavior Among the General Population in Switzerland. *American Journal of Public Health* 1997; 87:558-566.

[43] Adam BD et al. *Living With Combination Therapies*. Toronto: Ontario HIV Treatment Network, 2001: at 54

[44] Ibid.

[45] Sumartojo E et al. *Structural Barriers and Facilitators in HIV Prevention: Executive Summary of A Meeting Sponsored by the Behavioral Intervention Research Branch; Division of HIV/AIDS Prevention; National Center for HIV, STD, and TB Prevention and Control; Centers for Disease Control and Prevention.* Atlanta, GA, 22-23 February 1999.

[46] *Health, Law and Human Rights: Exploring the Connections - An International Cross-Disciplinary Conference Honoring Jonathan M. Mann*. Sponsored by the American Society of Law, Medicine and Ethics; Temple University Beasley School of Law; American Foundation for AIDS Research. Philadelphia, PA, September 29 - October 1, 2001.

[47] Mann JM, Tarantola DMJ. *AIDS in the World II.* New York: Oxford University Press, 1996.

2.2.1 Indirect or distal effects

At the broadest indirect level, elements of the structural (economic, cultural, legal/policy) environment affect HIV risk and confound or facilitate HIV prevention and care. Laws/policies regulate, which is to say that they not only define prohibited behaviour, but also explicitly or by implication authorize behaviour. For example, a law/policy that prohibits employment discrimination against a person living with HIV who can perform his or her job with or without a reasonable accommodation also by implication authorizes discrimination against a person with HIV whose disability more seriously impairs the ability to perform the job function. Discrimination, in this respect, is also a legal concept (freedom from discrimination is a human right) and a structural factor than can have indirect effects on health. HIV/AIDS-related discrimination has been defined as "any measure entailing any arbitrary distinction among persons depending on their confirmed or suspected HIV serostatus or state of health".[48] These societal attitudes and AIDS-related stigma, in turn, may impede specialized prevention programs targeting high-risk groups, or lead to legal barriers to accessing other health services. Structural factors have distal effects on health because the health outcome is far removed and outside individuals' direct control.

Laws/policies operate as a mechanism of deeper social factors by imposing cost or benefit, or by rationing access to health-related behaviours, services or products.[49] In either role, laws/policies most powerfully operate indirectly — by influencing expectations or the understanding of experience, rather than by explicitly compelling or forbidding specific acts or guarding certain perquisites. For example, the beliefs that HIV is easily spread and that people living with HIV/AIDS should be blamed for their illness are important ingredients of discrimination and stigma. These beliefs have been incorporated in coercive and punitive legal/policy measures directed at those vulnerable to or living with HIV/AIDS, such as quarantine or compulsory HIV testing without prior consent or protection of confidentiality.[50] Some research has considered the indirect impact of stigmatisation on HIV prevention and care. For example:

- One US survey found that fewer Americans now want to quarantine people with AIDS (PWAs) compared to ten years ago — 12% of those polled in 1999 agreed that PWAs should be separated from the rest of society, compared to 34% in 1991, but growing numbers blame

[48] Joint United Nations Programme on HIV/AIDS cited in: Canadian HIV/AIDS Legal Network. *HIV/AIDS and Discrimination. InfoSheet 2 - Stigma and Discrimination: Definitions and Concepts.* Montreal: The Network, 1999.

[49] Blankenship et al. *Op. Cit.*: at S11-21

[50] Bayer R. *Private Acts, Social Consequences. AIDS and the Politics of Public Health*. New York: The Free Press, 1989.

PWAs for their illness and don't understand how HIV/AIDS is and is not transmitted.[51] The authors concluded that: "such fears are likely to have detrimental effects on PWAs and persons at risk for HIV. They will also affect the success of programs and policies intended to prevent HIV transmission. Thus, eradicating AIDS stigma remains an important public health goal for effectively combating HIV."

- Another US study found that stigma associated with sexually transmitted diseases is a very powerful barrier to obtaining such care.[52] Other studies have shown that fear of stigma has deterred individuals from being tested for HIV and from disclosing their seropositive status to sexual partners, family, and friends; this is especially true for women living with HIV/AIDS.[53, 54, 55, 56, 57]

- One study on HIV-related attitudes and behaviours in the general population of Quebec also concluded that this kind of research data can be used to tailor HIV information and prevention campaigns as well as to measure the impact of such campaigns on changes in attitudes towards people living with HIV/AIDS over time.[58]

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[51] Herek GM et al. HIV-Related Stigma and Knowledge in the United States: Prevalence and Trends, 1991-1999. *American Journal of Public Health* 2002; 92 (3): 371-377. This study compared findings from national telephone surveys completed in 1991, 1997, and 1999, which measured public attitudes toward people diagnosed with AIDS. More than 2,500 American adults were asked to share their opinions about people with AIDS (PWAs) and various, government AIDS policies. The researchers found a 40% increase between 1991 and 1997 in the number of Americans believing that people who got AIDS through sex or drug use deserve their illness. While 20% expressed this view in 1991, 28% did so in 1997. By 1999, the figure had declined to 25%, but was still higher than at the beginning of the decade. They also found that many Americans still express fear and discomfort about people with AIDS. In 1999, 30% of those polled would feel uncomfortable having their children attend school with another child who has AIDS, and 22% would feel uncomfortable around an office co-worker with AIDS. The proportion saying they felt afraid of people with AIDS declined from 35% in 1991, but was still one in five. The study also found that mistaken beliefs about how AIDS is transmitted remain widespread, and in some cases even increased over the 1990s. In 1999, 41% believed they could get AIDS from using public toilets, compared to 34% in 1991. And 50% of those surveyed in 1999 believed that they could get AIDS from being coughed on by a person with AIDS, compared to 46% in 1991. In addition, about half of those surveyed in 1999 believed they could get AIDS by sharing a drinking glass, and one third believed that AIDS can be contracted by donating blood.

[52] Fortenberry JD et al. Relationships of Stigma and Shame to Gonorrhea and HIV Screening. *American Journal of Public Health* 2002; 92: 378–381.

[53] Chesney MA, Smith AW. Critical Delays in HIV Testing and Care: The Potential Role of Stigma. *American Behavioral Scientist* 1999; 42:1162–1174.

[54] Gielen AC et al. Women's Disclosure of HIV Status: Experiences of Mistreatment and Violence in an Urban Setting. *Women's Health* 1997; 25: 19–31.

[55] Derlega VJ et al. "Personal Accounts on Disclosing and Concealing HIV-Positive Test Results: Weighing the Benefits and Risks." In: Derlega VJ, Barbee AP (eds). *HIV and Social Interaction*. Thousand Oaks, CA: Sage, 1998: at 147–164.

[56] Simoni JM et al. Women's Self-Disclosure of HIV Infection: Rates, Reasons, and Reactions. *Journal of Consulting and Clinical Psychology* 1995; 63: 474–478.

[57] Lester P, Partridge JC, Chesney MA, Cooke M. The consequences of a positive prenatal HIV antibody test for women. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology* 1995; 10: 341–349.

[58] Leaune V, Adrien A. *Les Québécois face au sida: Attitudes envers les personnes vivant avec le VIH et gestions des risques.* Montreal: Direction de la santé publique, Régie régionale de la santé et des services sociaux de Montréal-Centre, 1998.

Discrimination and stigmatization have indirect or distal effects on health because they are far removed from individuals' control. They affect health through inequalities in health distribution, thereby exacerbating the risk. Indirect effects accumulate into significant health differences over time in the life course of individuals and populations, and are often mediated through direct effects. [59]

2.2.2 Direct or proximal effects

At a direct level (proximal effects), structural factors affect HIV prevention and care more immediately, such as when policies are put into place (e.g., to make HIV prevention services legal, accessible and acceptable) or when there are changes in laws/policies (e.g., regarding entitlement to or delivery of care, treatment and support services to improve the quality of life). Here structural barriers or facilitators are closely linked to specific behaviours or related to specific health outcomes. Some research has considered the direct impact of structural factors on health. For example:

- One study in Louisiana US assessing the impact of price on condom use found that when a program based on distribution of condoms at no charge was replaced with one providing low-cost condoms (25 cents), the percentage of condom use among persons reporting 2 or more sex partners decreased (from 77% to 64%).[60] Researchers found that individuals who reported picking up free condoms were significantly more likely to report using condoms during their last sexual encounter than those who reported not picking up free condoms. The authors concluded that cost is a barrier to the acquisition and use of condoms, and that free condoms should be available to persons at risk for HIV. This kind of research takes into account the idea that individuals may know they should use condoms but be unable to access them or use them because of the legal and policy environment prevents them from doing so or makes it more difficult for them to do so. Healthy public policy informed by this data would strive toward increasing free access to condoms wherever possible.
- Another example concerns how changes in policy are closely related to specific health outcomes: the 1993 revision of the surveillance case definition of AIDS.[61] The definition of AIDS in Canada was changed in such a way that three new indicator clinical conditions were added: pulmonary tuberculosis, recurrent bacterial pneumonia and invasive cervical cancer. The inclusion of these three new indicator diseases addressed to some degree concerns of underestimating AIDS in women and injection drug users (the new classification increased the number of women and IDUs diagnosed as having AIDS, thereby allowing these populations access to AIDS-related prevention, care, treatment and support) and also provided a new administrative framework that affected the very understanding of this disease's epidemiology.

Direct or proximal effects of laws/policies impact closely on individuals' and population health and are more easily amenable to direct structural interventions aimed at promoting health.

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[59] Lerer LB et al. Health for All: Vision to Strategy – The Role of Health Status and Determinants. *World Health Statistics Quarterly*, 1998, 51: 7–20.

[60] Cohen D et al. Cost As A Barrier to Condom Use: The Evidence For Condom Subsidies in the United States. *American Journal of Public Health* 1999; 89:567-568.

[61] Laboratory Center for Disease Control and Prevention (Health Canada). Revision of the Surveillance Case Definition for AIDS in Canada. *Canada Communicable Disease Report*, August 1993; 19-15: 116-117.

2.2.3 Simultaneous direct and indirect effects

In addition, in any given moment, laws/policies may impact simultaneously at both direct and indirect levels. Proximal structural factors include laws/policies that might directly affect the behaviour of a segment of society, such as IDUs or recipients of publicly funded services, while having a more indirect impact on the general population.[62] These direct and indirect effects on the health of individuals and populations are amenable to structural interventions, either by acting on the proximal determinants by removing legal/policy barriers or by instituting legal policy changes addressing the distal factors.

In sum, laws/policies operate as determinants of the determinants of health. This determination can involve one or more determinant(s) of health. In all cases, there is a cumulative ultimate effect on health. Sometimes that cumulative effect is through law/policy's simultaneous impact through several different determinants from different directions; other times the cumulative effect is more like an onion or a set of Russian dolls, with multiple layers of effect on a single determinant. As one author points out: "current 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."[63] These three areas of HIV/AIDS-related health outcomes are understood here as the result of the complex impact of structural determinants of health which affect (other) determinants of health.

Illustrations

The following illustrations outline the complex character of law/policy as structural determinants of HIV/AIDS-related health outcomes.

- Figure D shows how law/policy prohibiting the unauthorized possession of controlled substances, combined with prison policies prohibiting the possession of syringes inside prison, have cumulative, synergistic effects on several determinants of health in prisoners, which ultimately heighten prisoners' vulnerability to HIV infection, the progression of their HIV disease, and their ability to cope/live with HIV/AIDS in prisons. This means the impact of drug laws needs to be considered in shaping (1) policy aimed at preventing HIV infection; (2) policies aimed at ensuring or improving access to care, treatment and support for persons with HIV disease; and (3) policies aimed at mitigating the broader impact of HIV/AIDS.
- Still using the same example, but adding an additional layer of complexity, Figure E illustrates in more detail how drug laws operate to affect one specific determinant of health (i.e., *personal health practices*), thereby having an impact on health.

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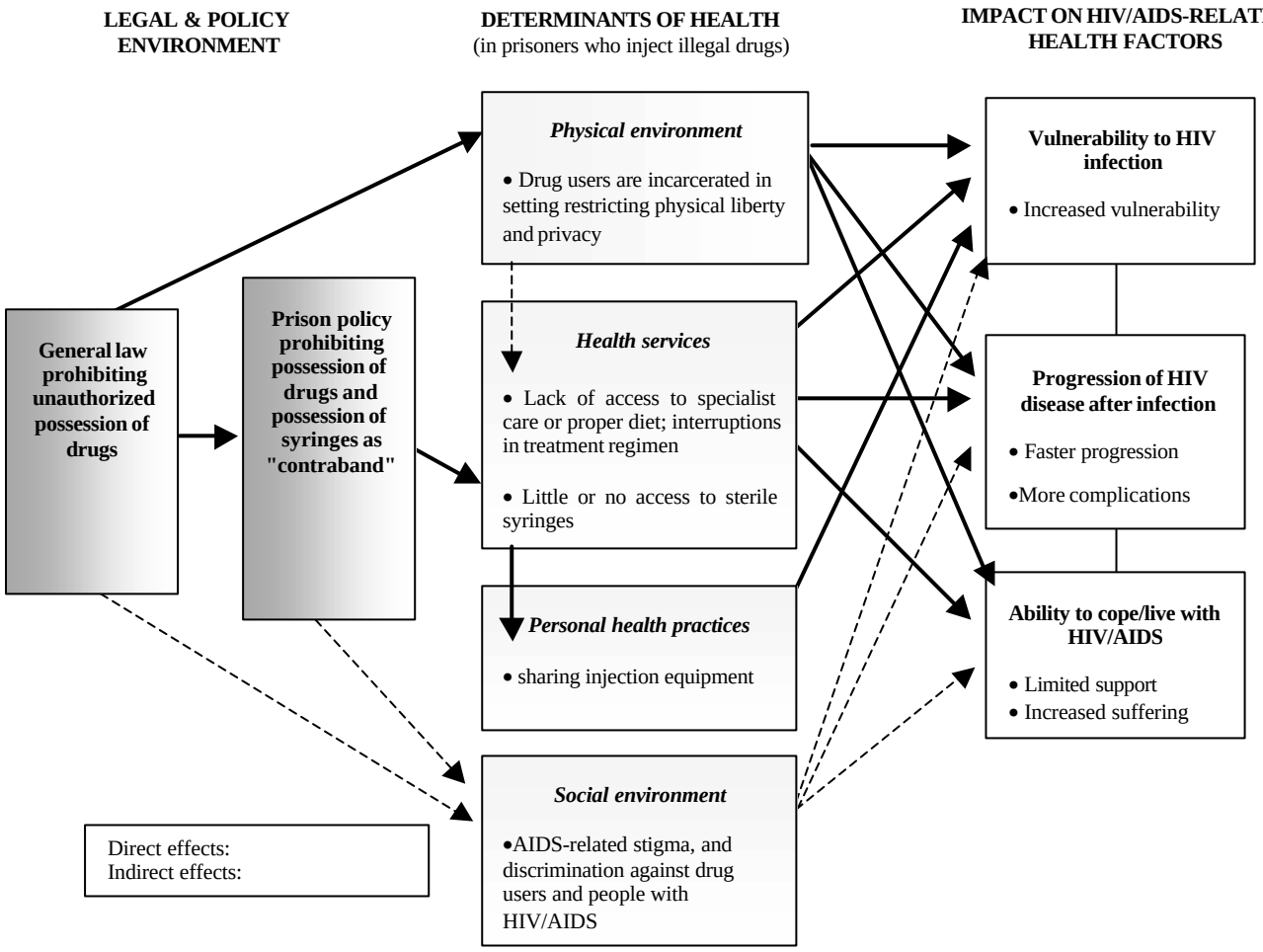
[62] Sweat MD, Denison JA. Reducing HIV Incidence in Developing Countries With Structural and Environmental Interventions. *AIDS* 1995; 9: S251-S257.

[63] Spigelman M et al. *HIV/AIDS and Health Determinants: Lessons for Coordinating Policy and Action - A Discussion Paper for the Ministerial Council on HIV/AIDS*. Ottawa: Health Canada, 2002: at 36.

Figure D. Cumulative Impact of Drug Laws and Policies on the Health of Prisoners



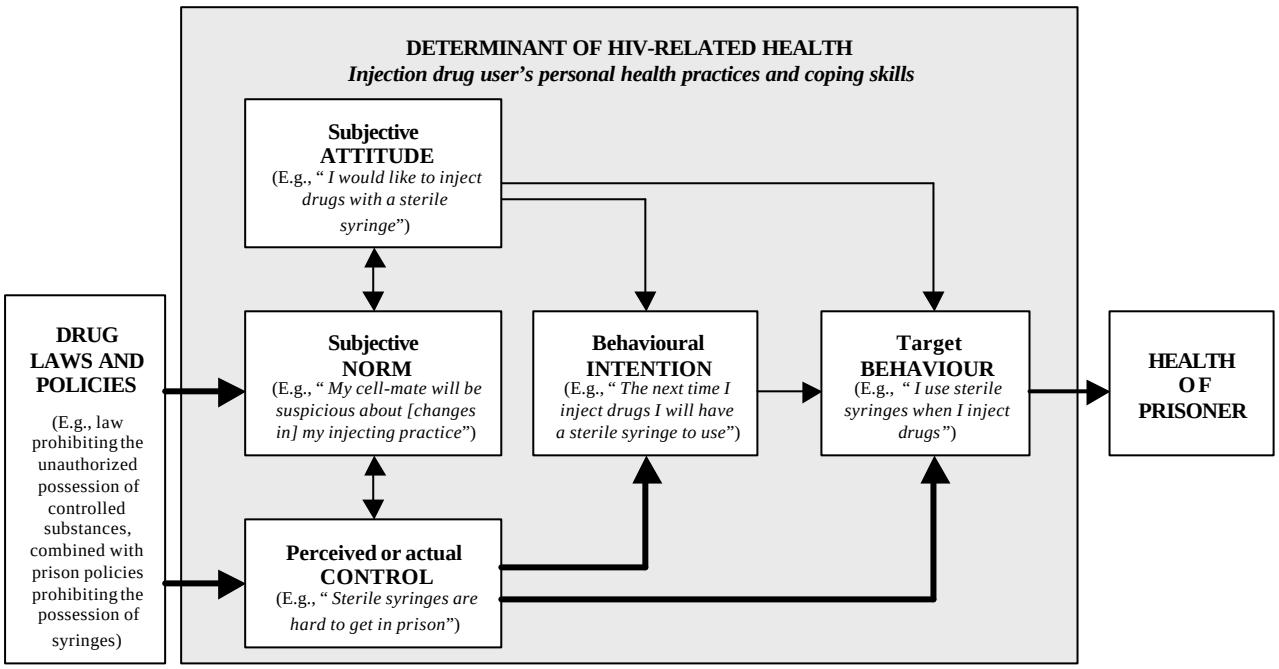
Notes: A law prohibiting the possession of controlled substances, and applied so as to impose incarceration as a chief penalty, increases the number of drug users for whom prison is their *physical environment*. The prohibition on possession of illicit drugs has a further, direct effect on the *physical environment* for injection drug users in prison, in that it creates physical conditions requiring rapid, clandestine use of those drugs. The law therefore affects the determinant of health that is *physical environment* in at least these two ways.

Both drug laws and policies may incorporate drug- or AIDS-related stigma directed at those vulnerable to or living with HIV/AIDS. This stigmatisation may, in turn may have an indirect effect on the *social environment* of prisoners.

Institutional policies prohibiting syringes in prison as "contraband" compound the health effects by influencing at least two other health determinants: the prohibition has an as a direct effect on *health services* for prisoners who inject drugs (i.e., denying or hindering access to sterile injection equipment), which has a direct impact on *personal health practices* (i.e., sharing injection equipment). In this example, through a variety of direct and indirect means, law/policy has a negative impact on the health of prisoners because it heightens their vulnerability to HIV infection. Healthy public policy aimed at facilitating HIV prevention would change this.

Furthermore, the fact that the law has imposed prison as the *physical environment* for drug users often has a further ripple effect on the determinant that is *health services*: e.g., as a result of their imprisonment, prisoners will often experience limited access to specialist care for treating HIV disease and related conditions, interruptions in their regimen of medications (e.g., for anti-retroviral drugs), inadequate diet necessary to maintain health (particularly if their HIV medication regimen is accompanied by specific dietary requirements), little or no access to psycho-social support services, etc. Access (or lack thereof) to health services then has an impact on both the progression of HIV disease and the broader ability of the individual to cope/live with HIV/AIDS.

Figure E: How Law and Policy affects "Personal health practices and coping skills"



Notes: The determinant of health *Personal Health Practices and Coping Skills* refer to those actions or behaviours by which individuals can prevent diseases and promote self-care, cope with challenges, and develop self-reliance, solve problems and make choices that enhance health.[64] Personal health practices include the influences of individual factors and of structural factors such as laws/policies on the decisions people make about their health. The use of sterile syringes as a safer injection practice is considered here as a personal health practice of injection drug users that reduces the risks of acquiring or transmitting HIV.

Azjen's theory of planned behaviour is applied as the framework for behavior change at the individual level. The theory assumes that behavior change is predicted by: (1) people's intention to change behavior, (2) their attitude toward the behavior, (3) how they believe others view the behaviour, and (4) their perceptions of the control they have over enacting the behavior - this control includes actual physical barriers to making the behavior change and perceptions of self-efficacy or competence in making the behaviour change. Here the theory allows the detailing of how drug laws/policies operate to affect health: the legal and policy environment influences a prisoner's behavioural "choices".[65]

Drug laws/policies directly affect perceived or actual control towards safer drug use. If one considers the existence of a policy prohibiting the possession of syringes in prisons, clearly prisoners face greater difficulty in achieving the target personal health practice of using sterile syringes. In other words, if the person perceives little or no control in accessing sterile syringes in prison, this will negatively affect the intention to use a sterile syringe (i.e., behavioural intention and the actual use of a clean needle (i.e. target behaviour). Structural interventions would support the creation of a law/policy environment that enhances rather than deter the capacity of individuals to make healthy lifestyle choices in a prison context.[66]

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[64] Information at: http://www.hc-sc.gc.ca/hppb/phdd/determinants/e_determinants.html#personalhealth

[65] See: Azjen I. From Intention to Actions: A Theory of Planned Behavior, in Kuhl J, Beckmann J (eds). *Action-Control: From Cognition to* Behavior. Heidelberg: Springer, 1985: at 11-39; and Prediction of Goal-Directed Behavior: Attitudes, Intentions, and Perceived Behavior Control. *Journal of Experimental Social Psychology* 1986; 7: 259-276.

[66] For a useful application of this model on the impact of using criminal to prevent HIV transmission or exposure, see: Lazzarini Z et al. Evaluating the impact of Criminal Laws on HIV Risk Behavior. *Journal of Law, Medicine and Ethics* 2002; 30: 239-253.

Research which could inform structural intervention would focus on issues such as: how to engage community leaders in encouraging health enabling environments; how to reduce discrimination, stigmatization and other social forces that make populations particularly susceptible to HIV risk behaviours; or what is or will be the impact of enacting a particular law or adopting a particular policy on the spread of HIV, the access of those who are HIV-positive to care, treatment and support, or the ability of individuals, families or communities to cope with HIV/AIDS. However, new methodologies are required to document and evaluate the effects of structural factors, which by their very nature involve large-scale elements that cannot be easily controlled by traditional (experimental or quasi-experimental) research designs. A review of the methods currently being used to do this type of work is presented in the next section. These are innovative, interdisciplinary approaches attempt to move beyond the limited successes of traditional behavioural research and explicitly strive to achieve (and evaluate) broader social and structural change.

2.2.3 Evidence-Based Policy and Health Impact Assessment

In order to be "healthy", public policy should be informed by a consideration of its impact on health. Therefore, it is important to generate the necessary evidence to assess the effects of different legal and policy options on the health of individuals, communities and populations infected and affected by HIV/AIDS. In particular, this project is a first step toward identifying and designing a research project that establishes empirical evidence that policy which respects and promotes the human rights of people living with HIV/AIDS and those vulnerable to infection is also sound policy from the point of view of promoting public health.

It is one thing to assert that health and human rights are interdependent, and that policy that respects and promotes the human rights of people living with HIV/AIDS and vulnerable groups is also sound public health policy. But when the data on laws/policies as structural determinants of health is under-developed, it is an additional challenge to ensure that human rights principles inform public policy. What is required is research data analysing the connections between particular legal/policy options and their impact on health, so that a human rights assessment of laws/policies can be conjoined with a public health assessment to illustrate their complementarity. In other words, "effective population health strategies must be built on a foundation of sound evidence about factors that determine health, and information about the potential impact of interventions and programs to address those determinants".[67] Literature in the area of evidence-based research and policy points to the fact obtaining sound evidence of the impact of law/policy on health and human rights "will demand new methods and coalitions".[68]

The development of *health impact assessment* (HIA) is one new method for evaluating the impacts on health of laws, policies, programs or projects, with a view to minimising the negative impacts and enhancing positive impacts.[69] Several methods of carrying out such assessments

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[67] Federal/Provincial/Territorial Advisory Committee on Population Health. *Strategies for Population Health: Investing in the Health of Canadians.* Ottawa: Minister of public Works and Government Services Canada, 1994: 29.

[68] Sumartojo E et al. Enriching the Mix: Incorporating Structural Factors Into HIV Prevention. *AIDS* 2000; 14 (Suppl 1): S1-S2.

[69] MacIntyre S, Petticrew M. *Methods of Health Impact Assessment: A Literature Review*. Glasgow: Medical Research Council Social; Public Health Sciences Unit, Occasional Paper, December 1999.

have been proposed and a wide variety of evidence can be used, from expert opinion to prospective epidemiological studies and literature reviews. From literature produced by the Merseyside Health Impact Assessment Steering Group in the UK, four core propositions can be derived (for the present purposes). [70]

(1) HIA is the estimation of the effects of a specified action on the health of a defined population.

(2) Ideally, such work should be prospective; it should precede the start of the project, programme, law or policy concerned in order that any potential negative health effects can be avoided or reduced, and any positive ones enhanced.

(3) A "health impact" is a change in health status (or in the determinants of health status) of an individual or group attributable to a project, program, law or policy.

(4) The results of HIA are used to change the project, program, law or policy such that the health of the community or population is protected and improved; in other words, to develop healthy public policy.

These core propositions are important because they point towards the methodological underpinnings of *how* the impact of structural determinants of health can be measured. HIA procedures and methods include:[71]

- Screening to determine which law/policy should be subject to HIA (i.e., policy analysis, profiling the areas and communities affected).
- Scoping to define the boundaries the HIA (i.e., involving stakeholders and key informants in predicting potential health impacts, using a predefined model of health).
- Appraisal of health impacts of the law/policy and what changes may be suggested to minimise the negative and maximise the positive (i.e., identification of potential positive and negative health impacts, assessment of health risks, quantification and valuation of health impacts, ranking and researching the most important impacts).
- Decision-making about which recommendations to change the law/policy should be adopted (i.e., consideration of alternative options and recommendations for management of priority impacts).
- Monitoring and evaluation (i.e., appreciation of the health outcomes of implementing the law/policy as modified by the HIA, and how the HIA process can be improved).

Another innovative methodology to measure law/policy impact on population health is called Rapid Assessment and Response (RAR) and has been applied to study structural determinants of

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[70] Scott-Samuel A et al. *The Merseyside Guidelines for Health Impact Assessment. 2nd Edition*. Liverpool: Meyerside Health Impact Assessment Steering Group, Liverpool Public Health Observatory, Department of Public Health, University of Liverpool, 2001. The first edition, published in 1998, is available at: http://www.liv.ac.uk/~mhb/publicat/merseygui/

[71] Ison E. *Rapid Appraisal Tool for Health Impact Assessment. A Task-Based Approach - Eleventh Iteration.* Commissioned by the Directors of Public Health of Berkshire, Buckinghamshire, Northamptonshire, and Oxfordshire, January 2002. http://www.fphm.org.uk/Policy/Rapid_Appraisal_Toolkit/Rapid_Appraisal_Toolkit.htm

health and issues of sexual risk behaviour as well as injection drug use.[72, 73] RAR is a means for depicting the extent and nature of social and health problems and for suggesting ways in which they may be improved. The principles of RAR are similar to HIA methods; they encompass both the assessment of the problem and an assessment of the resources available or that might be needed to address the problem. Recently a team of US researchers working with International Harm Reduction Development has adapted RAR to evaluate and document how current drug laws and health policies impact on the spread of HIV among IDUs.[74] This project is using the Rapid Policy Assessment Tool (RPAT) to provide standardized data and analysis of the legal environment within and across five countries — Russia, Ukraine, Kazakhstan, Poland, and Slovenia.[75] Much of the quantitative data will come from existing HIV/AIDS sources and qualitative data will be collected through interviews with local key informants on the actual practices of law/policy, as distinct from what is "on the books." RPAT also analyses international, national, and local laws and legal practices in the targeted community, including international drug conventions, constitutional law, health law, criminal law, criminal procedure, and human rights laws.

HIA, RAR and RPAT draw on evidence-based policy-making, which is predicated upon certain assumptions about (1) the nature of "knowledge" and "evidence"; (2) about the ways scientific research can provide the evidence needed; (3) and about the ways in which scientific evidence is applied in "improving" law/policy. In all these respects there is debate and disagreement among academics, evaluation and policy specialists, and community-based organizations. Across these disagreements however, what is widely accepted is that it is desirable or preferable that policy decisions be based upon a solid empirical foundation using research that has applied rigorous methods.

According to the Canadian Health Services Research Foundation, evidence-based health policy is a logical extension of the interest in and resources committed to evidence-based medicine,[76] which is defined as the conscientious, explicit, and judicious use of current best evidence in making decisions about health care — at the level of both individual patients and on a system-wide, policy level.[77] In 1997, the National Forum on Health recommended "the systematic application of the best available evidence to the evaluation of options and to decision-making in

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[72] Rhodes T et al (eds). *The Rapid Assessment and Response Guide on Substance Use and Sexual Risk Behaviour (Draft for Field Testing)*. Geneva: World Health Organization Substance Abuse Department and UNAIDS. Available at: http://www.who.int/substance_abuse/docs/sex_rar.pdf

[73] Stimson G et al (eds). *The Rapid Assessment and Response Guide on Injecting Drug Use (Draft for Field Testing)*. Geneva: World Health Organization Substance Abuse Department, 1998. Available at: http://www.who.int/substance_abuse/docs/idu_rar.pdf

[74] Welsh J, Lazzarini Z. Analyzing Drug Laws and Health Policies. *Harm Reduction News* 2002; 3(1): 8.

[75] Lazzarini Z et al. Rapid assessment of drug and harm reduction policies in Eastern Europe and the former Soviet Union – Abstract No. MoOrG1124. Presented at the XIVth International AIDS Conference, Barcelona (Spain), 9 July 2002.

[76] Canadian Health Services Research Foundation. *Health Services and Evidence-Based Decision-Making.* Ottawa: The Foundation, June 2000.

[77] Sackett DL et al (eds). *Evidence-Based Medicine: How to Practice and Teach EEB.* London: Churchill Livingstone, 1997.

clinical, management and policy settings".[78] In a review of the conceptions about evidenced-based medicine, authors concluded that the thoughtful extension of evidence-based principles to the realms of public policy is important for all those who wish to improve human well being.[79]

The process of making decisions based on evidence may not translate directly from the clinical medical context to the work of policy makers, but the principle is sound. However, judging what constitutes sound evidence can be difficult because of the sheer quantity, diversity, and complexity of "evidence" available today; the various research methodologies that have been advanced for assembling, evaluating, and interpreting such information; and the guides for applying research evidence to individual community or populations.

[78] Health Canada National Forum on Health. *Summary Report. Evidence-based Decision-making: A Dialogue on Health Information*, 1997. Available at: http://wwwnfh.hc-sc.gc.ca/publicat/evidence/idxebdme.htm

[79] MacIntyre S, Petticrew M. Good Intentions and Received Wisdom Are Not Enough. *Journal of Epidemiology and Community Health* 2000; 54:802-03.

Section III - Literature on Impact of Law/Policy in Specific HIV/AIDS-related Areas

As one author points out: "current 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."[80] These three HIV/AIDS-related health outcomes are understood here as the result of the complex impact of structural determinants of health which affect (other) determinants of health. This section of this report provides a review of literature regarding the impact of law/policy on health determinants in 4 specific areas related to HIV/AIDS. The literature reviewed is twofold. First, the review outlines the theoretical impact of various structural legal and policy factors associated with HIV/AIDS. Second, the review summarizes quantitative and qualitative studies that make the connections between structural factors and the impact on health.

3.1 Laws and Policies Regarding HIV Testing, Reporting and Partner Notification

3.1.1 Theoretical Literature

In the area of HIV testing policies, most of the literature reviewed recommends that policy-making should not dismiss the importance of respecting people's rights and the risk of discrimination, and suggests it would be imprudent to implement coercive measures, particularly when stigma and discrimination persist, treatments are not accessible for many of those living with HIV, their long-term effects remain uncertain, and the efficacy of coercive strategies is at best questionable. Testing policy generally, and in pregnancy and aboriginal settings in particular, is believed to require constant re-evaluation as treatments and technology evolve.[81, 82, 83] A careful consideration of risks and benefits that takes account of an individual's human rights and society's need to maintain public health is understood as the appropriate basis of ethical legal and policy approaches to HIV testing.[84] In addition, the literature recognises that new testing technologies, new treatments and the availability of post-exposure prophylaxis constitute a huge step forward but do not represent a solution to all problems faced by people with HIV/AIDS such as the problems that stem from gender inequities, poverty and discrimination,[85,]

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[80] Spigelman M et al. 2002. *op. cit.*: at 36.

[81] Stoltz L, Shap L. *HIV Testing and Pregnancy: Medical and Legal Parameters of the Policy Debate*. Ottawa: Health Canada, 1999.

[82] Matiation S. *HIV Testing and Confidentiality: Issues for the Aboriginal Community* (2nd Edition). Canadian HIV/AIDS Legal Network, Canadian Aboriginal AIDS Network, 1999.

[83] Tseng AL. Anonymous HIV Testing in the Canadian Aboriginal Population. *Canadian Family Physician* 1996; 42: 1734-1740.

[84] Jürgens R. *HIV Testing and Confidentiality: Final Report* (2nd Edition). Montreal: Canadian HIV/AIDS Legal Network, 2001.

[85] Elliott R, Jürgens R. *Rapid HIV Screening at the Point of Care: Legal and Ethical Questions.* Montreal: Canadian HIV/AIDS Legal Network, 1999.

[86] meaning that these advances do not automatically signify that HIV testing policies must change or that principles such as informed consent become less important touchstones for HIV-related law/policy.

Another view holds that the reasons why many people at risk of HIV infection are not tested probably have more to do with the "social risk of being tested" (e.g., Will the test cost something? Will I have to disclose my serostatus?), rather than with fear of discrimination and stigma per se.[87] While confirming the need to address HIV-related discrimination and stigma through legal and other means, this view suggests the need for researchers to use a "richer model" to understand more fully the reasons why people at risk of acquiring HIV will not get tested, which understanding should inform action in the policy arena and elsewhere.

Analysis of the theoretical impact of HIV testing policies suggests that while early detection of HIV infection is a pressing priority, making HIV testing routine or mandating HIV testing needs to be treated with great caution. There is a lack of consensus among authors reviewed regarding whether mandatory/compulsory testing, at least for certain populations or in certain circumstances, is to be favoured over voluntary testing. However, by far the predominant view is that voluntary testing is preferred over mandatory or compulsory testing. Some support compulsory testing in populations that are at high risk of HIV (e.g., sex workers). Proponents argue this measure would allow health care providers to intervene early and control the spread of the disease. For example, one author argued that in US prison settings compulsory testing is an important means to reducing the impact of the spread of the virus both within prison and in the non-offender population.[88]

Regarding the issue of anonymous testing, some argue this is the best HIV testing option because it ensures patient confidentiality, and thus encourages individuals to undergo testing.[89, 90] These authors tend to argue that reluctance to use testing could be due to lack of access to anonymous testing sites, language barriers, cultural nuances or preference for traditional healing options as well as to difficulty of the maintaining confidentiality in small communities, and fear of negative consequences of HIV testing.

For others, there is no clear-cut "best testing option" if one considers variations in policy options from one country to another. One article compared policies on nominal HIV testing in Britain, Hungary and Sweden, and considered the extent to which these policies are based on evidence of

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[86] Lert F. Advances in HIV Treatment and Prevention: Should Treatment Optimism Lead to Prevention Pessimism? *AIDS Care*. 2000; 12(6): 745-55.

[87] Burris S. Driving the Epidemic Underground? A New Look at Law and the Social Risk of HIV Testing. *AIDS and Public Policy Journal*. 1997; 12(2 Summer): 66-78

[88] Amankwaa AA et al. Revisiting the Debate of Voluntary Versus Mandatory HIV/AIDS Testing in US Prisons. *Journal of Health & Human Services Administration* 1999; 22(2): 220-36.

[89] Jürgens R. *HIV Testing and Confidentiality: Final Report* (2nd Edition). Montreal: Canadian HIV/AIDS Legal Network, 2001.

[90] Matiation S. *HIV Testing and Confidentiality: Issues for the Aboriginal Community* (2nd Edition). Canadian HIV/AIDS Legal Network, Canadian Aboriginal AIDS Network, 1999.

their effectiveness in encouraging testing or on other, more contextual, factors.[91] The paper describes how in Britain, testing has not featured significantly as a prevention strategy and nominal testing has generally been carried out only with the voluntary, informed consent of individuals; in Hungary, testing is central to HIV prevention and is required by law of certain groups; and that in Sweden HIV testing is carried out mainly on a voluntary basis, but unlike in Britain, public health authorities have actively promoted it. The authors contrast the British legal/policy environment where the "right not to know" one's HIV status is widely respected with the contexts in Hungary and Sweden where the "responsibility to find out" is more pervasive. Although policy makers in all three countries appear convinced that theirs is the right approach, the authors suggest that there appears to be a dearth of convincing evidence to support either anonymous or nominal testing as the necessarily better option.

The debate concerning the most appropriate testing policy to implement extends to discussions on policy regarding partner notification and reporting of HIV seropositivity. Most analyses agree that one of the guiding principles for partner notification should be voluntary participation.[92, 93] The consequences of partner notification, however, are complex and may not be uniformly beneficial to infected persons, their partners, and the community. One author argues that partner notification has demonstrable flaws because it infringes on civil liberties: "Partner notification presents a cost to individuals in loss of privacy and in discrimination. For women, it can result in abandonment, neglect, and abuse. For these reasons, alternative strategies like social network analysis should be considered to supplement or replace partner notification".[94]

The rationale for why HIV should or should not be reportable is often based on the benefits and problems associated with partner notification. The common objection to making HIV reportable by name is that this will cause individuals who could benefit from testing to avoid testing. However, the literature is inadequate to make firm conclusions on this point. Close analysis of individual's willingness to test in the U.S. indicates that many people who seek HIV testing are unaware of whether HIV is reportable in that state.[95, 96] Fear of receiving a positive diagnosis is a deemed much greater deterrent to testing than the reportability status of HIV. However, the extent to which reportability (and the method of reporting) affects willingness to test has not been studied carefully, particularly not with respect to specific populations that may be at different levels of risk and/or be drawn from different socio-economic strata, and there are conflicting studies on this issue.

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[91] Danziger R. HIV testing for HIV prevention: A Comparative Analysis of Policies in Britain, Hungary and Sweden. *AIDS Care* 1998; 10 (5): 563-70.

[92] Federal/Provincial/Territorial Advisory Committee on AIDS Working Group on Partner Notification. *Guidelines for Practice of Partner Notification in HIV/AIDS*, January 1997.

[93] Dimas JT, Richland JH. Partner Notification and HIV Infection: Misconceptions and Recommendations. *AIDS & Public Policy Journal* 1989; 4 (4): 206-211.

[94] Gostin LO, Hodge JG. Piercing the Veil of Secrecy in HIV/AIDS and Other Sexually Transmitted Diseases: Theories of Privacy and Disclosure in Partner Notification. *Duke Journal of Gender Law Policy.* 1998; 5: at 87-88.

[95] Fleming, PL et al. Guidelines for National Human Immunodeficiency Virus Case Surveillance, Including Monitoring for Human Immunodeficiency Virus Infection and Acquired Immunodeficiency Syndrome. *Mortality and Morbidity Weekly Report.* December 10, 1999; 48 (RR13); 1-28.

[96] — New Treatments Give HIV Reporting Added Weight. *AIDS Alert*. July 1997; 80-83.

In the US, the Centers for Disease Control and Prevention, mainstream medical journals and many state legislatures have supported state-level proposals that require public health officials to adopt named reporting of HIV test results instead of reporting using number identification assuring anonymity.[97, 98, 99, 100] US literature reports that even name-based surveillance does not directly deter individuals at risk of HIV from being tested, or expose them to significant social risks. Theoretically, as one author noted, rather than focusing piecemeal on specific barriers to testing and care, an appreciation of the surveillance debate *in context* recommends "a positive undertaking in public health policy to provide the conditions of opportunity, information, motivation and confidence that people with HIV need to accept an effective program of early intervention".[101]

Conversely, one US author recommends that a determination should be made as to whether the potential long-term benefits of name-based reporting outweigh the risks before the practice of nominal reporting is more widely adopted.[102] Similarly, another review of rationales for name-based reporting and case reports based on unique identifiers concluded that neither method for surveillance could provide HIV incidence data.[103] Such data is said to be obtainable only through statistical estimation based on "snapshot estimates" of HIV incidence in sample cohorts.

Considering that most jurisdictions in Canada have adopted laws requiring name-based reporting of cases of HIV seropositivity, and in light of the theoretical implications regarding various testing options and debate over data collection, research on the impact of such change in public health law/policy is needed. In Quebec, for instance, these changes have occurred and although in this case the individual's name will not be transmitted from the public health laboratory to the health ministry's list of data, there is concern within AIDS service organizations that the new policy may compromise the anonymity and confidentiality of people living with HIV, as well as generate a false sense of security in the general public.[104]

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[97] For an excellent review of this literature, see: Beckerman NL, Gelman SR. A Shift in HIV Reporting Practices: A Biopolitical Analysis. *Journal of Health & Social Policy* 2000; 12(2): 73-87. See also: Gostin 1997 (supra).

[98] Grumman C. Activists Speak Out on HIV Reporting: Confidentiality Seen as a Problem. *The Illinois Times,* 28 April 1998: C2.

[99] Richardson L. AIDS Group Opposes Use of Names in HIV Reports. *The New York Times,* 17 January 1998: B6.

[100] Valdiserri RO. et al. The Context of HIV/AIDS Surveillance. *Journal of Acquired Immune Deficiency Syndromes.* 2000; 25 (Suppl. 2): S97-104.

[101] Burris S. Surveillance, Social Risk, and Symbolism: Framing the Analysis for Research and Policy. *Journal of Acquired Immune Deficiency Syndrome* 2000; 25(Suppl 2): S120-127.

[102] Colfax GN, Bindman AB. Health Benefits and Risks of Reporting HIV-Infected Individuals by Name. *American Journal of Public Health.* 1998; 88(6): 876-87.

[103] Johri M et al. New Approaches to HIV Surveillance: Means and Ends. Summary Report of Conference Held at Yale University, 21-22 May 1998, by the Law, Policy and Ethics Core, Center for Interdisciplinary Research on AIDS, Yale University. *AIDS & Public Policy Journal* 1999; 14(4): 136-46.

[104] Paré I, Dutrisac R. Santé publique: Le VIH sera une maladie à déclaration obligatoire. L'anonymat des personnes porteuses sera protégé, *Le Devoir,* 19 September 2001.

3.1.2 Empirical Data

Empirical assessments of the theoretical impacts of HIV testing policy are available. They explore primarily the test experience and confidentiality; stigma and the social risks of testing; testing approaches; and policy regarding HIV testing of pregnant women.

A study on HIV testing in Ontario specifically explored the reality of HIV test counselling and evaluated the impact of those counselling efforts so as to inform the development of HIV counselling programs and policies.[105] The investigators included both HIV test providers and recipients in their qualitative interview scheme. Test providers included physicians, none of whom reported having any formal training in HIV/AIDS. A number of test recipients acknowledged social risks of being tested. They universally valued confidentiality in testing and preferred anonymous testing settings. The findings lead to a series of recommendations to improve and enhance the pre-test encounter between test providers and recipients; the period waiting for test results; the post-test encounter; HIV testing guidelines; education, training and support for test providers; and future research into the process of testing. The study suggests that HIV/AIDS continues to raise many issues that relate to stigmatization. To maintain and improve the effectiveness of the test as a prevention and treatment intervention, it is important to continue to evaluate the impact of the HIV test on recipients and providers, as well as to understand the impact of systemic changes in societal attitudes, policies, and laws.

A second study on the experiences of persons living with HIV in rural areas in North Carolina demonstrated the importance of developing appropriate policies and procedures regarding confidentiality.[106] This study was not specifically about HIV testing but on the issue of confidentiality in general, with likely applications for HIV testing policy. Most respondents had experienced or knew someone who had experienced a breach in confidentiality - either "obvious" breaches (e.g., a nurse tells her child that her patient was HIV-positive out of concern that her child would play with the patient's child) and more "subtle" breaches (e.g., a health care provider releasing a patient's HIV status to other providers without the patient's consent). Respondents claimed to make decisions about where to seek care based on the degree of professionalism of medical staff (which included respecting confidentiality), clinic location and level of security of the organization's computer network since they believed that computers increase information access. Finally, respondents recommend that confidentiality policies require health care providers to: explain procedures for sharing information; request patients' specific consent for access to their medical records, even among other providers; and punish those who breach confidentiality.

Stigma and the social risks of testing

On the social risks of testing, some research has focused on AIDS-related stigma, negative public attitudes towards people living with HIV/AIDS and the impact of such stigmatization. Of particular relevance here is one US study which found that stigma surrounding sexually

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[105] Myers T et al. *The HIV Test Experience Study: An Analysis of Test Providers' and Test Recipients' Descriptions and Critical Appraisals of the HIV Antibody Test Experience*. Toronto: University of Toronto, 1998.

[106] Whetten-Goldstein K et al. So much for Keeping Secrets: The Importance of Considering Patient's Perspectives on Maintaining Confidentiality. *AIDS Care* 2001; 13(4): 457-466.

transmitted diseases is a very powerful barrier to obtaining such care.[107] The researchers concluded that increasing knowledge or health care access may not address the barriers posed by stigmatisation: what is needed are structural interventions that acknowledge societal attitudes regarding sexual behaviours and perceived negative judgments of those with STDs. These findings are consistent with widely held assumptions about the role of stigma as a barrier to HIV prevention and care.

In addition, several researchers have found that fear of stigma deters individuals from being tested for HIV and from disclosing their seropositive status to sexual partners, family, and friends. One study examined the ways in which AIDS-related stigma is associated with psychological distress and can delay testing.[108] Findings also suggest that stigma affected people with HIV/AIDS in terms of their decisions to disclose HIV serostatus to physicians, family and friends, and to entering and adhering to care. Another study found that the reasons why individuals who do not disclose information about being HIV seropositive are related to the desire to maintain privacy and, therefore, to control who has access to the information about the diagnosis.[109] Two other US studies looked at rates of disclosure in ethnically diverse samples of HIV-positive women. Findings suggest that women are very likely to avoid disclosing their seropositivity because of perceived AIDS-related stigma; in particular stigma deterred disclosure in women from Spanish-speaking Latina communities[110] as well as in women who fear partner violence.[111] These data support the idea that, if incorporated in law/policy, stigmatization will have substantial indirect HIV-related effects on health.

Anonymity and Confidentiality of testing

On the subject of HIV testing approaches, one study compared patterns of anonymous and confidential testing in all US federally funded counselling and voluntary testing programs from 1995 through 1997.[112] The report documents the importance of both types of testing opportunities. Findings suggest the decline in anonymous testing may reflect the perceived positive impact of new laws and regulations on decreasing the risk of confidentiality violations. The CDC concludes that because of the potential benefits of anonymous testing it will encourage states to include anonymous testing as an integral component of HIV testing and counselling programs.

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[107] Fortenberry JD et al. Relationships of Stigma and Shame to Gonorrhea and HIV Screening. *American Journal of Public Health* 2002; 92: 378–381.

[108] Chesney MA, Smith AW. Critical Delays in HIV Testing and Care: The Potential Role of Stigma. *American Behavioral Scientist* 1999; 42:1162–1174.

[109] Derlega VJ et al. "Personal Accounts on Disclosing and Concealing HIV-Positive Test Results: Weighing the Benefits and Risks." In: Derlega VJ, Barbee AP (eds). *HIV and Social Interaction*. Thousand Oaks, CA: Sage, 1998: at 147–164.

[110] Simoni JM et al. Women's Self-Disclosure of HIV Infection: Rates, Reasons, and Reactions. *Journal of Consulting and Clinical Psychology* 1995; 63: 474–478.

[111] Gielen AC et al. Women's Disclosure of HIV Status: Experiences of Mistreatment and Violence in an Urban Setting. *Women Health* 1997; 25: 19–31.

[112] CDC "Anonymous or Confidential HIV Counseling and Voluntary Testing in Federally Funded Testing Sites: United States, 1995-1997", *Morbidity and Mortality Weekly Report* 1999 (June 25); 48(24): 509-513.

Similarly, two studies examined the impact of the closing of anonymous test sites in North Carolina. The first found that HIV testing increased more rapidly in counties that maintained anonymous testing compared to counties that did not.[113] The second concluded that while eliminating anonymous testing had a relatively small effect on rates of HIV testing and on partner notification, it had a large effect on the relationship between the advocacy community and the public health department.[114] Together these data suggest that a policy that encourages confidential testing while maintaining the availability of anonymous testing may maximize the effectiveness of both testing and partner notification, as well as fostering healthier relationships between communities and public health with a likely indirect positive impact on other aspects of public health policy and initiatives. In addition the acceptability of confidential testing could be enhanced by policies using unique identifiers as opposed to names for HIV reporting and strengthening anti-discrimination policies and laws.

HIV test reporting policy

US literature on the subject of HIV/AIDS surveillance system and the issues raised by nominal reporting of HIV seropositivity suggests that there is little evidence that name-based surveillance directly deters individuals at risk of HIV from being tested, or exposes them to significant social risks.[115] A common objection to making HIV reportable is that this will cause individuals who could benefit from testing to avoid testing. However, this claim is not substantiated in the literature. In fact, the evidence indicates that many people who seek HIV testing are unaware of whether HIV is reportable in that province or state. For example, one study used the counseling and testing data from six state health departments (Louisiana, Michigan, Nebraska, Nevada, New Jersey, and Tennessee) to compare HIV testing and counseling rates 12-months before and 12-months after HIV nominal reporting was introduced.[116] The results were that no significant declines in the total number of HIV tests provided occurred in the months following implementation of nominal reporting of HIV test results (other than those expected trends present before HIV reporting). Fear of receiving a positive diagnosis is a much greater deterrent to testing than the reportability status of HIV.

Partner notification policy

Another important finding first published more than a decade ago is that generally most index patients are willing to participate in partner notification programs if their anonymity can be

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[113] Hertz-Picciotto I, Lee L, Hoyo C "HIV Test-Seeking Before and After the Restriction of Anonymous Testing in North Carolina, USA", *American Journal of Public Health* 1996; 86 (10): 1446-1449.

[114] Kassler WJ et al. Eliminating access to anonymous HIV antibody testing in North Carolina: effects on HIV testing and partner notification. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology* 1997; 14(3): 281-289.

[115] Fleming, PL et al. Guidelines for national human immunodeficiency virus case surveillance, including monitoring for human immunodeficiency virus infection and acquired immunodeficiency syndrome. *Mortality and Morbidity Weekly Report* 1999; 48 (RR13):1-28. This document is the US Centers for Disease Control's guidelines for surveillance of HIV and AIDS. It recommends that all US States extend their current AIDS surveillance activities to include HIV. The Guidelines include an important section on the effect of making HIV nominally reportable and the evidence about testing behaviours. There is no strong evidence that people would not be tested simply because HIV is reportable.

[116] Nakashima AK et al. Effect of HIV Reporting by Name on Use of HIV Testing in Publicly Funded Counseling and Testing Programs. *Journal of the American Medical Association* 1998; 280: 1421-1426.

guaranteed.[117] A 1989 study of 25 HIV-positive women in New Jersey showed that 68% of the participants were willing to give the names of their sexual partners to the health department as long as confidentiality was maintained; 20% of the women would agree to partner notification if their names were disclosed to the partner. Similarly, in 1999, a survey of persons who tested positive for HIV before the date of their AIDS diagnosis in five US states with name-based surveillance found that persons who were tested anonymously and those who were tested confidentially did not differ in the mean number of sex and needle-sharing partners notified. Nor was health department follow-up of a reported HIV infection associated with more timely receipt of medical care after a positive HIV test result.[118] These results suggest that the potential for positive or negative effects of name-based surveillance of HIV infection on partner notification and on access to health care may have been exaggerated, and that other factors may be more significant.

The bulk of other empirical data reviewed in the area of testing policies was comprised of a large number of studies outside Canada that examine HIV testing options in pregnancy.[119, 120, 121, 122] While much of this literature reveals that testing policies which combine universal counselling with voluntary testing impact positively on pregnant individual's willingness to test, little data is available on the effectiveness of such policies in women generally (non pregnant) and in men considering fathering a child.

3.2 Drug Laws and Policies

3.2.1 Theoretical Literature

The theoretical impact of drug legislation and policies on health and human rights has been extensively addressed.[123, 124, 125, 126, 127, 128, 129] Some literature exists regarding the negative impact

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[117] Chevernak JL, Weiss SH. Sexual Partner Notification: Attitudes and Actions of HIV-Infected Women. 5th *International Conference on AIDS*. Montreal, June 1989; abstract DP4.

[118] Osmond DH et al. Name-based surveillance and public health interventions for persons with HIV infection. Multistate Evaluation of Surveillance for HIV Study Group. *Annals of Internal Medicine* 1999; 131(10): 775-9.

[119] Rey D et al. Mandatory Prenatal Screening for Human Immunodeficiency Virus: The Experience in South-Eastern France of a National Policy, 1992-1994. *British Journal of Obstetrics and Gynaecology* 1998; 105(3): 269-274.

[120] Bergenstrom A, Sherr L. A Review of HIV Testing Policies and Procedures For Pregnant Women in Public Maternity Units of Porto Alegre, Rio Grande do Sul, Brazil. *AIDS Care* 2000; 12(2): 177-86.

[121] McNeeley DF et al. Newborn Screening for Human Immunodeficiency Virus Infection in the Bronx, NY, and Evolving Public Health Policy. *American Journal of Perinatology* 1999; 16(10): 503-7.

[122] Royce RZ et al. Barriers to Universal Prenatal HIV Testing in 4 US Locations in 1997. *American Journal of Public Health* 2001; 91(5): 727-733.

[123] Canadian HIV/AIDS Legal Network. *Injection Drug Use and HIV/AIDS: Legal and Ethical Issues.* Montreal: The Network, 1999.

[124] Gilmore N. Drug Use and Human Rights: Privacy, Vulnerability, Disability and Human Rights Infringements. *Journal of Contemporary Health Law and Policy* 1996; 12: 355-448. Available at: http://www.drugtext.org/books/gilmore/gilmcont.htm

[125] Hilton BA et al. Harm reduction theories and strategies for control of human immunodeficiency virus: a review of the literature. *Journal of Advanced Nursing* 2001; 33(3): 357-70.

of laws prohibiting the unauthorized possession of certain drugs on access to HIV prevention and care in people who inject drugs. Specific laws/policies have been the focus of these analyses (e.g., restrictions in the sale, distribution, or possession of syringes) while others have not been studied (e.g., welfare laws/policies). Similarly, there exists discussion on the positive health impact of harm reduction interventions, such as the implementation of needle-exchange programs. Theoretical literature takes issue with the pervasive structuring effects of drug laws/policies on the HIV epidemic associated with injection drug use and argue that this epidemic can be slowed, stopped or even reversed by the removal of laws/policies that criminalize drug use, which act as structural factors impeding HIV prevention and access to care, treatment and support for drug users.

Historical analyses of drug laws, regulations and policies in Canada and the US bring attention to institutional, professional and political determinants of health and addiction; and argue that drug laws/policies should be considered direct structural barriers or facilitators of HIV prevention and care.[130, 131, 132, 133] Their effect is closely linked to specific behaviours, such as when they influence the availability of legal and accessible HIV prevention services (e.g., access to sterile injection equipment to reduce the likelihood of infection) or willingness to access care, treatment or support services that impose abstinence from drug use as a requirement.[134, 135]

For example, one national survey of laws and regulations governing the sale and possession of needles and syringes in the US discusses legal and public health proposals to increase the availability of sterile syringes, as a measure to prevent HIV for persons who continue to inject drugs.[136] The analysis revealed that:

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[126] Kirby M. Sex, Drugs and the Family. [Australian] *National AIDS Bulletin* 1994; 7(12): 20-22.

[127] Oscapella E. *Le Dain* Revisited: 21 Years Later. *Lawyers Weekly* 1995; 14 (35): 5.

[128] Riley D, Oscapella E. Bill C-7: Implications for HIV/AIDS Prevention. *Canadian HIV/AIDS Policy & Law Review* 1995; 1 (2): 11-13.

[129] Stimson GV et al (eds). *Drug Injecting and HIV Infection: Global Dimensions and Local Responses*. London: Taylor & Francis, 1998.

[130] Fischer B. Prescriptions, Power and Politics: The Turbulent History of Methadone Maintenance in Canada. *Journal of Public Health Policy* 2000; 21(2): 187-210.

[131] Fischer B. "The Battle for a New Canadian Drug Law: A Legal Basis for Harm Reduction or a New Rhetoric for Prohibition? A Chronology", in *Harm Reduction: A New Direction for Drug Policies and Programs* (P Erickson et al, eds). Toronto: University of Toronto Press, 1997.

[132] Hadaway P, BL Beyerstein, JVM Youdale. Canadian drug policies: irrational, futile and unjust. *Journal of Drug Issues* 1991; 21(2): 183-197.

[133] Oscapella E. Witch Hunts and Chemical McCarthyism: The Criminal Law and Twentieth-Century. In P Basham (Ed.) *Sensible Solutions to the Urban Drug Problem.* Vancouver: The Fraser Institute, August 2001. Available at: www.fraserinstitute.ca.

[134] Des Jarlais DC. Structural Interventions to Reduce HIV Transmission Among Injection Drug Users. *AIDS* 2000; 14 (Suppl 1): S41-46.

[135] Taussig JA et al. Syringe Laws and Pharmacy Regulations are Structural Constraints on HIV Prevention in the US. *AIDS* 2000; 14 (Suppl 1): S47-51.

[136] Gostin LO, Lazzarini Z, Jones TS, et al. Prevention of HIV/AIDS and other blood-borne diseases among injection drug users: a national survey on the regulation of syringes and needles. *Journal of the American Medial Association* 1997; 277: 53-62.

> To the extent that these laws, regulations, and ordinances restrict access to sterile syringes, they contribute to the spread of blood-borne diseases among IDUs, their sexual contacts, and their children. In addition, because of criminal and professional sanctions, they deter pharmacists, physicians, and public health professionals from providing important HIV prevention services to persons who continue to inject drugs.[137]

According to these authors, laws/policies that penalize the possession of syringes are problematic for a number of reasons: (1) drug users who are arrested on a drug paraphernalia charge are subject to fines and possible incarceration; (2) the "possession" itself marks the person as a drug user and may subject him or her to more intense police surveillance; (3) once an individual is found to possess drug paraphernalia, he or she is more likely to undergo a police search for illicit drugs;[138] (4) the threat of arrest and prosecution for possession of drug injection equipment makes it less likely that active IDUs will carry, and hence use sterile syringes. The authors suggest that deregulation of syringe sale and possession would reduce morbidity and mortality associated with blood-borne disease among IDUs, and can be implemented without harmful social repercussions as one component of a comprehensive, well-financed strategy to impede the dual epidemics of drug use and HIV/AIDS.

In addition, while drug laws/policies directly affect the behaviour of a segment of society by criminalizing drug-related activities they have a more indirect impact on the general population. Stigmatization and marginalization of criminalized behaviours and of drug users in general can therefore be understood as an indirect structural barrier to HIV prevention and care.

> First, we sentence drug users to prison; then we do not give them the means to prevent HIV infection from the high levels of drug-use in prisons. Not until recently did we make condoms available to prisoners, in part out of fear that condoms would be used to hide drugs. Still, despite finally acknowledging that drug use in prisons is widespread, we have refused to help prisoners with some of the essential means that are available outside prisons to prevent the spread of blood-borne diseases. [Society] cares little about HIV infection among drug users and prisoners because it had been taught to care little for drug users and prisoners themselves. [139]

The literature generally recommends that drug use be dealt with as a health issue, not a criminal issue; in part, because the legal status of drugs in Canada contributes to the difficulty of addressing HIV among people who inject drugs. For example, one author points out: "It is only by separating drug use from drug prohibition that one is able to assess whether or not the harmful side effects of prohibition overwhelm the benefits of supposed lower drug consumption and the resulting lower social costs".[140] Similarly, the International Harm Reduction Development Program reports that providing IDUs with sterile needles, condoms, and safer sex information is

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[137] Ibid.

[138] In the US, discovery of a syringe, or even bleach, may provide probable cause under the Fourth Amendment to conduct a broader search of the drug user and his or her possessions, leading to confiscation of illicit drugs and prosecution for sale or use. [See Gostin LO, Lazzarini Z, Jones TS, et al., 1997. op. cit.]

[139] Oscapella E. 2001, op.cit.

[140] Basham P. Re-evaluating the 'War on Drugs'. In his *Sensible Solutions to the Urban Drug Problem*, The Fraser Institute, 2001. Available at: www.fraserinstitute.ca

less costly for a society's overall health and welfare than treating a person with AIDS.[141] In addition it is argued that the HIV epidemic associated with injection drug use can be slowed, stopped or even reversed by way of harm reduction measures engaging in community outreach that provides IDUs with HIV information and helps them trust health care providers; and distributing sterile injection equipment widely.

An in-depth examination of the legal and ethical issues surrounding HIV/AIDS and injection drug use in Canada suggests the need for major long-term changes to drug legislation and policies; and recommends that complete, honest, and non-judgmental information on drugs be accessible and widely distributed; that correctional systems make sterile needles available to inmates; and, in general, that a repressive, prohibitionist approach make way for approaches premised on harm reduction.[142]

One harm reduction initiative that is well documented is needle-exchange programs. Much literature reviewed is comprised of analyses that look at needle-exchange programs in various stages of development, and identify these as a useful medical, social, economic, and political intervention to decrease rates of HIV transmission in IDUs.[143, 144, 145, 146] Policies and programs that insist on needle exchange rather than the distribution of needles are the preferred intervention, and needle exchange is considered one component of a comprehensive program that should also include counselling, support, and education. It has been suggested that rules and practices surrounding needle exchange in Canada, particularly in Vancouver (such as 1-for-1 exchanges, quota limitations, needle exchange service locations and hours of operation) create significant barriers to the use of these programs.[147, 148, 149]

Other harm reduction initiatives that have been the focus of theoretical discussions include the establishment of "safe injection facilities" (SIF) — which have been used successfully in Switzerland, Germany, and the Netherlands, Spain and, most recently, at a trial facility in

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[141] International Harm Reduction Development Program. *Drug, AIDS, and Harm Reduction: How to Slow the HIV Epidemic in Eastern Europe and the Former Soviet Union*. Open Society Institute, 2001. Available at: http://www.soros.org/harm-reduction/

[142] Canadian HIV/AIDS Legal Network. *Injection Drug Use and HIV/AIDS: Legal and Ethical Issues*. Montreal: The Network, 1999.

[143] Bruneau J et al. High Rates of HIV Infection Among Injection Drug Users Participating in Needle Exchange Programs in Montreal: Results of a Cohort Study. *American Journal of Epidemiology* 1997; 146(12): 994-1006.

[144] Coleman LJ, Stenlund KJ. Marketing Syringe/Needle Exchange Programs. *Health Marketing Quarterly* 1999; 17(2): 67-73.

[145] Clark PA. The Ethics of Needle-Exchange Programs. *AIDS & Public Policy Journal* 1998; 13(4): 131-139.

[146] Taussig JA et al. Syringe Laws and Pharmacy Regulations are Structural Constraints on HIV Prevention in the US. *AIDS* 2000; 14 Suppl 1: S47-51.

[147] Strathdee S et al. Needle exchange is not enough: lessons from the Vancouver injecting drug use study. *AIDS* 1997; 11(8): F59-65.

[148] Hankins C. Syringe exchange in Canada: good but not enough to stem the HIV tide. *Substance Use and Misuse* 1998; 33: 1129.

[149] Schechter MT et al. Do Needle Exchange Programmes Increase the Spread of HIV Among Injection Drug Users? An Investigation of the Vancouver Outbreak. *AIDS* 1999; 13: F45-51.

Australia;[150, 151] and proposals for and in some cases experiments with methadone maintenance treatment[152] and heroin maintenance,[153] the latter being more controversial and not as widespread as the former.

3.2.2 Empirical Data

Much theoretical literature exists regarding the negative impact criminalization of drug use has on access to HIV prevention and care for people who inject drugs. Complementing the extensive theoretical analysis, empirical assessments have examined factors that facilitate the vulnerability of people who inject drugs to HIV as well as the positive impact of harm reduction programmes and policies. Empirical literature confirms that many of the serious problems we associate with illegal drug use are caused directly or indirectly not by drug use itself but by drug prohibition. Drug laws/policies are thus important structural determinants of health.

The vulnerability of IDUs to HIV is well documented empirically. For example, one study found that social determinants of health, such as a history of sexual abuse, were among the strongest predictors of needle-sharing activity among Vancouver's drug using community.[154] Another qualitative study examined the biographic and pre-dispositional determinants of HIV preventive behaviours in IDUs, including avoiding sharing injection equipment and using condoms.[155] Results indicate that a predisposition to reject sharing injection equipment correlates with safer injection drug use and condom use. Needle exchange programs that target only one HIV preventative behaviour rather than both (avoid sharing injection equipment and use condoms) would seem to be inadequate. To enhance targeted interventions, the study recommends changes in public and agency policy that create a social environment conductive to behaviour change. Also, in a Toronto study of untreated opiate addicts, 41% of the respondents reported having experienced at least one incident in the previous 12 months in which they thought they needed medical assistance but in the end did not seek it.[156] Barriers to seeking medical care may include a non-conducive social environment. Research in Vancouver has identified structural barriers to HIV prevention among IDUs such as substandard housing, limited access to addiction services, ever diminishing socio-economic status and little or no mental health services.[157] These are all

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[150] Elliott R, Malkin I, Gold J. *Establishing Safe Injection Facilities in Canada: Legal and Ethical Issues*. Montreal: Canadian HIV/AIDS Legal Network, 2002.

[151] Kerr T. *Safe Injection Facilities: Proposal for a Vancouver Pilot Project*. Prepared for the Harm Reduction Action Society. Vancouver, 2000.

[152] Ward J et al (eds). *Methadone Maintenance Treatment and Other Opioid Replacement Therapies*. Amsterdam: Harwood Academic Publishers, 1998.

[153] Fischer B. The Case For a Heroin Substitution Treatment Trial in Canada. *Canadian Journal of Public Health* 1997; 88: 367.

[154] Strathdee SA et al. Social Determinants Predict Needle-Sharing Behaviour among Injection Drug Users in Vancouver Canada. *Addictions* 1997, 92(10): 1339-47.

[155] Myers T et al. A Comparison of the Determinants of Safe Injecting and Condom Use Among Injecting Drug Users. *Addictions* 1995; 90(2): 217-26.

[156] Fischer B et al. Profile of Illicit and Untreated Opiate Users in Toronto, Canada. *Addiction Research* 1999; 7(5): 377-415.

[157] O'Shaughnessy MV et al. "Deadly Public Policy". 12th *International Conference on AIDS*, 12: 982 [Abstract no. 44233], 1998.

determinants of health (e.g., physical environment; access to health services; income; social status), which are affected by law/policy. The authors conclude that existing public policies "in essence" force drug users into situations where their social status was further diminished, resulting in ever-riskier behaviour and higher incidence rates.

Another important series of studies described the impact in the US of a structurally imposed barrier on HIV preventative behaviours. Researchers assessed the impact of the closure of a needle-exchange program for injection drug users in a town in Connecticut. Before closure, 14% of IDUs reported unsafe sources for syringes and 16% reported sharing a syringe in the past 30 days.[158] After closure of the exchange, those reporting unsafe sources increased to 51% and those reporting sharing a syringe increased to 34%.[159] After closure, the rate of reusing syringes doubled among those surveyed.

US data also suggests that the legal status of drugs and drug use equipment may also affect access to needle-exchange programs. One study found that police action and the threat of police action decreased utilization of needle-exchange programs by drug users, limited the number and diversity of volunteers, and inhibited the operation and expansion of the program.[160] Another study identified fear of identification and/or police harassment as one of three major obstacles to accessing needle-exchange programs.[161] (The other two obstacles were lack of awareness of the program and inconvenient location or hours.)

'Safe injection' or 'supervised injection' facilities (SIF) are another example of a harm-reduction response to injection drug use. The available evidence suggests that including SIFs as a component of a policy response to HIV/AIDS is likely to produce significant benefits for both drug users and the general community, and that at the very least such initiatives must be tried.[162] From the perspectives of IDUs, for example, 94.4 percent of 195 Montreal drug users participating in a survey indicated they thought implementing a SIF was a good idea, and identified safety, health issues, and the services that could be available at the facility as major reasons for supporting them.[163] From the perspective of those proposing such trials, there have been few thorough impact evaluation studies on SIFs conducted in Europe, and the majority of

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[158] Groseclose SL et al. Impact of Increased Legal Access to Needles and Syringes on Practices of Injecting Drug Users and Police Officers – Connecticut, 1992-1993. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology* 1995; 10: 82-89.

[159] Broadhead RS et al. Termination of an Established Needle-exchange: A Study of Claims and Their Impact. *Social Problems* 1999; 46:48-66

[160] Bluthenthal RN et al. Impact of Law Enforcement on Syringe Exchange Programs: A Look at Oakland and San Francisco. *Medical Anthropology* 1997; 18(1): 61-83.

[161] Rich JD et al. Obstacles to Needle Exchange Participation in Rhode Island. *Journal of Acquired Immune Deficiency Syndromes* 1999; 21(5): 396-400.

[162] R Elliott, I Malkin, J Gold. *Establishing Safe Injection Facilities in Canada: Legal and Ethical Issues*. Montreal: Canadian HIV/AIDS Legal Network, 2002; T Kerr. Safe Injection Facilities: Proposal for a Vancouver Pilot Project. Prepared for the Harm Reduction Action Society. Vancouver, 2000.

[163] T Craig Green. My Place, Your Place, or a Safe Place: the Intention to Use a Supervised Injection Facility (SIF) in Montreal Injecting Drug Users. Data presented at *Les sites d'injection supervises: Journée scientifique de L'Unité Maladies infectieuses*, Direction de la santé publique de Montréal-Centre, 23 November 2001.

the published literature does not currently appear in English.[164] Available studies, however, provide some evidence in relation to the four main expected benefits of such facilities: (1) reduced visibility and public nuisance of the drug scene;[165, 166, 167] (2) improved access and uptake of health and other welfare services;[168, 169, 170] (3) reduced opioid-related overdose risk; [171, 172, 173] and (4) reduced risk of blood-borne virus transmission, such as HIV/AIDS and hepatitis C.[174, 175, 176, 177] While there is no direct epidemiological evidence to show reduced incidence of HIV transmission among clients of safe injection facilities, observed reductions in needle sharing and increased condom use reported by clients indicate a reduction in HIV risk behaviours.

In addition, two reviews of empirical assessments of SIF's health impact on IDUs, reported that prior to the establishment of such facilities, evidence from Germany and Switzerland indicated that health services were reaching only a small portion of drug users (20% or less).[178, 179] Substantial increases in the use of medium and high threshold services (e.g., abstinence-based treatment, methadone clinics, out-patient drug counselling) were noted in Switzerland following the introduction of a harm reduction strategy that included SIFs - 50% of drug users were

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[164] Dolan K. et al. Drug Consumption Facilities in Europe and the Establishment of Supervised Injecting Centres in Australia. *Drug and Alcohol Review* 2000; 19: 337-346.

[165] Ronco C. et al. Evaluation for Alley-rooms I, II and III in Basel. *Social and Preventative Medicine* 1996; 41: S58-68.

[166] Jacob J. et al. *Entstehung und Praxis eines Gesundheitsraumangebotes für Drogenkonsumierende. Abschlußbericht der einjährigen Evaluation des - drop-in Fixpunkt, Hanover*. Oldenburg, Bibliotheks -und Informationssystem der Universität Oldenburg, 1999. Available at: http://www.archido.de/rezensjacobstoever.htm

[167] Kemmesies UE. *The open drug scene and the safe injection room offers in Frankfurt am Main 1995*. Frankfurt, Germany: Stadt Frankfurt/Dezernat Frauen und Gesundheit, Drogenreferat, 1999 (Original German version published INDRO 1995).

[168] Ronco C. et al., *op. cit*.

[169] Nejedly MM, Bürki C. *Monitoring HIV Risk Behaviours in a Street Agency With Injection Room in Switzerland*. Bern, Medizinischen Fakultät: Universität Bern, 1996.

[170] Kressig MM, Nydegger LB, Schuhmacher C. *Nutzen niedrigschwelliger Drogenarbeit am Beispiel der Stadt Zürich*. Schlussberict der Gesamtevaluation der niedrigschwelligen Drogenhilfe in der Stadt Zürich. Zürich, Institut für Suchtforschung, 1996. (IDRS). Technical Report No. 73. Sydney: NDARC, 1999.

[171] AIDS Hilfe Frankfurt *La Strada Drogenhilfeprojekt: Jahresbericht, 1998*. Frankfurt: AIDS-Hilfe Frankfurt eV, 1998.

[172] Happel HV. *Konsumräumew – Eine effecktive Maßnahme zur Schadensminimierung bei DrogengebraucherInnen und BürgerInnen*. Frankfurt: Fachhochschule Frankfurt, 2000.

[173] *Integrative Drogenhilfe Jahresbericht 1996*. Frankfurt: Integrative Drogenhilfe, 1997.

[174] Ronco C et al, *op. cit.*

[175] Jacob J, *op. cit*.

[176] Nejedly MM and Bürki C, *op. cit*.

[177] Warner MN. *Over de Drempel: Onderzoek naar de mogelijkheid om harddruggebruik binnen een opvangvoorziening in Arnhem te reguleren* [Research Into the Possibility of Regulating Hard Drug Use Indoors in Arnhem]. Arnhem, Netherlands: Gelders Centrum voor Verslavingszorg, 1997. *Health* 1997; 51: 692.7.

[178] MacPherson D. *Comprehensive Systems of Care for Drug Users in Switzerland and Frankfurt, Germany* - A Report From the 10th International Conference on the Reduction of Drug Related Harm and a Tour of Harm Reduction Services in Frankfurt, Germany. Vancouver: Social Planning Department, 1999.

[179] Lindesmith Center. *Safer Injection Rooms*. New York: The Center, 1999. Available at: http://www.lindesmith.org/cites_sources/safer_injection.pdf

registered in methadone maintenance, 15% were in abstinence-based treatment, and the remaining 35% were in regular contact with harm reduction services.[180] This kind of research data illustrates how SIFs can enable contact with the most marginalized drug users and act as gateways to other systems of care and treatment. Ultimately, available data, although limited, points to the positive impact of harm reduction programmes and policies.

Similarly, one comparative study explored the hypothesis that the degree and progression of illness and death among IDUs in a given law/policy environment correlate directly with the extent to which harm prevention measures and treatment are available to, and reach, IDUs.[181] These measures include needle and syringe exchange services and treatment, particularly methadone treatment for opiate addiction, as well as other social and health intervention services. Researchers adopted a time-trends perspective to compare key indicators of harm (including HIV infection rates) and preventive measures in Canada over the years 1988-1999, with similar indicators from European jurisdictions. Findings suggest that expanding coverage and reach of preventive measures for IDUs do, in fact, correlate with consistent stabilization or lessening of relevant harm indicators. In particular, in Canada throughout the 1990s, consistently limited coverage and reach of preventive measures (both secondary and tertiary) were correlated with substantial increases in rates of illness and death associated with IDU. The authors concluded that "it is time for Canada to regain its status as an advanced developed nation as judged by the quality and effects of its IDU policy."[182]

3.3 Laws and Policies that Regulate Sex Work

3.3.1 Theoretical Literature

There is a large body of theoretical literature concerned with sex workers as a prime vulnerable group to HIV, and that explores the impact of prostitution laws on health and human rights. Yet some have argued that it is difficult to assess the true epidemiology of HIV infection among sex workers generally because epidemiological data is often extrapolated from specific vulnerable communities, identified early on as being at risk for HIV infection. In Canada for example, information available on male sex workers is drawn on samples of street youth and IDUs[183] while data on female sex workers is drawn from among prisoners and/or IDUs.[184]

Sex workers who are deemed most vulnerable to HIV are those in prisons and those who inject drugs, those sharing non-sterile needles and those having unprotected sex with non-paying partners. In this regard, close analysis of HIV and sex work in Canada argues that prostitutes practice safer sex with their clients, suggesting needle use, not prostitution, is the main source of

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[180] Cited in MacPherson D 1999. *op. cit*.

[181] Fischer B et al. Injection Drug Use and Preventive Measures: A Comparison of Canadian and Western European Jurisdictions over time. *Canadian Medical Association Journal* 2000; 162 (12): 1709-1713.

[182] Ibid, at: 1712.

[183] Allman D. *M is for Mutual A is for Acts: Male Sex Work and AIDS in Canada*. Health Canada, AIDS Vancouver, the HIV Social, Behavioural and Epidemiological Studies Unit at the University of Toronto, and the Sex Workers Alliance of Vancouver, 1999.

[184] Gendron S, Hankins CA *Prostitution et VIH au Québec: bilan des connaissances*. Montréal: Centre Québécois de coordination sur le sida, Ministère de la santé et des services sociaux, Gouvernement du Québec, 1995.

HIV infection.[185] The risks for acquiring HIV in the context of sex work are also theoretically related to the criminalization of sex trade, the use of coercive measures in settings where sex work is regulated, as well as related precarious working conditions that make sex workers more vulnerable to infection.[186]

Laws/policies that regulate sex work are considered direct structural barriers to HIV prevention and care, while abuse, discrimination and stigmatization against persons who prostitute, operate as indirect structural barriers to HIV prevention and care.[187, 188, 189] For example, one author writes: "Sex workers without rights in their place of work are uniquely vulnerable to infection with HIV and other sexually transmitted diseases, as they routinely lack the information, materials or authority to protect themselves and their clients".[190] This direct impact of laws/policies is in turn associated with an indirect impact: a social and physical environment fraught with violence, discrimination and stigmatization.

> How do prostitution laws affect the spread of HIV among prostitutes? The criminalization of sex for money means that hookers who are subject to abuse from their customers are less able to report their abusers. It also makes it difficult for them to insist on condom use with their customers, and thus increases their chances of becoming infected. In conversations I had with a number of women who were raped by their customers, without condoms, they said that because their work is illegal they are not willing to prosecute these men. Instead, they maintain a "bad date" list and disseminate it to other hookers. In contrast, it has been found that decriminalization of prostitution enables those in the sex trade to practise safe sex, and will ultimately result in lower infection rates.[191]

The failure of criminal prohibition to abolish the sex trade is well documented,[192, 193, 194] and there exists much theoretical discussion of various legal and policy options to decriminalize

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[185] Shaver F. "Occupational Health and Safety on the Dark Side of the Service Industry". In T Fleming (ed.) *Post Critical Criminology*, Scarborough: Prentice Hall, 1995: at 42-55.

[186] Brock DR. Prostitutes are Scapegoats in the AIDS Panic. *Resources for Feminist Research* 1989; 18(2): 13-17.

[187] Benoit C, Millar A *Dispelling Myths and Understanding Realities: Working Conditions, Health Status, and Exiting Experiences of Sex* Workers. Victoria: Department of Sociology, University of Victoria, 2001.

[188] Lowman J, Fraser L. *Violence Against Persons Who Prostitute: The Experience in British Columbia.* Ottawa: Department of Justice Canada, 1995.

[189] Achilles R. *The Regulation Of Prostitution*: *Background Paper*. Presented at a workshop on harm reduction organized by the Canadian Public Health Association, 14 April 1995.

[190] Bindman Jo. *Redefining Prostitution As Sex Work On The International Agenda*. Anti-Slavery International and The Network of Sex Work Projects, 1997. Available at: http://www.walnet.org/csis/papers/redefining.html

[191] Bastow K. Prostitution and HIV/AIDS. *Canadian HIV/AIDS Policy & Law Review* 1996; 2 (2): 13-15.

[192] Federal/Provincial/Territorial Working Group on Prostitution. *Report and Recommendations in Respect of Legislation, Policy and Practices Concerning Prostitution-Related Activities*. Ottawa: The Working Group, 1998.

[193] Gemme R, Payment N. Évaluation de la répression de la prostitution de rue à Montréal de 1970 à 1991. *Revue sexologique* 1993; 1(2): 161-192.

[194] Shaver F. The Regulation of Prostitution: Avoiding the Morality Traps. *Canadian Journal of Law and Society* 1994; 9(1): 123-145.

prostitution.[195, 196, 197, 198] Arguments for decriminalization of voluntary adult sex work point to the potential to empower sex workers to better safeguard their own health.

> Major public health objectives in reforming prostitution laws are as follows: removing provisions that make it difficult for sex workers and their clients to take steps to protect themselves against infection; encouraging responsible behaviour by workers and clients; alleviating the stigma associated with the industry; promoting conditions within the culture of the sex industry to permit and encourage safer sex activities; and improving working conditions within the industry.[199]

In addition, occupational health hazards of sex work include: repetitive stress injuries, respiratory infections, dependence on alcohol and other psychoactive substances, emotional stress (particularly related to managing stigma), and sexually transmitted diseases. One author discusses the impact of illegality on sex workers' health and calls for the repeal of criminal laws and the use of labour and occupational safety and health regulations to reduce workplace hazards.[200] These include the development of non-judgmental health care focused on the full range of occupational safety and health hazards of sex work, not simply sexual and reproductive health issues.

Finally, there is little analysis to document how legalization and licensing of sex workers affects access to HIV prevention and care in people who work in the sex industry as well as in their clients. In settings where prostitution-related activities are not criminalized, some literature specifically analyses the impact of coercive measures such as compulsory HIV testing and regular medical examination on the well-being of sex workers.[201, 202] Others suggest that mandatory HIV testing of prostitutes creates the illusion that infected sex workers have been identified and excluded from the workplace, encouraging clients to refuse to use a condom, thereby increasing, not decreasing, the risk for infection for both the sex worker and the client.[203, 204]

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[195] Brock DB. *Making Work, Making Trouble: Prostitution As A Social Problem.* Toronto: University of Toronto Press, 1998.

[196] Davis S, Shaffer M. *Prostitution in Canada: the Invisible Menace or the Menace of Invisibility*, 1994. Available at: http://www.walnet.org/csis/papers/sdavis.html

[197] Lowman J. *Prostitution Law Reform in Canada* Tokyo: Chuo University Press, 1998: at 919-946.

[198] Patterson D. HIV/AIDS-Related Law Reform in Australia. *Canadian HIV/AIDS Policy & Law Review*. 1995; 1(3): 11.

[199] Watchirs H. *A Rights Analysis Instrument to Measure Compliance with The International Guidelines on HIV/AIDS and Human Rights*. Australian National Council on AIDS and Related Diseases, 1999.

[200] Alexander P. Sex Work and Health: A Question of Safety in the Workplace. *Journal of American Medical Women's Association* 1998; 53(2): 77-82.

[201] Sanchez J et al. Sexually Transmitted Infections in Female Sex Workers: Reduced by Condom Use But Not By a Limited Periodic Examination Programme. *Sexually Transmitted Diseases*. 1998; 25(3): 82-89.

[202] Chen YA et al. Surveys of HIV-1, HTLV-1, and Other Sexually Transmitted Diseases in Female Sex Workers in Taipei City, Taiwan, from 1993 to 1996. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology* 1998; 18: 299-303.

[203] Alexander P. "Bathhouses and Brothels: Symbolic Sites in Discourse and Practice. In *Dangerous Bedfellows* (Colter EG et al., Eds.). Boston: South End Press, 1996: at 221-249.

[204] Metzenrath S. To Test or Not To Test. *Social Alternatives* 1999; 18(3): 25-30.

3.3.2 Empirical Data

Empirical investigation of on-the-ground-effect of local codes, regulations and municipal by-laws on HIV prevention and care in sex workers exists, but is less extensive than the large amount of theoretical analysis on the subject.

Policies requiring the use of condoms in brothels have been reported to increase condom use among commercial sex workers in Thailand[205] and in Nevada US,[206] although the application of such policies in practice raises human rights questions.[207]

On the assessment of the impact of criminal law and policing policy on sex workers' health, one study combined US-based ethnographic work conducted among female street sex workers in New Haven and among active IDUs in Denver.[208] The researchers located this empirical data in a broad conceptual framework which views law/policy as a structural determinant of health that puts social groups at risk for HIV. The findings demonstrate three ways that criminal law and policing affect HIV risk and incidence in female street sex workers and active IDUs: (1) they directly affect risk by affecting both the availability of protective equipment (syringes and condoms) and the conditions in which their use is negotiated; (2) they indirectly affect risk by increasing the vulnerability of sex workers and IDUs to incarceration — the fear and reality of arrest shape many of the activities of those interviewed, including activities related to health; and (3) they have an indirect impact because they validate stigma, racism, sexism and oppression thereby reproducing the social inequalities that comprise the more fundamental determinants of HIV risks. The authors conclude that laws/policies aimed at promoting coercive social control produce health risk by undermining the social conditions necessary for good health, and that this health impact disproportionately affects marginalized communities.

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[205] Hanenberg RS et al. Impact of Thailand's HIV-control Programme As Indicated By The Decline of Sexually Transmitted Diseases. *Lancet* 1994; 344: 243-245.

[206] Albert A et al. Condom Use Among Female Commercial Sex Workers in Nevada's Legal Brothels. *American Journal of Public Health* 1995; 85: 1514-1520.

[207] Laws/policies introduced to protect the interests of prostitutes' clients tend to assume that Sex workers have been considered as vectors of transmission rather than persons who, for many reasons, including legal reasons, are vulnerable to contracting HIV. However, research evidence demonstrates that sex workers can and do protect themselves and their clients against the risk of HIV and other sexually transmitted infections. For example in some studies sex workers reported regularly accessing HIV testing and that the prevalence rates for HIV among this group is not significantly higher than that of the general population. [See: Allman D. et al. Exchanging Financial and Non Financial Rewards For Sex: An Analysis of Prostitution and HIV Testing Practices in a Rural Population of the Interior of British Columbia, Canada. *13th International Conference on AIDS* (Abstract no. ThPeD5569); 2000 ; and Outwater A et al. Patterns of Partnership and Condom Use in Two Communities of Female Sex Workers in Tanzania. *Journal of the Association of Nurses in AIDS Care* 2000; 11(4):46-54.] Some results also indicated that 100% of female sex workers interviewed use condoms for every sexual transaction while only 48% of female college students consistently report using condoms. [See: Shaver F. "Occupational Health and Safety on the Dark Side of the Service Industry". In Fleming T (ed.) *Post Critical Criminology*, Scarborough: Prentice Hall, 1995: at 42-55.]

[208] Blankenship KM, Koester S. Criminal Law, Policing Policy, and HIV Risk in Street Sex Workers and IDUS. In conference materials from *Health, Law and Human Rights: Exploring the Connections, An International Cross-Disciplinary Conference Honoring Jonathan M. Mann*. Philadelphia, 2001; at 879-883.

One Canadian study assessed the impact of non-criminal regulatory frameworks on exotic dancers' vulnerability to HIV.[209] Researchers found that the introduction of lap dancing regulations[210] increased the vulnerability to HIV of all exotic dancers, career and goal oriented alike. During a time lag of two years (February 10, 1994 to February 9, 1996) lap dancing was legally accepted as "decent behaviour" in Ontario and interpreted by club owners, managers and dancers as permission to eliminate the "no touch rule" and offer lap dancing to their customers.[211] The researchers conclude that such regulations present a potential for direct skin to skin, genital to genital, or oral to genital contact in the guise of dancing; they increase the probability that dancers may be sexually coerced or assaulted; and blur the boundary between entertainment that relies on sexual fantasy and that which involves physical contact. The authors suggest that there is a need for a change in policy regarding the regulation of strip clubs and their patrons if vulnerability to HIV is going to be decreased in these two groups of sex workers. The development of healthy public policy would involve municipal (e.g., licensing, policing, advertising), provincial (e.g., health, education, licensing, tourism) and federal (e.g., immigration, tourism, employment, health) policies as well as provision of services in a variety of sectors.

Another study examined the potential impact of licensing escort services on the spread of sexually transmitted infections between the USA and Canada.[212] This timely research focuses on the opening of a casino in Windsor, Canada, that attracts thousands of visitors from the USA, a change to the municipal policies and legislation related to certain forms of sex work that accompanied this opening, and potential transmission of sexually transmitted infections from US clientele to Canadian escorts. The study concludes that licensing of escorts and escort agencies has potential to contribute to HIV prevention through: legitimating escort work, empowering

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[209] Lewis J, Maticka-Tyndale E. *Final Report - Erotic/exotic Dancing: HIV-Related Risk Factors*. Windsor: University of Windsor, Department of Sociology and Anthropology, 1998.

[210] Lap dancing usually refers to a striptease where a dancer performs while wearing little or no clothing and is seated on the customer's lap or between his legs, often in a private or semiprivate location in the strip club. In 1997, the Supreme Court of Canada upheld a decision of the Ontario Court of Appeal in ruling that lap dancing was not "indecent behaviour", as long as it doesn't occur in public, i.e. on the main floor of the club. Although there is the potential for this type of interpretation, municipalities still have the power to regulate lap dancing through the implementation and enforcement of bylaws designed to control such activities. Toronto was the first municipality to institute a lap dancing bylaw. The authority of the City of Toronto to create such a bylaw was challenged and upheld in *Ontario Adult Entertainment Bar Association* v. *Metropolitan Toronto (Municipality)*, (1997) [118 C.C.C. (3d) 481, aff'g. (1996), 27 O.R. (3d) 643]. The bylaws introduced to control lap dancing required the re-establishment of the "no touch rule" (e.g., City of Mississauga, By-law No. 351-95; Municipality of Metropolitan Toronto, By-law No. 129-95) and, in some jurisdictions, the removal of private enclosures (e.g., VIP Rooms) within the clubs (e.g., City of Mississauga, By-law No. 351-95; Municipality of Metropolitan Toronto, By-law No. 123-96). These changes were reinforced by imposing hefty fines on violators. The problem with using municipal bylaws to control lap dancing is that the bylaws only affect the supply side of the industry. Municipal jurisdiction in Canada is limited to regulating adult entertainment clubs and dancers through licensing and workplace standards; it cannot regulate morality or criminal law. The result is that only those who are specified in the bylaws can be charged. As a result, similar to prostitution laws, enforcement efforts target clubs owners, managers and dancers, not customers. [See: City of Mississauga, Bylaw No. 572-79; Municipality of Metropolitan Toronto, Schedule 36 to By-Law No. 20-85;].

[211] See: *R.* v. *Mara*, [1994] O.J. No. 264 (Ont Ct Prov Div) (QL) (holding lap dancing not indecent); *R.* v. *Mara* (1996), 27 O.R. (3d) 643 (CA) (reversing trial judgment); and *R.* v. *Mara* [1997] 2 SCR 630 (reversing appeal decision, agreeing that lap dancing not indecent).

[212] Maticka-Tyndale E, Lewis J. *Escort Services in a Border Town: Transmission Dynamics of Sexually Transmitted Infections Within and Between Communities – Literature and Policy Summary*. Windsor: University of Windsor, Department of Sociology and Anthropology, 1999.

escorts, and enhancing their integration in the community and potential access to community and health services. The authors recommend that there be further study in this area and policy-making from the perspectives of occupational health and safety standards.

Finally, one ongoing study, the *Sex Trade Advocacy Research* (STAR) project, is to develop an understanding of the way public policies (e.g., health, social service, employment, policing, municipal regulations, federal law, immigration) impact on health, safety and well being of sex workers in Montreal and Toronto.[213] This project is: (1) developing methods to examine a diversity of public policies from the perspective of their impact on health, safety and well-being; (2) providing in-depth information on how various policies influence health, safety and well-being in the sex industry; (3) developing guidelines for the sex industry for maximizing health, safety and well-being; (4) developing guidelines for policy to maximize health, safety and well-being in the sex industry; (5) developing guidelines for those engaged in advocacy, community organizations and frontline workers. Results will be available in 2003.

One study in the US hints at the way in which law/policy in different areas can have cumulative effects on health along various routes. It found that among women who participate in syringe exchanges, those who do sex work are more likely to share needles, inject daily, and use shooting galleries. They were also less likely to use a condom with private partners and reported higher levels of psychological stress.[214] Although the authors do not explicitly point this out, one may conclude from these findings that if you are spending long hours on the street looking for clients, you might have to rely on the convenience of shooting galleries as a source of both drugs and needles. Moreover, you might not want to carry needles with you at work, both because you might not want clients to see them and because as a sex worker, you are more likely to be arrested than a non sex worker, and would not want to risk a drug-related charge. Thus, this study suggests the double jeopardy of being both a sex worker and an IDU in a society that criminalizes both activities.

Finally, economic determinants of health in terms of workplace and income are also studied as indicators of vulnerability to HIV. For example, two studies suggest that trading sex for drugs is closely related to conditions of poverty and homelessness and that lower socio-economic status (e.g., street-based sex work) is more likely to be associated with vulnerability to HIV than higher socio-economic status (e.g., hotel-based sex works).[215, 216] These studies point to the complex interactions among poverty, income, drug use and workplace, as having a direct influence on sex workers' vulnerability to HIV infection or disease progression for those infected.

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[213] The Sex Trade Advocacy Research Group is undertaking a project called *Canadian Public Policy and The Health and Well-Being of Sex Workers, 1999-2003*. Co-investigators have published background materials including a project summary and interview guide. Available at: http://venus.uwindsor.ca/courses/sociology/maticka/star/index.html

[214] Paone D et al. HIV Risk Behaviours of Current Sex Workers Attending Syringe Exchange: The Experience of Women in Five US Cities *AIDS Care* 1999; 11(3): 269-280.

[215] Elwood W et al. Powerlessness and HIV Prevention Among People Who Trade Sex for Drugs ('strawberries'). *AIDS Care* 1997; 9(3): 273-284.

[216] Estébanez P, Grant JC. The Value of Workplace Versus Income in Determining HIV Status and Other STDs Among a Sample of Spanish Sex Workers. *Sexually Transmitted Diseases* 1998; 25(4): 194-195.

3.4 Criminalizing HIV Transmission/Exposure

3.4.1 Theoretical Literature

A number of cases have been reported in which people living with HIV have been criminally charged for a variety of acts that transmit HIV, risk transmission, or are perceived as risking transmission. The criminalization of HIV transmission or exposure has focused primarily on physical assault (e.g., rape and other sexual assault, biting, splashing of body fluids), and sexual activity with ostensibly consenting partners by HIV-positive individuals who conceal or do not disclose their status. There is some literature on the application of criminal law to breastfeeding of infants by HIV-positive women, [217, 218, 219, 220] but limited discussion exists on the application of criminal law to HIV-positive health-care workers who undertake certain medical procedures, to the sharing of drug injection equipment by HIV-positive persons.[221] The issue has received public and academic commentary and available literature raises the question of whether criminal laws and prosecutions represent healthy public policy responses to conduct that carries the risk of HIV transmission.

Criminal sanctions are generally understood as serving four primary functions: incapacitation, rehabilitation, retribution and deterrence. Socio-legal scholarship has identified various modes through which a specific law, legal institution or legal actor can influence behaviour.[222, 223] The intended effects of criminal law include: (1) "coercion", the immediate and direct application of force to compel behaviour, such as in the incapacitating and retributive functions of criminal law that seek to remove people who expose others to HIV from the population or punish them for it; (2) "compliance", the voluntary obedience to law, such as in the case where a person obeys the law out of respect for legitimate authority or in the rehabilitation function of criminal law that seeks to enable the offender to change his/her future behaviour so as to avoid harming others; and (3) "reliance", referring to the fact that laws are often passed with the intention of influencing people who are not direct objects of the law's regulatory commands or prohibitions, such as in situations where one could rely on the criminal justice system for retribution for HIV transmission or exposure resulting from wrongful doing.

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[217] Closen ML, Isaacman SH. Criminally Pregnant: Are AIDS Transmission Laws Encouraging Abortion? *American Bar Association Journal* 1990; 76: 76-78.

[218] Field MA. Pregnancy and AIDS. *Maryland Law Review* 1993; 52: 402.

[219] Sprintz H. The Criminalization of Perinatal AIDS Transmission. *Health Matrix* 1993; 3: 495-537.

[220] Panossian AA et al. Criminalizing of Perinatal Transmission, *Journal of Legal Medicine* 1988; 19; 223-255.

[221] Elliott R. *Criminal Law and HIV/AIDS: Final Report*. Canadian HIV/AIDS Legal Network and Canadian AIDS Society, 1997.

[222] Sarat A, Kearns TR (eds). *Law in Everyday Life.* Arbor: University of Michigan Press, 1993.

[223] Burris S. "The Social Construction of Legality". In Ewick P, Silbey SS (eds). *The Common Place of Law: Stories From Everyday Life.* Chicago: The University of Chicago Press, 1998: at 18-23.

Some writers considered the possible detrimental effects of using criminal law to prosecute people for transmitting HIV or engaging in activities that risk transmission, on health and public health initiatives.[224] These include:

- Reinforcing HIV/AIDS-related stigma and the idea that people living with the disease are 'potential criminals' or a "threat to the general public";
- Spreading misinformation about how HIV is transmitted, resulting in very serious charges and sentences where there is no significant risk of transmission;
- Disincentive to HIV testing if the person who knows their HIV-positive status is exposed to possible criminal prosecution;
- Hindering access to counselling and support by compromising confidentiality if the information that people living with HIV/AIDS discuss with a counsellor is not protected from search and seizure by police and prosecutors or by affecting the willingness to seek treatment; and
- Creating a false sense of security among people who are (or think they are) HIV-negative.

In addition, the paper argues that the use of criminal law may impact on human rights through the risk of selective prosecution, directed disproportionately at those who are socially, culturally and/or economically marginalized; gender inequality and criminalization; and invasions of privacy. The author concludes that any such legislation must be carefully drafted to avoid unjustifiably infringing on health and human rights.

A comprehensive review of Canadian criminal law relating to HIV examined the arguments "for" and "against" against criminalization of activity that transmits or risks transmitting HIV and discussed whether measures available under public health legislation offer a preferable alternative to using the criminal law.[225]

Other Canadian literature raises questions about the possible impact of using the criminal law on persons living with HIV/AIDS' access to support (i.e., counsellors) because of concerns about information being used as evidence in criminal prosecutions. [226, 227]

Much literature from various jurisdictions around the world raises concerns about the invasion of privacy rights and compounding stigma in light of the probability that criminalization may in and

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[224] Elliott R. Canadian HIV/AIDS Legal Network. *Criminal Law, Public Health and HIV Transmission: A Policy Options Paper*. Geneva: Joint United Nation Programme on HIV/AIDS, Best practice collection, June 2002. Available at: http://www.unaids.org/publications/documents/human/JC733-CriminalLaw-E.pdf

[225] Elliott R. *Criminal Law and HIV/AIDS: Final Report*. Canadian HIV/AIDS Legal Network and Canadian AIDS Society, 1997.

[226] Elliott R. *After Cuerrier: Canadian Criminal Law and the Non-Disclosure of HIV-Positive Status.* Canadian HIV/AIDS Legal Network, 1999.

[227] Elliott R. *Criminal Law and HIV/AIDS: Strategic Considerations A Discussion Paper.* Prepared for the Canadian HIV/AIDS Legal Network and the AIDS Law Project in connection with "Putting Third First – Critical Legal Issues and HIV/AIDS", a satellite meeting co-hosted by UNAIDS. Durban, South Africa, 7 July 2000.

of itself reinforce rather than redress patterns of discrimination against people living with HIV.[228, 229, 230, 231, 232, 233, 234, 235] Overall, legal and policy analyses identify the need to assess whether criminalization of HIV transmission actually satisfies the goals of criminal justice and/or health objectives, and suggest re-directing law/policy interventions toward existing public health measures rather than creating more, or resorting too quickly to, criminal sanctions.

A number of recommendations aimed at informing the development of sound public policy in the area of criminal law and HIV/AIDS have been made.[236]

- The best available scientific evidence regarding modes of HIV transmission and levels of risk must be the basis for rationally determining if, and when, conduct should attract criminal liability.
- Healthy public policy should facilitate HIV prevention, care, treatment and support (including the protection against discrimination; the protection of privacy; addressing the underlying causes of vulnerability to HIV infection and risk-related activities; ensuring access to good-quality HIV testing, counselling and support for risk reduction; ensuring access to anti-HIV treatment following exposure; repeal or amendment of laws that impede HIV prevention, care, treatment and support);
- Healthy public policy should minimise the use of criminal or coercive public health laws (including using coercive measures as a last resort and the setting of parameters on the use of criminal law to avoid its over-extension — e.g., no HIV-specific legislation); and
- Healthy public policy should ensure fair legal proceedings (including ensuring safeguards against misuse of public health laws and powers; establishing prosecutorial guidelines to avoid misuse of criminal law; the provision of legal support and services; ensuring the right to counsel; educating judiciary, police, prosecutors and defence lawyers; protecting the confidentiality of medical/counselling information; and protecting confidentiality during legal proceedings).

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[228] American Civil Liberties Union (AIDS and Civil Liberties Project). *Criminalizing Transmission of the Virus.* New York, NY: ACLU (undated).

[229] Buchanan D. The Law and HIV Transmission: Help or Hindrance? *Venereology* 1999; 12(2): 57-66.

[230] Kanyangarara S. Proposed Use of the Criminal Law to Deal with HIV Transmission in Zimbabwe. *Canadian HIV/AIDS Policy & Law Review* 1999; 4 (2/3): 98-101.

[231] McGolgin DL, Hey ET. "Criminal Law". In DW Webber (ed). *AIDS and the Law* (3rd Edition). New York: John Wiley & Sons Inc, 1997: at: 259-345 (and supplement).

[232] Terrence Higgins Trust. *Consent in the Criminal Law* - Response to [UK] Law Commission - Consultation Paper No. 139. London, UK: The Trust, 1996.

[233] Gostin LO, Webber DW. The AIDS Litigation Project, Part I: HIV/AIDS in the Courts in the 1990s. *AIDS & Public Policy Journal*. 1998; 13(1); and Part II. *AIDS & Public Policy Journal* 1998; 13 (2).

[234] Gostin LO. *The AIDS Litigation Project, Part III: A Look at HIV/AIDS in the courts of the 1990's*. Georgetown University Law Centre & Kaiser Family Foundation, 1996.

[235] AIDS Law Project South Africa (H Axam et al). *Aspects of the Law Relating to AIDS: The Need for a Statutory Offence Aimed at Harmful HIV-Related Behaviour* - Response Paper to the South African Law Commission, 1999. [South African Law Commission. *The Need for a Statutory Offence Aimed at Harmful HIV-Related Behaviour.* Discussion Paper 80, Project 85, October 1998.]

[236] Elliott R. 2002. *op. cit*.

3.4.2 Empirical Data

There is a dearth of empirical evidence documenting the effects on health of the criminalization of HIV transmission/exposure, at both the individual level and the level of public health more generally. This overwhelming lack of data makes it difficult to adequately address the impact of such laws on HIV prevention or access to HIV/AIDS-related care, treatment and support. Only one study was found and its preliminary results indicate the need for research in this area.

A three-year research project is underway in the US to evaluate the impact of criminal laws on behaviour using a multi-disciplinary theory-based that combines legal (deterrence and norm-setting) with a psychological (theory of planned behaviour) approaches.[237] The research team hypothesizes that laws and law enforcement practices influence: (1) subjective norms related to engaging in unsafe sexual behaviour, by influencing peers' attitudes towards the behaviour; (2) attitudes towards unsafe sexual behaviour, by changing the costs and benefits of the behaviour; and (3) behavioural control by imposing actual or perceived limitations on the person's ability to have risky sex. A report of the first year's findings provides the most complete picture to date of the existence and applications of criminal laws related to HIV risk behaviour in the US.[238] The researchers documented laws adopted by states and territories, and the number of prosecutions that have been reported in legal decisions and the press between 1986-2001. They found that:

- Of the 316 unique cases of prosecutions of persons for exposure or transmission of HIV reviewed, "sexual exposure" was the most common basis for prosecution (67%), followed by "spiting, biting or scratching" (23,4%); only a few cases involved "syringe injection or threat" (3,8%) and "selling blood" (1,6%); and no charges arose out of needle-sharing. Sexual exposure cases included prosecutions for "prostitution", "solicitation of prostitutes", "consensual sex" — which included cases in which the defendant did not inform a partner of his or her HIV infection, or in which the partner's knowledge and consent to exposure was either disputed or not a valid defence — and "unconsensual sex, unclear consent".
- There is no evidence of the systematic enforcement of HIV exposure laws.[239] According to these researchers, what seems to determine who gets prosecuted is the accident of being caught and brought to the attention of a willing prosecutor; and the most prominent shared characteristic of those charged with HIV-related crimes is that their alleged behaviour was already criminal without regard to their HIV status.

The authors argued that: "Seen broadly, our data do not support the view that the adoption of HIV-specific statutes establish clear rules for behaviour that direct the force of law to people

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[237] Lazzarini Z et al. "Evaluating the Impact of Criminal Laws on HIV Sexual Risk Behavior" Presented at the *One World: Global Health - 129th Annual Meeting of the American Public Health Association*, Session No. 3039.0. Atlanta, 22 October 2001.

[238] Lazzarini Z et al. Evaluating the impact of Criminal Laws on HIV Risk Behavior. *Journal of Law, Medicine and Ethics* 2002; 30: 239-253.

[239] Different types of laws are applicable: public health statutes criminalizing exposure or transmission of communicable disease or STIs; HIV-specific exposure or transmission laws; and other HIV-specific crimes or sentence enhancements — statutes that deal with acts that are already crimes (e.g., prostitution, rape, assault), but are punished separately or more severely when the perpetrator knows he/she has HIV.

engaging in clearly wrongful and dangerous behaviour. The clearest rules are aimed at conduct that is already plainly illegal, such as prostitution or intentional infection of another".[240]

In terms of the primary functions or intended effects of criminal law, this study also suggested ways that law/policy may impact on HIV prevention and care. Tentative conclusions are made with respect to incapacitation, legitimacy and deterrence effects of criminalizing HIV transmission/exposure as well as privacy issues. In the absence of rigorous estimates of the effect of such prosecutions on HIV transmission, the authors noted that their research data urge caution in assuming that criminal law as currently administered is significantly influencing the HIV epidemic and in relying on criminal law as a structural intervention to prevent HIV. Caution is also justified by a consideration of criminal law's potential cost to public health.

- First, from a policy perspective, any incapacitation benefit to prevention would have to be offset by the extent to which risk is redirected into prisons where condoms and sterile needles are almost uniformly unavailable.
- Second, the findings suggest that although the media covers criminal prosecutions, the number of articles is quite low and they rarely provide clear information about the laws being applied; therefore people may not be aware of the laws and of exactly what norms of behaviour they set forth.
- Third, if we nevertheless assume that people are aware that the law prohibits consensual sex without explicit disclosure of HIV infection, we face another problem: mistrust of "the system" may be widespread in populations most vulnerable to HIV/AIDS, and therefore the legitimacy of the law generally may be suspect. "They simply may not believe that government rules about how to behave in matters of sex and drug use are due any obedience. Legitimacy quite evidently does not move gay men to obey sodomy laws or drug users to obey drug control laws. A sense of selective prosecution could also undermine legitimacy, as could personal experiences of unfairness."[241]
- Fourth, deterrence that requires a person know his or her contemplated conduct is illegal, and be sufficiently concerned about likelihood of punishment to modify his/her behaviour. We have already discussed the problem of whether current laws, or news reports of prosecutions, give adequate or accurate notice to people of what behaviour is prohibited. In addition, it is speculated that the threat of punishment may not deter the individual if he or she understands HIV infection as a terminal illness. Any effect on behaviour also likely depends on the person's view as to the likelihood of public humiliation and incarceration.
- Finally, the researchers outline that the investigation of an HIV-related crime can raise difficult issues for public health officials since one of the key elements that a prosecutor will have to prove is that the defendant knew of his or her HIV infection by, for example, drawing information from the public health department's testing and counselling records, which are otherwise confidential.

Results from the larger study will provide useful data on the direct and indirect health impact of law and law enforcement practices and likely correlations between the punitiveness of states' laws and HIV sexual risk data.

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[240] Lazzarini Z et al. 2002. *op. cit.*: at 247.

[241] Lazzarini Z et al. 2002. *op. cit.*: at 250.

Section IV - Environmental Scan

This section summarises the input provided by 20 individuals in Canada interviewed during the environmental scan. These views and suggestions constitute an essential component of the assessment of law/policy impacts as key respondents testify to realities associated with structural barriers and facilitators to HIV prevention and care. The interview scheme consisted of open-ended questions, which means that key respondents' views are much broader that the research areas of the literature review. While each respondent individually had much to say about the impact of law/policy on health and other human rights, it is unclear to what extent respondents as a group shared the same understanding of the difference between the types of literature reviewed (theoretical v. empirical) and the need for more research. For many respondents, there was confusion in articulating a difference between where more research is needed, and what research the Canadian HIV/AIDS Legal Network can undertake. Key respondents' input reflects where new research would be most useful for them, as well as the perceived role of the Legal Network in generating legal and policy analyses for community-based organizations.

For the sake of clarity and consistency, this section extracts the legal/policy concerns from key respondents' views and outlines the perceived effects of laws/policies on HIV prevention and care according to these views. Unfortunately, this means that all the content from the interviews that took place cannot be detailed here. The comments from key respondents are grouped as follows: (1) the general category of law/policy as a structural determinant of health, and then (2) according to each of the four specific areas analysed in the literature review.

4.1 Law and Policy as Structural Determinants of Health

Based on their experience of working with people and communities living with and affected by HIV/AIDS, all key respondents interviewed were cognizant of the role that laws/policies play as structural determinants of health. For example, they stated the following:

> *Issues of systemic poverty are not negligible. Think of government cutbacks to income security programs, education, and "employability" programs. These laws have an impact on people's health. HIV rates are a clear demonstration of existing inequalities in our society and of the increasing fragility of certain groups in terms of social isolation. All this because some people are not afforded the means to control their own lives. Laws that minimize health increase these vulnerabilities.*
>
> *There is a condom ban in our province for people who are incarcerated. Access to welfare is impossible without an address; and often prison is not an address. It takes weeks then to get a welfare cheque. Availability of medications during the weekend is another issue for incarcerated people with HIV. These people are very vulnerable.*
>
> *Laws and policies affect a number of human rights other than the right to health. Think of the denial of adequate health care information or the right of employment of HIV-positive health-care workers or violations with respect to adequate housing, food, and health care. These affect people living with HIV in all walks of life.*

Historically and currently, the concept of individual rights for Aboriginal people requires understanding the individual's relationship within an Aboriginal society that is organized very differently than a centralized nation state. This is a key point of contention for Aboriginal nations and is often mistakenly viewed as a simplified conflict between collective and individual rights. It is difficult and of limited value to attempt to discuss rights in Aboriginal societies in a vacuum, outside of human relationships and social organization.

Overall, key respondents identified laws/policies as having a direct or indirect effect on HIV prevention efforts and initiatives, as well as on the health and other human rights of people living with HIV/AIDS.

4.1.1 Access to HIV Prevention, Care, Treatment and Support

For 16% of key respondents "access to HIV prevention, care, treatment and support" was the clearest example of how they understood the direct and indirect impacts of structural factors on the human rights of people living with HIV and those who are vulnerable. They talked about access to medicines and treatment, the role of non-governmental and community-based organizations in facilitating this access; laws/policies regulating pre- and post-approval of pharmaceutical products and pricing; and general health care system issues. Access to care, treatment and support for gay men, youth, sex workers and IDUs were also emphasized. In particular, a number of key respondents found access to medicines to be a key area where the effects of laws/policies can be seen. For example:

From my experience there is one issue regarding HIV/AIDS and the legal system and it's the issue of access to drugs.

An effective policy would also include access to marijuana for medical use and access to support services in those who are severely handicapped and those with mental health issues.

I am aware of the restrictive rules that regulate our patented medicines, and also that Canadian patent laws are constrained by international laws and therefore dragged along with those of other countries. Policies for drug approval and for surveillance of approved drugs actually limit access to drugs in people living with HIV. There is also a lack of funding for complementary health goods and inadequate funding for support of people living with HIV. This creates poverty and chaos when we know that empowerment is what makes health.

In addition, Canadian laws/policies were mentioned as having an overarching structural role in facilitating or inhibiting access to HIV prevention and care in Aboriginal populations. One respondent explained:

In a general sense all Canadian Aboriginal laws impact on the health of Aboriginal people living with HIV/AIDS. Canadian doctrines of Aboriginal rights, title and sovereignty are founded on the premise that the dominant Euro-Canadian society is superior to Aboriginal peoples in Canada. Within this oppressive legal regime Aboriginal people are constantly fighting against barriers to viable, healthy communities. Although this survey is not the place to address these issues it is important to state the broad legal context in which Aboriginal people with HIV/AIDS struggle to maintain their health.

4.1.2 Responsibility and Accountability

For another 6% of key respondents "responsibility and accountability for the impact of law/policy" was located in public officials, ministries, and allied health professions. Key respondents suggest means of redressing the situation in cases where, for one respondent, "*there is enforcement or maintenance of laws and policies that are known to foster harm on Canadians*" or, for a second respondent, there is "*failing to respect fundamental human rights*". Another respondent put forward the idea that "*the minister of health have the right of veto in any deliberation concerning a law that will have a negative impact on health*" as a possible solution.

4.2 Links to Other Determinants of Health

Overall, 26% of key respondents specifically understood the connection between law/policy and health as mediated through (other) determinants of health. In other words, respondents understood the cumulative effects on health of structural factors and determinants of health: that various laws/policies have an impact on various determinants of health, and that these determinants, in turn, affect the health of people living with HIV and those vulnerable to HIV. For example:

> *The determinants of health, social and economic or other, should always be integrated in policy analysis. The impact of laws that minimize such determinants is definite. Of course there is no direct causal relationship between law and health, the impact is due to an ensemble of different things that intervene between the two. For example, changes to the young offender laws combined with cutbacks to education and income security programs together will have an effect on the health of all populations. The combination of these factors will make communities more fragile and therefore diminish health.*
>
> *Determinants of health are multiple and human rights are broad. Only an integrated approach can grasp these complexities. And we still need to figure out what we mean by evidence and go beyond the traditional model of evidence-based research.*

The following suggestions characterize how key respondents addressed specific determinants of health, and illustrate their intuitive understanding that the various determinants of health are themselves inter-dependent.

4.2.1 Income, Employment and Working Conditions, Physical Environment

For 14% of key respondents, structural determinants of the determinants of health included issues of access to guaranteed annual "income", government as well as private health insurance and disability policies; access to affordable and adequate housing; and access to HIV-seropositive-friendly "employment and working conditions". For example:

> *In terms of income and employment equity legislations, we need longitudinal studies that acknowledge the difficulties in making the links between law/policy and health.*
>
> *So many questions: Is there an adequate insurance disability program available? Is there simply a lack of disability insurance? What plans are put into place to accommodate*

persons with HIV within the work setting? What changes in human resources policies are made "for" them and are these equitable?

To my knowledge, 20% of seropositive people in the province live beneath the threshold of what are considered acceptable economic conditions. Another 20% are on welfare and the remaining majority are in this fragile state of the in-between: they maintain control over their lives by holding a minimum wage job. Yet that control is always already at risk of being minimized since their occupation is precarious and they could end up on income security programs at any time.

Respondents also recognized the interdependence among economic and other determinants of health. In their view, income, employment and working conditions were connected to the "physical environment" in which people living with HIV can, or cannot, control their "personal health practices". For example:

How can HIV-positive people who are homeless develop ways to adhere to their treatment regimen? How can you keep or even access your medication if you don't have or can't afford a refrigerator? We need to integrate this in the discussion on compliance to treatments rather than blame the individual.

Similarly, employment and working conditions were linked to personal health practices and access to health services. For example, as another key respondent reported:

Shift-work is not compatible with managing your medication. Plus you need a doctor's note each time. Often, working HIV-positive people are subject to the "wrath of the union" and when problems arise they have to disclose in order to obtain the shift work they need. Union representatives do not come to their defence. Time off and rest periods necessarily affect people living with HIV. The problem can be extended to the entire aging populace.

4.2.2 Education

For another 8% of key respondents, laws/policies that broadly structure "education" were perceived as inhibiting HIV prevention and care. First, education policies and cutbacks to educational programs across Canada were seen as having important indirect effects on HIV prevention, especially in terms of sexual health. The rationale for this is that HIV information and education is understood as inappropriately structured. For example:

There is no coordinated cross-national policy for the evaluation of HIV education and prevention efforts.

Public education is inconsistent, fosters homophobia and fails to speak to those who are infected.

Why is there not more continuing HIV/AIDS education for health care professionals that includes discussions of the emotional and psychological consequences of living with HIV?

Second, public funding — or lack or inadequacy thereof — to community-based organizations doing HIV work was understood as having a more direct impact prevention and education. The systemic issues of how we can measure, as one key respondent put it, "*whether education works*", were seen as directly tied to the fact that "*not enough funding is allotted to national and community HIV awareness campaigns*". Measuring HIV programs' effectiveness in terms of

whether they reach targeted populations was understood as an organisational constraint. As one respondent explained:

> *We know that HIV prevention and care programmes are funded, that the money is spent, but there are no clear measures of their effectivity because we can't tell if one case of HIV has been prevented. It may be easier to identify impacts in HIV care than in HIV prevention programmes. Yet evaluation efforts rely on community-based organization that are often volunteer-run and resources are limited. Targeted evaluations should be funded and then we'd have a clearer picture.*

Ultimately, the impact is considered definite and extensive. Another key respondent stated: "*If there is no funding, there is no access to prevention, care, and medicines*".

4.2.3 Social Environment and Discrimination

Finally, another 4% of key respondents saw law/policy as broadly structuring the "social environment" in cases of pervasive systemic discrimination against people living with HIV and those vulnerable. For example, one respondent reported:

> *Even as an AIDS service organization we encountered problems finding an insurance company that would provide us with a sensible collective insurance plan because the assumptions were that because we work with AIDS we will necessarily have a large number of claims. Imagine an individual trying to get insurance.*

These key respondents also identified problems that are raised by fragmenting population health according to "risk groups" as a discernable impact of laws/policies in relation to issues of human rights. For example:

> *The people affected are not "ordinary" people and as long as infection rates are confined to one or two "disposable" communities the situation may not change.*
>
> *If we stop fragmenting them according to "risk groups" the policy will be more adequate to deal with intersections of varying degrees and types of vulnerabilities, nationally and internationally.*

Finally, key respondents called for research into the ways in which discrimination could be considered a distinct determinant of health.

4.3 Impact of Specific Laws and Policies

Key respondents consistently raised the idea that *structural* determinants of health (and of other human rights) operate to either facilitate or hinder access to HIV prevention, care, treatment and support. The next sections list more specific examples of how key respondents understood the connections between health and structural factors associated with HIV laws/policies. These connections are presented here in the same order as those of the literature review.

4.3.1 Laws and Policies Regarding HIV Testing, Reporting and Partner notification

Public health laws/policies were addressed by 10% of key respondents as having profound effects on health and other human rights. The impact of structural factors was associated with access to HIV testing; informed consent for testing; and issues of privacy and confidentiality in reporting of HIV and partner notification. In addition to these issues, these key respondents emphasized broader issues such as: the balancing of individual rights against public rights, current changes in local public health law, and coercive policies to deal with behaviours risking HIV transmission. For example:

> *Over all, research should focus on the balance between individual rights versus public or population rights in Canadian society. How do policies that impact on a group also impact on individual rights? I know this is a philosophical debate… but the issues of identification, marginalization and stigmatization are at the core of this debate and must be addressed.*
>
> *Mandatory reporting of HIV risks delaying HIV testing in people generally and/or discourage HIV-positive people who have not been tested to seek health care. These behaviours could in turn result in people accessing the health care system only once they are at advanced stages of disease progression. We do not believe that confidentiality of personal information of those persons who wish to be tested anonymously will be respected if, by law, doctors are obliged to report HIV seropositivity to the health minister according to the new procedure.*

These views corroborate the theoretical and empirical literature reviewed with respect to anonymous and confidential testing practices, partner notification, as well as name-based surveillance and policies to report of HIV incidence and prevalence. The major difference between key respondents' views and results from the literature review can be situated in the area of reporting of HIV. While some key respondents feared mandatory name-based reporting of HIV might affect people's willingness to test for HIV, this perceived impact is not necessarily supported by available empirical data.

4.3.2 Drug Laws and Policies

For 16% of key respondents drug laws/policies were cited as having an impact on health and human rights. These key respondents raised issues of criminalization and incarceration of drug users; the acute regulation of injection drug use; the negative impact of prohibition; that drug addiction should be treated as health problem; and the legalization of marijuana for medical uses. In so doing, key respondents alluded to both proximal and distal levels of these structural factors. For example:

> *One concern is the legal status of marijuana and access to treatment for people who use drugs is another problem. Doctors are reluctant to prescribe HIV drugs if the person is using drugs. There needs to be a change: either decriminalization or legalization.*
>
> *The majority of Aboriginal health organizations, treatment centres, political organizations, and Elders advocate for the abstinence model. Addiction is seen as the source of the social disintegration of the community rather than as a symptom of oppression. Addiction is too often addressed in an environment of blame and shame.*

Canadian drug laws have direct effects since prohibition of possession criminalizes drug users. In turn, the laws imply that people will have to go underground, be marginalized and have less access to health care and services. The other direct impact is that drug users may access impure and dangerous forms of drugs on the black market.

Attitudes are an offshoot of policy. My concern is that the attitude toward drug users seems to be "It's OK to let them die". We don't treat them with respect, compassion and understanding. Drug users may already have a low self-esteem to begin with and we compound the problem by vilifying them. This is a consequence of our law. Laws should respond to societal needs, but we've maintained public attitudes that are hostile to drug users. (We) must make the link between "us" and "them" and we have to start caring about them, if only, in terms of enlightened self-interest.

If we maintain criminalization the immediate result or impact is that we are driving the injection drug use behaviours underground. This is a direct example of why we need a better response, an integrated response. And although supervised injection sites will save lives, it is an opportunity to provide more information and education. Proximal and distal interventions are needed.

Key respondents' views corroborate existing literature and empirical data. Drug laws/policies are understood as important structural determinants of health, and HIV prevention and care interventions are seen as most effective when they specifically address the ways in which drug laws/policies create or reduce vulnerability to HIV among people who use illegal drugs.

4.3.3 Laws and Policies That Regulate Sex Work

Key respondents also markedly emphasized the need for more research on the relationship between criminalization and discrimination in sex workers. For example:

Criminalization involves more than the enforcement of the Criminal Code because on a day-to-day basis sex workers are entered into the judicial systems not by means of criminal sanction, but rather by the discriminatory application of municipal by-laws for infractions such as jaywalking. Street prostitutes are deliberately targeted by "street sweeps", and they receive unequal treatment under the law just because they belong to a particular subgroup or category of person.

According to 14% of individuals interviewed, the most important effect of laws/policies is the creation, maintenance or aggravation of specific vulnerabilities to HIV. In particular, these key respondents referred to the need for more research on the role of structural factors in creating or reducing vulnerability to HIV in sex workers. For example:

The move in a number of municipalities is to keep tabs on sex workers, such as massage, body-rub and escort workers. These activities are "semi-legal" and thus the object of increased surveillance. The police have a strong desire to know what's going on in licensed establishment but giving them access to this information does not decrease criminality; rather it pushes sex workers underground and makes it difficult for them to access HIV prevention programs.

These respondents' concerns corroborate the literature review on drug legislation and policies as well as on criminal laws and policing that regulate sex work. In both these research areas, existing literature concentrates on structural determinants as core factors that create and maintain

various levels of vulnerabilities in IDUs and in sex workers. What remains to be fully researched are the on-the-ground-effects of local codes, regulations and municipal by-laws on HIV prevention and care in sex workers.

4.3.4 Criminalizing HIV Transmission/Exposure

Although scarce empirical data was found in the area of criminal law and HIV, 8% of key respondents readily made the connection between the criminalization of HIV transmission or exposure and its impact on disclosure. These key respondents called for research on the fallouts from the *Cuerrier* decision,[242] especially pertaining to disclosure of HIV status during protected sex as well as in discordant couples generally. For example:

> *What does disclosure mean? This court decision created a false sense of protection and there is an absence of interpretation of what is expected of the persons living with HIV and individuals at large. We live in a situation where HIV-positive people do not feel safe in disclosing their status because of systemic discrimination attached to the disease and reinforced by law. This will discourage people from being tested.*
>
> *The Cuerrier decision raises more questions with respect to the process and conditions of disclosing one's HIV status. There is always a certain level of error in the process of disclosure. The person who is told may not be able to process this information. And how reliable is this information in the first place? I am interested in the conceptual debate of how you can measure the impact of disclosure of HIV status in the context of private intimate relations.*

These key respondents identified that HIV prevention and care are connected to the broader legal and policy environment in Canada, and wondered whether using criminal law to respond to HIV risk behaviours may undermine public health goals.

> *More questions have to be raised and addressed. Currently, the public health framework acts on a case-by-case analysis in cases where an individual knows s/he is seropositive but continues to engage in high-risk activity. The result is that the case usually goes to criminal law de facto. Where do people think the responsibility of disclosure of HIV status in discordant couples lies? What is the responsibility to disclose? What do we think ought to be put in place for those who are "unwilling and unable"? In short, what is the appropriate public health framework?*

4.4 Suggestions for Research

In addition to providing their views on law/policy impact, key respondents raised methodological questions pertaining to how the Canadian HIV/AIDS Legal Network should or may participate in the design of a research project assessing the impact of law/policy on human rights and HIV

[242] In 1998, the Supreme Court of Canada ruled on the issue of whether the criminal law compels disclosure of one's HIV status to sexual partners. The Court held that a person who knows he or she is HIV-positive may be convicted of aggravated assault if, without disclosing their status to a sexual partner, they engage in activity that poses a "significant risk" of transmission. [See: *R v Cuerrier* (1998), 127 CCC (3d) 1 (SCC), rev'g (1996), III CCC (3d) 261 (BCCA).] This case appears to be among the first to reach a country's highest court and has been cited repeatedly in subsequent cases, law reform papers and submissions, and the legal literature.

prevention and care. In particular, community-based research issues and specific areas where more research is required were addressed.

4.4.1 Community-Based Research

Structural issues embedded in the ethical review process of community-based research project initiatives were an important concern for some key respondents. For example, one explains:

> *Community based research puts the issues and questions of community organizations and the communities they serve at the centre of the research. Yet methodology for research is fraught with power dynamics. Traditional science research methods in medicine and in sociology are viewed as the appropriate method while other ways and other knowledges are not. These are additional structural barriers on HIV research, including the requirement that community groups cannot access research funding if they are not connected to a university or a hospital.*

All key respondents felt that a research design that combines quantitative and qualitative methodologies could prove to be most useful in assessing the structural barriers or facilitators to HIV prevention and care. For example:

> *We need to combine methodologies. The intangible is difficult to measure. Interviews should include persons living with HIV and their different experiences at different stages of the illness. Quantitative data is also important since this is what policy-makers and the public will look at.*
>
> *A combined research program could allow you to assess the degradation of quality of life in HIV-positive people's experiences quantitatively and qualitatively. If you follow 20 persons living with HIV over a period of two years for instance, the probable scenario is that we will identify statistical and ethnographic markers of vulnerability and point to the ways in which structural factors are associated.*

Finally, community-based research was understood as a shared collaborative process that recognizes, encourages and supports the inclusion of communities in developing HIV/AIDS knowledge by implementing the diverse methodologies and principles of capacity building.

4.4.2 Specific Areas Where More Research is Required

Some key respondents provided suggestions as to what areas should be the focus of future research, based on what we know from existing literature and in an attempt to delineate the complex relationships between laws/policies and determinants of health. Three major research areas were alluded to throughout the environmental scan as areas in which the Canadian HIV/AIDS Legal Network could assess the impact of law/policy on HIV prevention and care. Key respondents called for more research on "access to HIV prevention, care, treatment and support" in relationship to: (1) determinants of health; (2) public health laws/policies; and (3) using criminal law to prevent HIV transmission.

In terms of research needed on the determinants of health, a research framework that addresses how law/policy determines some of the determinants of health was suggested. For example, one key respondent suggested the following rationale for research design:

Qualitative data has shown that people living with HIV who work or are returning to work face a number of structural challenges. We also now need to look at these challenges from a different angle and combined ethnographic data with quantitative estimations of the scope of the challenges. Research questions could include: Do all HIV-positive people living on combination therapies experience such challenges? To what extent do structural barriers or facilitators vary across Canada? What workplace settings or types of employment are most impacted by structural determinants (e.g., shift work, physical labour)? What kinds of workplace policies within each of these workplaces settings exist? How are the policies working for and against people living with HIV and how do they impact on their health? Inspiration for research design may be derived from workplace studies done in the 1970s re: equal pay issues. These studies developed categories of work settings and various methodologies.

This suggestion provides a framework for assessing the impact of law/policy that broadly structure "income", "employment and working conditions", and "physical and social environments". This example also allows for a research design that addresses the impact of discrimination on health and other human rights.

Second, public health laws/policies was another area where suggestions for research questions and design were provided. For example, another key respondent suggested the following: :

What is the impact of [nominal] *reporting HIV in Canada on the willingness to test for HIV and the ethics of disclosure? Do policies encourage confidential testing while maintaining the availability of anonymous testing? Does reporting maximize or minimize the effectiveness of testing, partner notification, and epidemiological surveillance? What other possible barriers are there? By combining interviews with people who have been notified through a partner notification program with quantitative data on volume of HIV testing across risk factors that are associated with testing by province since 1985; mapping these over time and across moments where mandatory reportability of HIV policies exists; a longitudinal study could yield an assessment of contact tracing practices, numbers of partners contacted in regions where reportability of HIV seropositivity is reportable; and whether these public health practices impact positively or negatively on individual behaviour, including disclosure of HIV status.*

Third, the application of criminal law to conduct that transmits or risks transmitting HIV was also suggested as an area for further inquiry. In light of the *Cuerrier* decision, key respondents raised questions about the extent to which the use of criminal sanctions facilitates or hinders personal health practices, such as disclosure of HIV status. For example, one key respondent raised the following:

What is the standard of conduct we require from persons living with HIV before they engage in protected sex? Are there legal requirements? Scientific requirements? Ethical requirements? Links should be made with other determinants of health so that the connection to vulnerability to HIV and how disclosure has positive and negative effects across vulnerable groups can be addressed. How is disclosure experienced in people who are in abusive relationships; in those without coping skills; in those with little education or inappropriate level of education to adequately receive this sensitive information? Etc.

Section V - Conclusions and Recommendations

Based on the results from the literature review and environmental scan, this last section provides recommendations for future research questions and priorities in five areas where research data is limited or non-existent. Although each research area or issue reviewed here is worthy of further empirical assessment, only one specific law/policy impact was selected for in-depth CBR as it ranked highest in terms of the selection criteria used (see section 1.3). Research areas are presented according to this ranking, from the least to the most likely terrain of future investigation.

5.1 Access to HIV Prevention, Care, Treatment and Support

There have been some attempts to document the structural barriers and facilitators to accessing HIV/AIDS prevention, care, treatment and support. Issues of access are systematically referred to in studies that examine the effects of various laws/policies that structure HIV testing, reporting and partner notification, drug use and sex work. For key respondents interviewed, these issues also constituted one of the clearest examples of how structural factors impact on the human rights of people living with HIV and those who are vulnerable.

This is a genuine area of concern for any future research endeavour undertaken. It should constitute a general research priority for the Legal Network's inquiry into the impact of law/policy on HIV prevention and care. This general area, however, is much too broad for the Legal Network to tackle at this point in time and under this particular CBR project formulation. A more narrowly defined research focus would be necessary, such as examining the effect of a specific law/policy (or set of laws/policies) on a particular population's access to HIV prevention and care, treatment and support.

5.2 Laws and Policies on HIV Testing, Reporting & Partner Notification

Most jurisdictions in Canada have adopted legislation requiring the reporting of cases of HIV seropositivity. In light of the theoretical implications regarding various testing options and the debate over data collection, research on the impact of such change in public health law/policy is timely. From US research data, we know that the impact of name-based surveillance on partner notification programs and on access to HIV testing may have been exaggerated. We also know that HIV and AIDS continue to raise many issues that relate to stigmatization and that a broader understanding of the impact of the HIV test on recipients and providers, as well as systemic changes in societal attitudes, is essential in order to maintain HIV testing as an effective measure for HIV prevention and for accessing treatment.

Further inquiry is needed to assess the impact of name-based reporting HIV in Canada, especially in the areas of the impact on people's willingness to test for HIV and the ethics of disclosure. Do policies encourage confidential testing while maintaining the availability of anonymous testing? Does a particular law/policy governing how HIV test results are reported to public health authorities maximize or minimize the effectiveness of testing, partner notification, and epidemiological surveillance? What other possible barriers are there? This is a research area in which the Canadian HIV/AIDS Legal Network has done theoretical work (i.e., its numerous

publications on issues of HIV testing and confidentiality), and could take on as a priority research area for the assessment of healthy public policy in Canada.

5.3 Drug Laws and Policies

Much analysis exists regarding the negative impact criminalization of drug use has on access to HIV prevention and care in people who inject illegal drugs, and there is some literature on the positive impact of harm reduction programs, such as the implementation of needle-exchange programs. Theoretical and empirical literature confirms that many of the serious problems associated with illegal drug use are caused directly or indirectly not by drug use itself but by drug prohibition. The impact of drug legislation and policies on HIV prevention and care is one research area reviewed that is well documented.

Theoretically, what is required now are legal and policy changes that minimise the negative impacts of structural barriers to HIV prevention and care in IDUs, and maximize the positive impacts of structural facilitators on HIV prevention, care, treatment and support. However, in order to do so in Canada, there is still the need for a stronger empirical base demonstrating the impact of Canadian drug laws/policies on HIV prevention among drug users and on drug users' access to care, treatment and support. For example, it would be valuable for the development of healthy drug law/policy to study the impact of new regulations on people's access to medical marijuana, or the impact on HIV prevention efforts of police enforcing prohibitions on possession of controlled substances (which definition includes needles containing drug residue). This is a research area in which the Canadian HIV/AIDS Legal Network has done theoretical work (i.e., its numerous publications on issues of HIV/AIDS and drug laws/policies), and could take on as a priority research area. In addition, there is an interest in this issue in other community-based organizations that are particularly well suited to collaborate the development of a community-based research proposal.

5.4 Laws and Policies that Regulate Sex Work

Theoretical literature concerned with sex workers as a prime population that is vulnerable to HIV, and analysis that explores the impact of prostitution laws on health and other human rights, is available. We know that decriminalization can theoretically impact positively on the determinants of health in sex workers. However, empirical investigation of this impact in Canada is impossible as long as prostitution laws are in effect in the Criminal Code. To this date then, we can only speculate and draw on the experiences from other jurisdictions where decriminalization of prostitution-related activities has occurred. Further research is required to delineate how policies that regulate sex work are structural factors which affect determinants of health; and how local codes and municipal by-laws across Canada impact on HIV prevention and care in people who work in the sex industry. This research question is at the core of the ongoing *Canadian Sex Trade Advocacy Research* initiative and the Canadian HIV/AIDS Legal Network should support the completion of this study, and assist with efforts to implement the lessons it will generate for law/policy reform.

What the Legal Network could focus on, however, are the ways in which sex workers are criminalized through the application of drug laws/policies. More research is needed to better understand how drug laws/policies are empirically tied to the criminalization of sex work. Based

on its expertise and numerous publications in the area of drug legislation and policies, the Legal Network can undoubtedly zone in on sex workers at the intersection of prostitution and drug laws and research how healthy public policy in Canada works to facilitate or hinder sex worker's vulnerability to HIV.

5.5 Criminalization of HIV transmission/exposure

Legal analysis of various uses of criminal sanctions to address conduct that transmits or risks transmitting HIV exists but there is no empirical data documenting the lived effects of the criminalization of HIV transmission/exposure on the health and human rights of either HIV-positive or HIV-negative persons, nor is there sound evidence to address the impact of such laws on HIV prevention or access to care, treatment and support. Available literature raises the question of whether criminal laws and prosecutions represent a public policy response to HIV-risking conduct that will, ultimately, promote health. In particular, there is some theoretical analysis speculating whether a law requiring people to disclose to sexual partners their HIV-positive status upon pain of criminal prosecution affects willingness to test for HIV, preference for anonymous or nominal testing, to whom they disclose, how and in what circumstances. Yet, research data regarding the empirical impact of criminalization of HIV transmission or exposure in Canada is non-existent.

Key respondents suggested that research be done on the fallouts of the *Cuerrier* decision, especially pertaining to disclosure of HIV status during protected consensual sexual activity. Research could also examine how criminal law can facilitate or hinder HIV prevention and care, and how criminalization structures determinants of health (e.g., personal health practices, accessing prevention, treatment and support services) that, in turn, may affect vulnerability to HIV, the health of persons who are HIV-positive, or the ability of individuals and communities to cope with HIV/AIDS. We know from the determinants of health literature that stigmatization is an indirect impact of structural determinants and that eradicating AIDS stigma remains an important goal of healthy public policy for effectively combating HIV. AIDS-related stigma can impede access to specialized HIV care, willingness to being tested for HIV and to disclose seropositive status, or lead to barriers to making HIV prevention materials available. These effects are indirect because the health outcome is far removed and outside individuals' direct control, can accumulate into significant health differences over time in the life course of individuals and populations, and are often mediated through direct effects.

We know from studies on laws/policies regulating drug use and sex work, that criminalization can have direct effects on certain communities while having a more distal impact on other populations. Criminalization creates structural barriers closely linked to specific healthy personal practices or to specific health outcomes in drug users and sex workers while having a more indirect impact on the general population. Empirical data confirms that many of the serious problems we associate with illegal drug use are caused directly or indirectly not by drug use itself but by drug prohibition. Research data also substantiate the idea that laws/policies that regulate sex work are direct structural determinants to HIV prevention and care, whereas abuse, discrimination and stigmatisation against persons who prostitute, operate as indirect structural barriers to HIV prevention and care. These direct and indirect effects on the health of individuals and populations are amenable to structural interventions, either by acting on the proximal determinants or by instituting policies addressing the distal factors.

We also know from legal analysis that the majority of criminal prosecutions of people living with HIV/AIDS for sexual conduct that risks HIV transmission have been laid against HIV-positive men for sex with women. Men who have sex with men and injection drug users have not used the criminal system in this manner and may mistrust the system because they do not believe that government rules about sexual conduct and drug use are legitimate. A sense of selective prosecution could also undermine legitimacy, as could personal experiences of unfairness. In the absence of empirical evidence, as the one US study reviewed in this area pointed out, assessment of criminal law's impact of HIV-related health raises more questions. For example:

- Do individuals with HIV or those at risk for infection know about the laws governing their sexual behaviour in general and about decisions (such as *R v Cuerrier*)? Do they believe they could or will be punished for violating these laws? What are their attitudes toward police, law, and the courts?
- Are there differences in knowledge, beliefs or attitudes, with regards to the perceived legitimacy of criminal charges for HIV-risking behaviour between heterosexual and gay male populations most vulnerable to HIV/AIDS? How would such differences range in terms of gendered, racialized and socio-economic determinants of health?
- Does criminal law impact on access to information about means of self-protection against HIV, about testing, or about treatment? How, and to what extent, do all the structural factors influence individual's perceived and actual control as related to their intention to change their behaviour to fit these laws' limitations?
- How is the criminal law used in dealing with HIV-risking behaviour? What are the attitudes of prosecutors and police toward invoking it? What specific practices in health care professionals and counsellors are affected by this decision?
- Does a law requiring people to disclose their HIV-positive status upon pain of criminal prosecution affect willingness to test for HIV? Does it affect preference for anonymous or nominal testing? To whom they disclose, how, in what circumstances? And how do these personal health practices vary across gender, ethno cultural background and socio-economic status?

Of course, this list of questions is not exhaustive and the issues raised are not necessarily entirely met by a health impact assessment approach. However, it provides a basis for law/policy impact research that is of most concern to people and communities in Canada, their advocates and policymakers and, especially, to people with HIV/AIDS.

The issues raised by the application of the criminal law to sexual behaviours that risk transmitting HIV are extremely relevant and timely for enhancing the potential of law/policy in responding to HIV/AIDS in Canada since the 1998 Supreme Court decision in *R v Cuerrier*. Empirical evidence of the indirect and direct health impacts of this decision can be used to: (1) facilitate HIV prevention, care, treatment and support; (2) minimise the potential negative consequences of criminal or coercive public health laws on people with HIV/AIDS; and (3) inform legal proceedings and court interventions in future similar prosecutions. The Canadian HIV/AIDS Legal Network is particularly well suited to undertake research in this area, as it has developed considerable theoretical expertise on this issue in Canada over several years and has been involved in litigation addressing this issue from a public policy perspective.

5.6 Designing a Community-Based Research Project

In conclusion, the Canadian HIV/AIDS Legal Network should retain the area of criminalization of HIV transmission/exposure as the key, under-researched, issue for further study in the second phase of this project. This issue is one for which:

- a rationale for empirical assessment can be based on available theoretical literature;
- Canadian research data is non-existent;
- the Canadian HIV/AIDS Legal Network has a theoretical expertise as the basis for undertaking further, empirical research;
- there is a need and an opportunity to better inform Canadian law/policy on this issue; and
- guiding principles of community-based research can be implemented in the research project.

The design of a community-based research proposal, in partnership with another community-based organisation and an experienced researcher, should focus on the general research question of: assessing the effects of using criminal prosecutions on HIV care and prevention — to evaluate whether the criminalization of behaviour that risks transmitting HIV has significant impacts on the lives of people living with HIV/AIDS in Canada and on population health generally.

Indirect health effects that can be measured include whether the use of the criminal law:

- reinforces AIDS stigma and the idea that people living with HIV are "potential criminals" or a "threat to the general public" and ultimately blamed for their illness; and/or
- creates a false sense of security among people who are (or think they are) HIV-negative.

Direct health effects that can be measured include whether the use of the criminal law:

- affects willingness to seek HIV testing in persons most vulnerable to HIV, in certain communities affected by HIV/AIDS or in the general population; and/or
- affects access to counselling and support services for people with HIV/AIDS or affects their willingness to seek treatment; and/or
- affects the circumstances in which, and the process by which, people disclose their HIV-positive status to sexual or needle-sharing partners.

The research design should account for collaboration with community-based organizations that involve those populations most affected by these issues researched across Canada (e.g., Vancouver, Toronto and Montreal). To overcome the limitations of this sampling, "validation workshops", where preliminary findings are presented to communities not included in the research, should take place over the course of the research in cities or regions not covered by the research design.

In addition, in putting forward a proposal for further research on the issues raised by criminalizing HIV transmission/exposure, it will be necessary to consider the feasibility, risks, and ethics of having people discuss whether they disclose their HIV status and the circumstances and characteristics (many of which are situation- and person-specific) which inhibit or support disclosure. For example, the research design will have to address whether participants in the

study can be protected from criminal prosecution or police seizure of data when disclosing possibly criminal behaviour in the context of the research.

Finally, the Canadian HIV/AIDS Legal Network should invite community participation as early as possible, to shape cooperative agreements about designing the proposal, particularly in terms of ethical issues, the treatment of data and the dissemination of findings. There is a need to maintain flexibility in the design to accommodate unforeseen and emerging research issues that have particular urgency attached to them in light of their real or potential interests for all research participants.

Appendix A: Subject Consent Form

Title of Research Project:

Healthy Public Policy: Assessing the Impact of Law and Policy on Human Rights and HIV Prevention and Care

Investigators' contact information:

Maria Nengeh Mensah, PhD Project Coordinator
tel (514) 282-1619
email mnm99@sympatico.ca

Ralf Jürgens, PhD Executive Director, Canadian HIV/AIDS Legal Network
tel (514) 397-6828 ext 223
email ralfj@aidslaw.ca

Richard Elliott, LLB Director, Policy & Research, Canadian HIV/AIDS Legal Network
tel (416) 595-1666
email relliott@aidslaw.ca

Purpose of the Research:

We invite you to participate in a research project with two goals.

(1) We want to identify what research has already been done, and what research still needs to be done, on the impact of laws and policies on the human rights of people and communities living with and affected by HIV/AIDS, and how this affects their health.

(2) Based on this, we want to identify an issue or area that still needs this kind of research, and design a project to do that research on the impact of the law on human rights and health.

The purpose of this research project is to make sure that we have research data that can be used to guide elected legislators, government policy-makers, judges, and individuals and organizations that run programs or provide services to people living with HIV/AIDS in making choices between different laws or policies. With data about the effects on health and human rights of different kinds of laws and policies, decision-makers can avoid enacting laws, or making judgments, or creating policies that damage people's human rights and that damage their health and the public health by undermining HIV prevention efforts or impeding access to care, treatment and support related to HIV/AIDS.

Description of the Research:

As part of this research, we plan to do the following:

- Review reports and research studies in medical, legal, public health or other journals or publications that examine any connection between people's health (specifically in relation to HIV/AIDS) and the adoption or implementation of laws or policies that respect or violate human rights standards. Just as an example, does a law requiring people to disclose their HIV-positive status to some people upon pain of criminal prosecution affect willingness to test for HIV (and/or a preference for anonymous vs. nominal testing)? Does it affect to whom they disclose, how, and in what circumstances?
- Do an "environmental scan" of important issues where the possible link between a law/policy and an effect on human rights and health should be investigated. This will be done by conducting interviews with several key respondents about what they see as the key issues where it is important for us to better understand the role the law plays in affecting HIV prevention or people's access to medical care or support services. You are one of those respondents that we are hoping to interview. We are also grateful to receive any additional comments or thoughts you wish to forward to us in writing outside the interview itself.
- Prepare a synthesis report from the results of the literature review and the environmental scan interviews. On those issues where the research already done has produced sufficient data, the report will draw some conclusions about how different laws and policies affect human rights and health. It will also identify those areas where there is little research, and make recommendations about which research should be pursued.
- With the participation of one or more other community-based organizations, and one or more people with experience in designing and conducting different kinds of research studies, we will design a community-based research project to gather data on a key, under-researched area where we need to better understand the relationship between the law, human rights, and health. These partners in the research will be identified through the course of conducting the literature review and the environmental scan. Once we have designed the research project, we will seek additional funding to actually carry out that research.

Potential Harms:

There are no known harms associated with being interviewed for this project or providing input in writing.

Potential Benefits:

You will not benefit directly from being interviewed for this project, or providing input in writing, but you will help us identify what community-based respondents doing HIV/AIDS-related work feel are the important issues to focus on in studying the impact the law has on HIV prevention and access to HIV/AIDS care, treatment and support. You may also help us with suggestions as to how this should be researched. Ultimately, we hope this will of benefit (a) to all those who make laws or policies that affect people living with HIV/AIDS and our efforts to respond to the epidemic, (b) to all those who advocate on behalf of the human rights of people living with HIV/AIDS or provide services to them; and therefore (c) to people living with HIV/AIDS, by ensuring that decisions are better informed about the consequences of different choices in our laws and policies.

Confidentiality:

Given the non-personal nature of the information we hope to obtain from you with the interview, we do not anticipate any need or desire to keep your input confidential, and we hope you will be willing to be identified as a key respondent in the synthesis report. However, if you request that your input be kept confidential, we will certainly do so, and while we will use your input in the synthesis report, it will not be used in a way that identifies you as the source of that information.

The results of this research will be presented to conferences, workshops and meetings related to HIV/AIDS, possibly to legal conferences, and may be submitted for publication. The synthesis report based on the literature review and the environmental scan in which you are participating will be posted on the website of the Canadian HIV/AIDS Legal Network and summarized in Legal Network publications, to keep our members and others informed about work on this project.

Participation & Reimbursement:

Obviously, your participation in this research is voluntary and you may choose to withdraw your participation in this research at any time without prejudice. There is no reimbursement provided for any of the key respondents.

Consent:

I acknowledge that the research project described above has been explained to me and that any questions I have asked have been answered to my satisfaction. I hereby consent to participate as a key respondent.

Name of Participant: _____

Signature: _____

Date: _____

Name of Person obtaining Consent: _____

Signature: _____

Date: _____

Appendix B: Key Respondents

Sharon Baxter	Canadian AIDS Society
Ansley Chapman	AIDS Community Care Montreal
Timothy Christie	Vancouver/Richmond Health Board
Richard Cloutier	Centre québécois de coordination sur le sida
Geoffrey Cole	Health Canada
Marc-André Donato	Bureau régional Action SIDA Outaouais
Deborah Foster	Network of Edmonton Society
Glen Hillson	Canadian Treatment Action Council
Perry Kendall	British Columbia Government, Office of the Provincial Health Officer
Roger LeClerc	Coalition des organismes communautaires de lutte contre le sida du Québec
Johanne Leroux	Comité des personnes atteintes de VIH du Québec
Rick Marchand	Community Based Research Centre Society
Eleanor Maticka-Tyndale	University of Windsor, Department of Sociology and Anthropology
Eugene Oscapella	Canadian Foundation for Drug Policy
Tarel Quandt	British Columbia Persons with AIDS Society
Claire Thiboutot	Stella, l'amie de Maimie
Mary Ann Torres	International Council of AIDS Service Organizations
Mark Randall	Consultant
Michael R Smith	Health Canada
Art Zoccole	Canadian Aboriginal AIDS Network

Appendix C: Interview Scheme

Designing a Community-Based Research Project on "Healthy Public Policy" – Phase 1: Environmental Scan

Part 1: Introduction

Question 1. Consent to participating in the environmental scan

- Please review the attached *Subject Consent Form* detailing the nature of your participation in this environmental scan before responding to the questionnaire. Once you have reviewed it, sign the consent form, keep one copy for your records and mail another copy back to the Canadian HIV/AIDS Legal Network at: Maria Nengeh Mensah, Canadian HIV/AIDS Legal Network, 417 rue Saint-Pierre, suite 408, Montreal QC H2Y 2M4.

Question 2. Key respondent information

- What is your position, type of work? If you are speaking on behalf of an organization, please explain its mandate or mission statement?
- What people and communities living with and affected by HIV/AIDS do you reach directly or indirectly? [e.g., target populations and geographic representation]
- How would you describe your fluency with Canadian laws and policies affecting or relevant to people living with HIV/AIDS or at risk of infection?
- In the context of your work with people and communities living with and vulnerable to HIV/AIDS, how would you describe any experience you've had with legal problems or the courts (e.g., specific laws or policies)?

Part 2: Impact of Laws and Policies on Health

Question 3. Based on your experience of working with people and communities living with and affected by HIV/AIDS, are there any laws and/or policies that you see as having a direct or indirect effect on the health of people living with HIV/AIDS?

Question 4. Can you provide an example (or several examples) of how you understand that specific laws/policies have direct or indirect effects on the health of PHAs?

- Example of law/policy:

  For clarification, note the following:
  - In your own words, what are the specific intended purposes of this law/policy?
  - Do you see the effects of this law/policy as positive or negative?
  - In your view, how does this law/policy affect individual and/or public health?
  - In your view, how does this law/policy impact on access to care, treatment, and support for PHAs?
  - In your view, how does the law or policy in question affect other factors influencing the health (e.g., economic and physical environments, gender, personal health practices, individual capacity and coping skills, human biology, early childhood development) of people living with or vulnerable to HIV/AIDS?

- In your view, how measurable is the impact of this law/policy on the health of PHAs (i.e., qualitative, estimable or calculable)?
- In your view, is the risk of the impact of this law/policy on health definite, probable or speculative?

Question 5. Based on your experience of working with people and communities living with and affected by HIV/AIDS, are there any laws and/or policies that you see as having a direct or indirect effect on HIV prevention efforts and initiatives?

Question 6. Can you give me an example (or several examples) of how you understand that specific laws/policies have direct or indirect effects on HIV prevention?

- Example of law/policy:

  For clarification, note the following:
  - In your own words, what are the specific intended purposes of this law/policy?
  - Do you see the effects of this law/policy on HIV prevention as positive or negative?
  - In your view, how does this law/policy affect individual and public HIV prevention efforts or initiatives?
  - In your view, how does the law or policy in question affect other factors that influence the health of people living with, or vulnerable to, HIV/AIDS (e.g., economic and physical environments, gender, personal health practices, individual capacity and coping skills, human biology, early childhood development)?
  - In your view, how measurable is the impact of this law/policy on HIV prevention (i.e., qualitative, estimable or calculable)?
  - In your view, is the risk of the impact of this law/policy on HIV prevention definite, probable or speculative?

Part 3: Impact of Laws and Policies on Other Human Rights

Question 7. Based on your experience of working with people and communities living with and affected by HIV/AIDS, are there any laws and/or policies that you see as having a direct or indirect effect on the human rights of people living with HIV/AIDS, other than the right to health?

- Example of law/policy:

  For clarification, you may note the following:
  - In your own words, which human rights do you think this law/policy affects?
  - Do you see the effects of this law/policy as positive or negative? Why?
  - If the effect is negative, are you aware of any existing system of monitoring, evaluation, accountability and redress?
  - In your view, how measurable is the impact of this law/policy on the human rights of PHAs (i.e., qualitative, estimable or calculable)?
  - In your view, is the risk of the impact of this law/policy on the human rights of PHAs definite, probable or speculative?

Part 4: Priority Research Areas for Further study

Question 8. Based on your experience of working with people and communities living with and affected by HIV/AIDS and in light of your input today, what do you see as the key issues or areas that should be the focus of a research project on the impact of laws and policies on human rights and health? Why?

Question 9. In your view, which one of these issues or areas should be the priority for further study? [If more than one, prioritize on a scale of 1-3.]

Part 5: Conclusion

Question 10. Is there anything you wish to add that we may not have touched on in our questionnaire or any additional comments or suggestions you would like to add?

Thank you for your valuable input!

MNM.