
Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 2-3 - Spring 1997

Dedication

This issue of the *Newsletter* is dedicated to the memory of Prof Benjamin Freedman. Benji was one of Canada's most respected bioethicists and, above all, a truly ethical person. He frequently wrote about issues related to HIV/AIDS policy and law and was a contributor to the October 1996 issue (vol 3, no 1) of the *Newsletter*. Benji will be dearly missed by all who admired him for his sharp intellect, moral integrity, humour, and never- ending dedication to pursue what is just.

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Guidelines on HIV/AIDS and Human Rights Adopted

The Joint United Nations Programme on HIV/AIDS (UNAIDS) and the United Nations High Commissioner for Human Rights/Centre for Human Rights held the Second International Consultation on HIV/AIDS and Human Rights in Geneva from 23 to 25 September 1996. The Consultation adopted guidelines on HIV/AIDS and human rights, aiming to ensure the protection and fulfilment of the human rights of people affected by HIV/AIDS.[1]

The Consultation

The Consultation, the second of its kind,[2] brought together 35 experts in the field of AIDS and human rights, comprising government officials and staff of national AIDS programs, people living with HIV/AIDS, human rights activists, academics, representatives of regional and national networks on ethics, law, human rights and HIV, and representatives of United Nations bodies and agencies, non-governmental organizations and AIDS service organizations (ASOs). From Canada, Ken Morrison, representing ICASO, the International Coalition of AIDS Service Organizations, and Ralf Jürgens, representing the Canadian HIV/AIDS Legal Network, participated.

The Consultation had before it five background papers, commissioned for the purpose of eliciting specific regional and thematic experiences and concerns regarding HIV/AIDS and human rights. The papers had been prepared by the following non-governmental organizations and networks of people living with HIV/AIDS:

- the Alternative Law Research and Development Center (ALTERLAW) (Philippines);
- the Network of African People Living with HIV/AIDS (NAP+) (Zambia);

- Colectivo Sol (Mexico);
- the International Community of Women Living with HIV/AIDS (ICW+); and
- the Global Network of People Living with HIV/AIDS (GNP+).

Each of these groups was asked to identify the most important human rights principles and concerns in the context of HIV/AIDS, and concrete measures that States could take to protect HIV-related human rights.

In addition, the Consultation had before it draft guidelines on HIV/AIDS and human rights, prepared by Helen Watchirs (Australia) on the basis of the five regional background papers and other materials consulted. Finally, the London-based association Rights and Humanity conducted a global survey to review existing strategies and identify other measures necessary to ensure respect for human rights in the context of HIV/AIDS. An analysis of the 40 responses received to the survey was presented to the Consultation.

The Consultation formed four working groups to

- discuss and finalize the draft guidelines, and
- develop recommendations concerning strategies to ensure the dissemination and implementation of the guidelines.

Conclusions of the Consultation

> HIV/AIDS continues to spread throughout the world at an alarming rate. Close in the wake of the epidemic is the widespread abuse of human rights and fundamental freedoms associated with HIV/AIDS in all parts of the world.[3]

In response to this situation, the experts at the Consultation concluded the following:

> [10] (a) The protection of human rights is essential to safeguard human dignity in the context of HIV/AIDS and to ensure an effective, rights-based response to HIV/AIDS. An effective response requires the implementation of all human rights, civil and political, economic, social and cultural, and fundamental freedoms of all people, in accordance with existing international human rights standards.
>
> (b) Public health interests do not conflict with human rights. On the contrary, it has been recognized that when human rights are protected, less people become infected and those living with HIV/AIDS and their families can better cope with HIV/AIDS

(c) A rights-based, effective response to the HIV/AIDS epidemic involves establishing appropriate governmental institutional responsibilities, implementing law reform and support services and promoting a supportive environment for groups vulnerable to HIV/AIDS and for those living with HIV/AIDS.

(d) In the context of HIV/AIDS, international human rights norms and pragmatic public health goals require States to consider measures that may be considered controversial, particularly regarding the status of women and children, sex workers, injecting drug users and men having sex with men. It is, however, the responsibility of all States to identify how they can best meet their human rights obligations and protect public health within their specific political, cultural and religious contexts.

(e) Although States have primary responsibility for implementing strategies that protect human rights and public health, United Nations bodies, agencies and programmes, regional intergovernmental bodies and non-governmental organizations, including networks of people living with HIV/AIDS, play critical roles in this regard.

The Guidelines on HIV/AIDS and Human Rights

The Guidelines' purpose is to translate international human rights norms into practical observance in the context of HIV/AIDS. To this end, the Guidelines consist of two parts:

- the human rights principles underlying a positive response to HIV/AIDS; and
- action-oriented measures to be employed by Governments in the areas of law, administrative policy and practice that will protect human rights and achieve HIV-related public health goals.

A summary of the 12 guidelines for States follows:

Guideline 1: States should establish an effective national framework for their response to HIV/AIDS which ensures a coordinated, participatory, transparent and accountable approach, integrating HIV/AIDS policy and programme responsibilities across all branches of Government.

Guideline 2: States should ensure, through political and financial support, that community consultation occurs in all phases of HIV/AIDS policy design, programme implementation and evaluation and that community organizations are enabled to carry out their activities, including in the field of ethics, law and human rights, effectively.

Guideline 3: States should review and reform public health laws to ensure that they adequately address public health issues raised by HIV/AIDS, that their provisions applicable to casually transmitted diseases are not inappropriately applied to HIV/AIDS and that they are consistent with international human rights obligations.

Guideline 4: States should review and reform criminal laws and correctional systems to ensure that they are consistent with international human rights obligations and are not misused in the context of HIV/AIDS or targeted against vulnerable groups.

Guideline 5: States should enact or strengthen anti-discrimination and other protective laws that protect vulnerable groups, people living with HIV/AIDS and people with disabilities from discrimination in both the public and private sectors, ensure privacy and confidentiality and ethics in research involving human subjects, emphasize education and conciliation, and provide for speedy and effective administrative and civil remedies.

Guideline 6: States should enact legislation to provide for the regulation of HIV-related goods, services and information, so as to ensure widespread availability of qualitative prevention measures and services, adequate HIV prevention and care information and safe and effective medication at an affordable price.

Guideline 7: States should implement and support legal support services that will educate people affected by HIV/AIDS about their rights, provide free legal services to enforce those rights, develop expertise on HIV-related legal issues and utilize means of protection in addition to the courts, such as offices of ministries of justice, ombudspersons, health complaint units and human rights commissions.

Guideline 8: States, in collaboration with and through the community, should promote a supportive and enabling environment for women, children and other vulnerable groups by addressing underlying prejudices and inequalities through community dialogue, specially designed social and health services and support to community groups.

Guideline 9: States should promote the wide and ongoing distribution of creative education, training and media programmes explicitly designed to change attitudes of discrimination and stigmatization associated with HIV/AIDS to understanding and acceptance.

Guideline 10: States should ensure that government and private sectors develop codes of conduct regarding HIV/AIDS issues that translate human rights principles into codes of professional responsibility and practice, with accompanying mechanisms to implement and enforce these codes.

Guideline 11: States should ensure monitoring and enforcement mechanisms to guarantee the protection of HIV-related human rights, including those of people living with HIV/

AIDS, their families and communities.

Guideline 12: States should cooperate through all relevant programmes and agencies of the United Nations system, including UNAIDS, to share knowledge and experience concerning HIV-related human rights issues and should ensure effective mechanisms to protect human rights in the context of HIV/AIDS at international level.

Recommendations for Dissemination and Implementation

Participants at the Consultation also considered strategies for dissemination and implementation of the Guidelines. Three groups of key actors were identified as being critical to the implementation of the Guidelines:

- States;

- the United Nations system and regional intergovernmental organizations; and

- non-governmental and community-based organizations.

States

14. States, at the highest level of Government (head of State, Prime Minister and/or relevant ministers) should promulgate the Guidelines and ensure that the political weight of the Government is behind the dissemination and implementation of the Guidelines throughout all branches of the executive, legislature and judiciary.

15. States, at highest level of Government, should assign appropriate governmental bodies/staff with the responsibility to devise and implement a strategy for dissemination and implementation of the Guidelines and establish periodic monitoring of this strategy through, for example, reports to the Executive Office and public hearings. States should establish within the executive branch a staff member(s) responsible for this strategy.

16. States should disseminate the Guidelines, endorsed by the executive, to relevant national bodies, such as interministerial and parliamentary committees on HIV/AIDS and national AIDS programmes, as well as to provincial and local-level bodies.

17. States, through these bodies, should give formal consideration to the Guidelines in order to identify ways to build them into existing activities and prioritize necessary new activities and policy review. States should also organize consensus workshops with the participation of non-governmental organizations, community-based organizations and AIDS service organizations (ASOs), networks of people living with HIV/AIDS (PLHAs), networks on ethics, law, human rights and HIV, United Nations Theme Groups on HIV/

AIDS, as well as political and religious groups:

(a) To discuss the relevance of the Guidelines to the local situation, to identify obstacles and needs, to propose interventions and solutions and to achieve consensus for the adoption of the Guidelines;

(b) To elaborate national, provincial and local plans of action for implementation and monitoring of the Guidelines within the local context;

(c) To mobilize and ensure the commitment of relevant governmental officials to apply the Guidelines as a working tool to be integrated into their individual workplans.

18. States, at national, subnational and local levels, should establish mechanisms to receive, process and refer issues, claims and information in relation to the Guidelines and to the human rights issues raised therein. States should create focal points to monitor the implementation of the Guidelines in relevant government departments.

19. States, in ways consistent with judicial independence, should disseminate the Guidelines widely throughout the judicial system and use them in the development of jurisprudence, conduct of court cases involving HIV-related matters and HIV-related training/continuing education of judicial officers.

20. States should disseminate the Guidelines throughout the legislative branch of Government and particularly to parliamentary committees involved in the formulation of policy and legislation relevant to the issues raised in the Guidelines. Such committees should assess the Guidelines to identify priority areas for action and a longer-term strategy to ensure that relevant policy and law are in conformity with the Guidelines. [back to the contents]

United Nations System and Regional Intergovernmental Bodies

21. The United Nations Secretary-General should submit the Guidelines to the Commission on Human Rights as part of the report on the Second International Consultation on HIV/AIDS and Human Rights.

22. The Secretary-General should transmit the Guidelines to heads of State:

(a) Recommending that the document be distributed nationally through the appropriate channels;

(b) Offering, within the mandates of UNAIDS and the United Nations High

Commissioner/Centre for Human Rights, technical cooperation in facilitating the implementation of the Guidelines;

(c) Requesting that compliance with the Guidelines be included in the national reports to existing human rights treaty bodies;

(d) Reminding Governments of the responsibility to uphold international human rights standards in promoting compliance with the Guidelines.

23. The Secretary-General should transmit the Guidelines to the heads of all relevant United Nations bodies and agencies, requesting that they be widely disseminated throughout the relevant programmes and activities of the bodies and agencies. The Secretary-General should request that all relevant United Nations bodies and agencies consider their activities and programmes on HIV/AIDS in the light of the provisions of the Guidelines and support the implementation of the Guidelines at the national level.

24. The Commission on Human Rights and the Sub-Commission on Prevention of Discrimination and Protection of Minorities, as well as all human rights treaty bodies, should consider and discuss the Guidelines with a view to incorporating relevant aspects of the Guidelines within their respective mandates. Human rights treaty bodies, in particular, should integrate the Guidelines, as relevant, in their respective reporting guidelines, questions to States, and when developing resolutions and general comments on related subjects.

25. The Commission on Human Rights should appoint a special rapporteur on human rights and HIV/AIDS with the mandate, inter alia, to encourage and monitor implementation of the Guidelines by States, as well as their promotion by the United Nations system, including human rights bodies, where applicable.

26. The United Nations High Commissioner/Centre for Human Rights should ensure that the Guidelines are disseminated throughout the Centre and incorporated into the activities and programmes of the Centre, particularly those involving support to the United Nations human rights bodies, technical assistance and monitoring. This should be coordinated by a staff member with exclusive responsibility for the Guidelines. Similarly, the United Nations Division for the Advancement of Women should ensure the full integration of the Guidelines into the work of the Committee on the Elimination of Discrimination Against Women.

27. UNAIDS should transmit the Guidelines widely throughout the system - to co-sponsors of the UNAIDS Programme Coordinating Board, United Nations Theme Groups on HIV/AIDS, UNAIDS staff, including country programme advisers and focal points - and should ensure that the Guidelines become a framework for action for the work of the

United Nations Theme Groups on HIV/AIDS and UNAIDS staff, including that Theme Groups use the Guidelines to assess the HIV-related human rights, legal and ethical situation in-country and to elaborate the best means to support implementation of the Guidelines at the country level.

28. Regional bodies (such as the Inter-American Commission on Human Rights, the Organization of American States, the African Commission on Human and Peoples' Rights, the Organization of African Unity, the European Commission on Human Rights, the European Commission, the Council of Europe, the Association of South-East Asian Nations, etc.) should receive the Guidelines and transmit them widely among members and relevant divisions with a view to assessing how their activities might be made consistent with the Guidelines and promote their implementation.

29. Specialized agencies and other concerned bodies (such as the International Labour Organization, the International Organization for Migration, the Office of the United Nations High Commissioner for Refugees, the United Nations Research Institute for Social Development and the World Trade Organization) should receive the Guidelines and transmit them widely among members and throughout their programmes with a view to assessing how their activities can be made consistent with the Guidelines and promote their implementation. [back to the contents]

Non-Governmental Organizations

30. NGOs should implement the Guidelines within a broad framework of communication around HIV and human rights, including through the establishment of ongoing communication between the HIV/AIDS community and the human rights community by:

(a) Establishing contacts at the international, regional and local levels between networks of ASOs and people living with HIV/AIDS and human rights NGOs;

(b) Developing mechanism(s) for ongoing communication and dissemination and implementation of the Guidelines, such as a bulletin board and/or home page on the Internet allowing for input and exchange of information on human rights and HIV and database linkages between groups working on human rights and HIV;

(c) Networking with human rights NGOs at meetings of United Nations human rights bodies;

(d) Promoting discussion of the Guidelines in their newsletters and other publications, as well as through other media;

(e) Developing an action-oriented and accessible version(s) of the Guidelines;

(f) Developing a strategy and process for the dissemination of the Guidelines and seeking funding and technical cooperation with regard to the dissemination.

31. Non-governmental organizations at the regional level should:

(a) Establish or use existing focal points to disseminate the Guidelines, with popularization and/or training;

(b) Establish a regional "technical group" to introduce the Guidelines to the region;

(c) Use the Guidelines as a tool for advocacy, interpretation, monitoring abuse and establishing best practice;

(d) Prepare regular reports on the implementation of the Guidelines to human rights bodies (human rights treaty bodies and United Nations extra-conventional fact-finding mechanisms, such as special rapporteurs and representatives, as well as regional commissions) and other relevant international agencies;

(e) Bring cases of HIV/AIDS-related discrimination and other violations of human rights in the context of HIV/AIDS to regional human rights judicial and quasi-judicial mechanisms.

32. NGOs at the national level, in order to advocate the Guidelines, should obtain consensus on their acceptance and establish a joint strategy with governmental and non-governmental partners as a baseline for monitoring the Guidelines, through the following means:

(a) Hold national NGO strategy meetings on the Guidelines that include human rights NGOs (including women's organizations and prisoners' rights organization), ASOs, community-based organizations, networks on ethics, law, human rights and HIV and networks of people living with HIV/AIDS;

(b) Hold meetings with national governmental human rights organisms;

(c) Hold meetings with national Government (relevant ministries), legislative and judiciary;

(d) Establish or use existing national focal points to gather information and develop systems of information exchange on HIV and human rights, including the Guidelines.

Commission on Human Rights Resolution

Since the Guidelines were adopted, the United Nations Commission on Human Rights passed resolution 1997/33,

- emphasizing, "in view of the continuing challenges presented by HIV/AIDS, the need for intensified efforts to ensure universal respect for and observance of human rights and fundamental freedoms for all to reduce vulnerability to HIV/AIDS and to prevent HIV/AIDS-related discrimination and stigma;"

- welcoming the report of the Secretary-General on the Second International Consultation on HIV/AIDS and Human Rights (E/CN.4/1997/37);

- inviting all States to consider the Guidelines;

- calling upon the United Nations High Commissioner for Human Rights, the Joint United Nations Programme on HIV/AIDS (UNAIDS), its co-sponsors and other partners to provide technical cooperation to States, upon the request of Governments when required, from within existing resources, with regard to the promotion and protection of human rights in the context of HIV/AIDS; and

- requesting the Secretary-General to solicit the opinion of Governments, specialized agencies, and international and non-governmental organizations and to prepare for consideration of the Commission at its fifty-fifth session a progress report on the follow-up to the present resolution.

Follow-Up

Too many guidelines and declarations on HIV/AIDS and human rights have been adopted in the past, without being implemented by States and, often, without even being known to community groups - although they could so well use them in their fight for responses to HIV/AIDS that respect the human rights of those affected by or living with HIV/AIDS. By including strategies for dissemination and implementation, the new Guidelines on HIV/AIDS and Human Rights have a better chance of influencing policy- and law-making on HIV/AIDS. They certainly deserve a better fate than their predecessors.

Future issues of the *Newsletter* will provide more information about the Guidelines and how to use them. The full text of the Guidelines on HIV/AIDS and Human Rights is available for browsing and retrieval at http://www.unhchr.ch. The Guidelines will also be issued as a United Nations publication, in all official languages of the United Nations.

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ENDNOTES

[1] The following text has been adapted from the Report of the Secretary-General, Commission on Human Rights, Fifty-third session, item 9(a) of the provisional agenda. United Nations publication E/CN.4/1997/37 of 20 January 1997.

[2] The first International Consultation on AIDS and Human Rights, organized by the United Nations Centre for Human Rights, in cooperation with the World Health Organization, had been held in Geneva from 26 to 28 July 1989. In the report of the first consultation (HR/PUB/90/2), the elaboration of guidelines on HIV/AIDS and human rights had already been proposed.

[3] Supra, note 1.

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Supreme Court to Hear *Cuerrier* Case

On 24 April 1997, the Supreme Court of Canada announced that it will hear the *Cuerrier* case – a criminal case involving a man from British Columbia who was accused of having unprotected sex with two women although he knew that he was HIV-positive. Both at trial and on appeal, the courts held that the man's acts of engaging in unprotected sex were reprehensible, but that the charge that had been laid against him – aggravated assault – did not apply to his conduct; he was therefore acquitted. It is now up to the Supreme Court to decide whether having unprotected sex knowing that one is HIV-positive, and without disclosing this to one's partner, constitutes "sexual assault." For persons living with HIV/AIDS in Canada, this may be the most important case ever to be decided by the Supreme Court.

The Facts[1]

In August 1992, Henry Cuerrier received the news from a BC health unit that he had tested HIV-antibody positive. Cuerrier was informed about the implications of this result, including the need to use condoms for sexual activity. He indicated he was aware of the ways in which HIV could be transmitted, but stated to the public health nurse that he could not disclose his status in the small community he was living in, and refused her offer to notify his sexual partners without disclosing his name.

About three weeks after receiving his results, Cuerrier began a relationship with KM, during which they frequently engaged in unprotected vaginal sex. At the beginning of this relationship, in response to KM's questions, Cuerrier indicated he had had a number of recent sexual encounters with women who had themselves had many sexual partners. KM did not specifically ask about HIV, but Cuerrier told her he had tested negative eight or nine months earlier; he did not tell her that he had tested positive within the past month.

In January 1993, Cuerrier and KM both attended an STD clinic and were tested. At that time, Cuerrier was asked if he had ever been tested previously; he responded that he had not. KM tested negative. Cuerrier was informed that his test had returned positive and advised of the risk of transmission to KM and the importance of using condoms. KM was then called in and informed of Cuerrier's test results. Cuerrier again said he did not wish to use condoms.

Cuerrier and KM continued in their relationship for another 15 months, during which time they continued to have occasional unprotected sex. KM testified that she loved Cuerrier, and that by that point she felt that it was likely she would soon test positive for HIV, given the unprotected sex they had already had.

In May 1994, the same public health nurse spoke by phone with Cuerrier to reiterate that it would be "preferable" for him to disclose his status to sexual partners and that he should use condoms. According to the nurse, Cuerrier stated he clearly understood the importance of practising safer sex, and "the legal implications of not complying and wilfully putting another individual at risk for HIV infection." This conversation was followed up with a hand-delivered letter in June 1994. At the same time, the nurse delivered an order from the Medical Health Officer that Cuerrier inform his sexual partners of his HIV status, use condoms, and meet quarterly with the public health nurse to confirm compliance with this order.

A second woman began a relationship with Cuerrier in June 1994, but ended it soon thereafter once she discovered he was HIV-positive.

The Trial

Cuerrier was indicted in November 1994 and charged with two counts of aggravated assault. [Section 268 of the *Criminal Code* provides that a person commits an aggravated assault when he or she wounds, maims, disfigures or endangers the life of a complainant. The term "assault" is defined in s 265 of the Code: a person commits an assault when, without the consent of another person, he or she applies force intentionally to the other person, directly or indirectly. For the purposes of s 265, no consent is obtained where the complainant submits or does not resist by reason of the application of force to the complainant or to another person. Consent is also vitiated by fraud or by threats or fear of the application of force to the complainant or to another person.] As of trial, both complainants had tested HIV-negative. At the end of the Crown's case, as in *Ssenyonga*,[2] the defence made a motion for a directed verdict of acquittal, on the ground that the Crown had not made out the offence of assault because the complainants had consented to the unprotected sex.

Drost J cited the decision of the Supreme Court of Canada in *Thornton* in concluding that the accused's acts of engaging in unprotected sex "endangered the lives" of the complainants and therefore could constitute aggravated assault. However, he noted that the facts and arguments in the case were virtually identical to those in *Ssenyonga*, and adopted the reasoning of McDermid J in that case in directing an acquittal on both counts.[3]

Appeal

The Crown appealed the acquittal, advancing the same arguments that had been put forward in *Ssenyonga*:

- the complainants' consent was vitiated by fraud;
- the complainants' consent was of no effect because it was not informed consent;
- the complainants' implied consent did not extend to the risk of HIV transmission; and
- the complainants' consent should be invalid on public policy grounds.

Both the British Columbia Civil Liberties Association and the Persons with AIDS Society of British Columbia were granted leave to intervene. In November 1996, a panel of five judges of the British Columbia Court of Appeal released its judgment dismissing the Crown's appeal. It ruled that conduct that creates a risk of HIV transmission cannot "reasonably be dealt with under the assault provisions of the Criminal Code."[4]

Consent Vitiated by Fraud

Reviewing the legislative and jurisprudential history, the Court concluded that

- Canadian law, like English and Australian law, only recognizes fraud as to the "nature and quality of the act" (or the identity of the offender) as vitiating consent to engage in sexual activity; and
- before and after the 1983 revisions to the *Criminal Code*, the "fraud" referred to in the assault provisions did not and does not extend so far as to cover any fraud "which has a causal connection with the giving of consent."[5]

Madam Justice Prowse (speaking for the majority) agreed with counsel that the language in which many of the judges in *Clarence* (the decision at the origin of this restricted view of "fraud")[6] framed their judgments reflects an attitude toward men and women and their relationships with one another that is outdated. However, she noted that

> while Clarence involved the infection of a woman by a man, the issue facing us in this case is one which equally affects men and women. The passages from the judgment of Stephen J. which I have quoted ... foreshadow contemporary concerns about the adequacy of the criminal law of assault to deal with the spread of contagious disease. They also reflect the problems inherent in attempting to draw lines separating private sexual

> behaviour which is truly consensual from that which is not.

Informed Consent

In response to the Crown's submission that the complainants' consent to sexual intercourse with Cuerrier was not legally valid because they were not informed about his HIV status, the Court noted: "In effect, he asks this Court to do what the trial judge declined to do, namely, to import the concept of informed consent from tort law into the criminal law." The Crown sought to rely on the judgment of LaForest J in the civil case of *Norberg v Wynrib*,[7] in which the plaintiff sued her physician for sexual assault, negligence, breach of fiduciary duty and breach of contract, after he exploited her drug dependency during the course of treatment by agreeing to supply her with drugs in return for sex. LaForest J, writing on behalf of Gonthier and Cory JJ as well, found the physician's liability sounded in the tort of battery because the plaintiff's apparent consent to sex with her doctor was not legally effective because of the extreme power imbalance between the parties and the exploitation of that imbalance by the defendant doctor. Citing LaForest J's approach, the Crown argued that Cuerrier had deprived the complainants of the knowledge that he was HIV-positive, which they required in order to make "an informed and autonomous choice"; therefore, a power imbalance existed between Cuerrier and his sexual partners analogous to that described by LaForest J in *Norberg*. The *Criminal Code* provides that there is no consent to sexual activity when the accused "induces the complainant to engage in the activity by abusing a position of trust, power or authority" (s 273.1(2)(c)).

However, Prowse JA concluded that the facts in *Cuerrier* could not satisfy the test set out by LaForest J (which in any event did not represent the view of a majority of the Supreme Court):

> In my view, the fact that Mr. Cuerrier withheld information concerning his medical condition from the complainants does not give rise to the combination of power imbalance and exploitation contemplated by LaForest J. in Norberg. LaForest J. made a point of confining his comments to the facts before him and to the nature of the action, which was one in tort. While the facts in Norberg might well have given rise to a similar result in a criminal context, bearing in mind s. 273.1 of the Code, the nature of the relationship between Mr. Cuerrier and the complainants in this case is significantly different from that of the plaintiff and the defendant in Norberg.

Prowse JA proceeded to express reservations about LaForest J's approach:

> Further, as a matter of policy, I have grave reservations about importing the concept of informed consent, as it has been developed primarily in medical malpractice cases, into the criminal law of assault. There is a recognized legal duty on a doctor to inform his or her patient of risks associated with medical procedures in order to permit the patient to give an informed consent to treatment. There is no recognized duty, enforceable through the criminal law power of the state, which requires a person to provide full disclosure of all known risks associated with sexual intercourse to his or her sexual partner as a

> condition precedent to the partner giving an effective consent to sexual intercourse. The criminal law of assault is, indeed, an unusual instrument for attempting to ensure safe sex. I share the trial judge's reluctance to have recourse to concepts of informed consent developed in civil proceedings in circumstances such as those confronting us here.

Limits of Implied Consent

In several cases, courts have permitted assault convictions for excessive force in sports activities necessarily involving some degree of physical contact; while players consent to a certain degree of force, they are not held to have provided an unlimited consent to any degree of force being applied.[8] In *Cuerrier*, the Crown argued by analogy that in consenting to have sex with Cuerrier, the complainants did not implicitly consent to the risk of transmission of HIV. Prowse JA concluded:

> While I do not disagree with that statement, I do not think that it assists the Crown's case. I agree with the trial judge that the "sports" cases focus on the degree of force applied to the participant in the activity. In this case, there is no evidence that the sexual acts engaged in by Mr. Cuerrier and the complainants involved any more force than is naturally inherent in the sexual act. The concern here is not one of excessive force, but one of withholding information. In that respect, this submission is similar to the Crown's submission with respect to informed consent. Taken to its logical conclusion, it seeks to impose criminal liability on an accused for failure to make full disclosure of any information which could reasonably be relevant to the question of whether the complainants would consent to sexual intercourse. Like the trial judge, I am of the view that such an approach is fraught with difficulties insofar as the criminal law of assault is concerned. I would not be prepared to extend the reasoning of the "sports" cases to circumstances such as these.

Public Policy Grounds

The Crown's final submission was that the complainants' consent was ineffective for public policy reasons. In *Jobidon*,[9] the Supreme Court concluded that the consent of adults to engage in the intentional application of force during the course of a fistfight would be vitiated at common law, for public policy reasons, where that force caused serious hurt or nontrivial bodily harm. The Crown argued by analogy that public policy should vitiate consent to sexual intercourse that creates a risk of HIV transmission, at least in situations in which the accused is aware of the risk and conceals it from the complainants. However, the BC Court of Appeal ultimately rejected this argument, noting that, unlike *Jobidon* and other cases dealing with the infliction of bodily harm in the course of sadomasochistic sexual activity,[10] the complainants in *Cuerrier* did not actually suffer physical injuries but were, rather, exposed to the risk of injury. As of the appeal, neither complainant had tested HIV-positive.

Prowse JA also noted the following submissions by the intervenors:

- historically, criminal sanctions have been ineffective in proscribing and limiting human sexual behaviour;

- unlike brawling, consensual sex serves a positive social purpose;

- noncoercive responses by governments such as education and promoting voluntary HIV testing, rather than criminal sanctions, would be of greater benefit in reducing the spread of HIV;

- criminalization of behaviour creating the risk of HIV transmission would have the likely effect of targeting marginalized groups in the high-risk category, including gays, prostitutes, and intravenous drug users; and

- public health measures are best suited to deal with people unable or unwilling to take precautions to change risky behaviour that threatens the safety of others.

Prowse JA concluded that the effect of vitiating consent in these circumstances would be to transform sexual intercourse into aggravated assault. This, in her view,

> would stretch the bounds of the law of assault beyond reasonable limits in order to achieve an end it was never designed to meet. I am also reluctant to create a further category of conduct which would vitiate consent in these circumstances, since to do so would come perilously close to creating a new offence, with Mr. Cuerrier being the first Canadian to suffer the consequences. One of the purposes of the criminal law and its codification is to warn the public in advance of the type of behaviour which will subject them to criminal sanction. ... It is contrary to basic criminal law principles to brand behaviour criminal, with all that entails, after the fact. ... In the result, I conclude that, to the extent that the criminalization of conduct creating a risk of the transmission of HIV is considered to be in the public interest, the assault provisions of the Code are not well-suited to the task.

Both the majority judgment and the separate concurring judgment of Williams JA suggest that Parliament consider an offence specifically designed to criminalize conduct such as Mr Cuerrier's:

- Prowse JA concludes that "Parliament is in the best position to strike the appropriate balance between the competing interests of promoting public health initiatives to control the spread of HIV, deterring harm-risking conduct, and protecting individual autonomy."

- Williams JA wrote: "The conduct of the appellant in this case is absolutely reprehensible and in my view deserving of some criminal sanction. Parliament has not seen fit to enact amendments to the Criminal Code which would clearly apply to the conduct of the accused in this case and in my view the Criminal Code as it now stands contains no provision which does."

The Appeal to the Supreme Court

Why is this case so important? As mentioned above, the Supreme Court will have to decide whether having unprotected sex knowing that one is HIV-positive, and without disclosing this to one's partner, constitutes "sexual assault." Regardless of the outcome of the case, there will be a lot of pressure on Parliament to amend the *Criminal Code* to create an offence specifically dealing with behaviour that puts people at risk of contracting HIV and/or other infectious diseases. As shown in *Criminal Law and HIV/AIDS: Final Report*,[11] this could have devastating effects for all persons living with HIV/AIDS and for efforts to prevent the spread of HIV in Canada.

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ENDNOTES

[1]Reprinted, in slightly edited form, from R Elliott. *Criminal Law and HIV/AIDS: Final Report*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1997, Appendix B.

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[3][1996] BCJ No. 2229 (BCCA) (QL); aff'g Court File No CC941279, unreported decision of 5 January 1995, Supreme Court of British Columbia (Vancouver), Drost J.

[4]*R v Cuerrier*, [1996] BCJ No. 2229 (BCCA) (QL).

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[6](1888), 22 QBD 23, [1886-1900 All ER Rep 133].

[7][1992] 2 SCR 226.

[8] *R v Cey* (1989), 48 CCC (3d) 480 (Sask CA); *R v Leclerc* (1991), 67 CCC (3d) 563 (Ont CA).

[9] [1991] 2 SCR 714, 66 CCC (3d) 454.

[10] *R v Brown*, [1993] 2 All ER 75 (HL); *R v Welch* (1995), 43 CR (4th) 225 (consent is not a defence to sadomasochistic sexual activity that results in bodily harm).

[11] Supra, note 1.

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Testing of Pregnant Women: Issues and Options

For many years, legislators and policymakers, particularly in the United States, but increasingly in Canada, have been debating how to offer HIV counselling and testing to pregnant women.

Four main options have been considered:

- HIV counselling and testing of pregnant women only in the presence of risk factors or on request (option 1);
- routinely offering the opportunity to undergo an HIV test during pregnancy and counselling about the advantages and disadvantages of HIV testing (option 2);
- routine testing of all pregnant women, with a possibility of opting out (option 3); and
- mandatory HIV counselling and testing of all pregnant women (option 4).

This article, a slightly revised version of the section on testing of pregnant women of *HIV Testing and Confidentiality: A Discussion Paper*,[1] discusses these options, concluding that the best option is routine HIV counselling and voluntary testing of all pregnant women, and that all Canadian provinces and territories should adopt policies to that end.

In addition, the article urges policymakers to broaden the debate. Rather than focus efforts to increase access to testing for women nearly exclusively on pregnant women – which makes it seem as if there is less concern about the welfare of women than for that of their children or potential children – it will be necessary to ensure that efforts encompass all women and take their needs, knowledge and varying life situations into consideration: testing policies for all women, whether pregnant or not, need to be related to women's real-life situations.

History

The debate about whether pregnant women should be mandatorily tested for HIV has changed significantly over the last years. For a pregnant woman, knowing her HIV status is now significantly more useful than in the 1980s and early 1990s:

- women testing positive can benefit from new treatments; and,
- since 1994, it has been known that treatments can significantly reduce the risk of HIV transmission from mother to child.

Before 1994

Initially, knowledge about HIV and pregnancy was scarce. Evidence suggested that about one-third of babies born to women who were HIV-positive prior to pregnancy would be HIV-positive themselves, and there was fear that pregnancy might accelerate the development of AIDS in women who were HIV-positive but asymptomatic. In addition, breast-feeding by HIV-positive women was discouraged because of the potential for HIV transmission. Due to a lack of information, the potential benefits of mandatory HIV testing were limited. As expressed by Field,

> [w]hile states undoubtedly have a strong interest in decreasing the number of children born with HIV infection, it is unclear how mandatory testing of pregnant women would serve that goal. Once a woman is pregnant, the test can help contain HIV only if it leads to abortion.[2]

Field continued by saying that "the spectre of the state encouraging or requiring abortion based on positive test results is a frightening one indeed." According to her, mandatory testing should not be contemplated: first, because the child of an HIV-positive woman is more likely to be HIV-negative than to be HIV-positive; and second, because requiring abortion would run counter to a woman's fundamental right to make decisions concerning procreation. There was general consensus that testing without informed consent offered no advantage over voluntary testing and counselling programs designed to assist women in making decisions about childbearing and/or breast-feeding. As stated by WHO,

> [t]hose women who want to know if they are infected before making such decisions generally would participate in voluntary testing and counselling programmes. Furthermore, not only is it unethical to pressure or force women to make reproductive or breast-feeding decisions for any reason, including their HIV infection status, but those women most likely to be HIV-infected may try to avoid mandatory testing, precisely in order to avoid pressure in such decision-making. Such avoidance may have the additional unwanted result of discouraging pregnant women from attending antenatal services.[3]

For the same reasons, in Canada, in 1988 the National Advisory Committee on AIDS concluded that mandatory or compulsory prenatal HIV-antibody screening was "not necessary."[4] In 1992, the Ontario Law Reform Commission pointed out that the testing of pregnant women would not significantly further any public health objective to prevent the spread of HIV because, at that time, no available treatment could prevent perinatal transmission or effectively treat asymptomatic HIV-positive infants. Therefore, the Commission concluded that "no exception to a general rule requiring voluntary, specific, and informed consent for all HIV-related testing is justified respecting pregnant women."[5] In practice, HIV counselling and testing was most often offered only to pregnant women considered by their physicians to be at risk for HIV, or was provided at the specific request of the patient herself.

Since 1994

In 1994, researchers at the (US) National Institutes of Health and its collaborators announced results from a randomized clinical trial (ACTG 076) indicating that antiretroviral medication provided to pregnant women during pregnancy, labour and delivery and to the newborn baby during the first six weeks of life can dramatically reduce the risk of mother-to-child transmission of HIV infection. Studies in France, the United States and Canada have confirmed a reduction in transmission from 25 percent or more to 8 percent or even less.[6]

Due to these new developments, the Canadian Medical Association now recommends offering HIV testing and counselling to all pregnant women.[7] Furthermore, some Canadian provinces have changed their (formal or informal) testing policies with regard to pregnant women, from offering testing only when a particular woman presented risk factors for HIV (option 1) to routinely offering the opportunity to be tested to every pregnant women (option 2). No Canadian province has thus far implemented a policy of routine or mandatory HIV testing of pregnant women (options 3 and 4). Several provinces have not as yet changed their policies, but are considering doing so in the near future.

Current Situation

The following is an overview of the (formal or informal) testing policies of the Canadian provinces and territories.

Newfoundland

In Newfoundland a policy recommending that all pregnant women have an HIV test and that physicians discuss the option of HIV testing with their patient during their prenatal visits has been in place since 1992. Approximately three-quarters of all pregnant women are being tested. The province is, however, considering moving toward a policy that would include testing for HIV as part of the routine antenatal laboratory tests.[8]

Prince Edward Island

There is no formal policy for testing of pregnant women in Prince Edward Island, but it is recommended that any woman who presents with risk factors for HIV be screened. The lack of a formal policy might in part be explained by the fact that a two-year seroprevalence study reported a prenatal seroprevalence rate of zero percent.[9]

Nova Scotia

Nova Scotia has no formal policy for testing pregnant women. However, the province has put forward recommendations strongly encouraging physicians to explore the risk factors with their patients and to provide them the option of being tested. The recommendations do not support mandatory testing and are premised on the assumption that pre- and post-test counselling, in conjunction with education programs, will facilitate "self-identification."[10]

New Brunswick

New Brunswick has no formal policy for testing of pregnant women. Whether a woman is tested and how the testing is conducted will vary from region to region. In most regions, reproductive health clinics offer pre-test counselling and anonymous testing to pregnant women. However, in one region the medical director of health has stated that reproductive health clinics in his region are no longer permitted to test pregnant women for HIV and that, if a pregnant woman wishes to be tested, she will have to be seen by her physician. This statement is significant not only because of its direct effect on women living in that particular region of New Brunswick, but also because of its potential impact on the decisions made by the medical officers of health in other regions of the province.

Outside the reproductive health clinic setting, testing of pregnant women is done by physicians on a discretionary basis. It is believed that some physicians may be testing women for HIV as part of the routine prenatal tests without their informed consent. Based on a seroprevalence study conducted by the University of New Brunswick Faculty of Nursing, doctors were sent a letter suggesting that they offer HIV testing to all pregnant women.[11]

Québec

In Québec, a new program that aims at offering the opportunity to undergo an HIV test during pregnancy to every pregnant woman and to every woman who wishes to become pregnant, was launched in the fall of 1996. Under the new program, the "indication for HIV testing during pregnancy will no longer be restricted to the presence of risk factors or patient request but will be simply the condition of pregnancy itself or the desire to conceive."[12] Discussion of HIV testing should occur as early as possible to permit "a full range of choices." At the first prenatal visit, attending physicians will provide pregnant women with information on the advantages and disadvantages of undergoing HIV testing during pregnancy in order to assist them in making a decision about the test and to explain testing conditions. At subsequent visits, physicians will conduct HIV risk evaluation, counselling and education as appropriate for each patient. The program emphasizes that women who are found to be HIV-positive require counselling concerning pregnancy interruption or continuation. Women who decide to continue with their pregnancy have the option of taking antiretroviral medication such as AZT, ZDV or 3TC, which are provided free of charge.

Ontario

In Ontario there is no formal policy governing testing of pregnant women, but the Ontario Advisory Committee on HIV/AIDS Testing of Pregnant Women For HIV and Use of Zidovudine recommended that HIV testing should be discussed with all pregnant women and all women considering pregnancy so that they can make a knowledgeable decision about being tested. All such testing must be done with pre- and post-test counselling and informed consent, as is the standard for all HIV testing in Ontario.

Similarly, the Chief Medical Officer of Health recommended that "HIV antibody testing be discussed with all pregnant women and women considering pregnancy. HIV antibody testing should be made available to any woman who requests it." This statement must, however, be considered within the context of the Chief Medical Officer of Health's further assertion that "[t]esting pregnant women with any risk factor for HIV infection is critically important. ... The success of this approach to the prevention of maternal–fetal HIV transmission depends on the ability of health care providers to identify women at increased risk."[13] Read in its entirety, the message being put forward suggests that the primary focus is to be placed on the identification of risk factors and not on the voluntary testing of all pregnant women and women considering pregnancy.

Manitoba

In 1994, Manitoba adopted a policy stating that all physicians should offer pre-test counselling and HIV testing to all pregnant women, and that the voluntary choice to be tested is to be based on informed consent.[14]

Saskatchewan

Saskatchewan has published guidelines for the prevention of perinatal transmission. The guidelines support testing on a voluntary basis and recommend that all physicians offer pre-natal counselling to their patients. They further state that physicians must be aware of any risk factors that a patient may present and suggest that if a patient exhibits any risk factor she should be offered counselling and the option of being tested.

Based on the results of an 18-month unlinked prenatal seroprevalence study – which detected a seroprevalence rate of 3 per 10,000 – the Province does not believe it necessary to change its policy with respect to the testing of pregnant women.[15]

Alberta

In Alberta the provincial branch of the Canadian Medical Association has appointed a working group to examine the possibility of developing a program of routine screening for pregnant women. If such a program were to be implemented, testing for HIV would be added to the list of prenatal screening assays and women would only have the choice of opting out. In other words, if they did not request that the test not be conducted, it would automatically be done.[16]

British Columbia

British Columbia was the first province to "strongly recommend" that all pregnant women be tested for HIV as a routine component of prenatal care. According to a press release of 29 June 1994, physicians in the province are advised to counsel all pregnant women about the advisability of being tested for HIV at the beginning of each pregnancy. The press release continues by saying that it is "not safe to assume that a woman who was HIV-negative in her previous pregnancy will remain so for subsequent pregnancies." It emphasizes that testing must be accompanied by adequate counselling and informed consent.[17]

A poster presented at the XI International Conference on AIDS gave an early assessment of the policy's impact. The conclusion was that

> recommending routine screening of all pregnant women has proven to be helpful and cost effective. We have prevented 2 infections in the first year. As sero prevalence rates in women increase, the benefit should be even greater.[18]

Yukon

In Yukon, for several years HIV testing has been recommended for all pregnant women, regardless of risk factors.[19]

Northwest Territories

In the Northwest Territories, doctors are routinely suggesting HIV testing to pregnant patients.[20]

Assessment

Counselling in the Presence of Risk Factors (Option 1) versus Routine Counselling and Voluntary Testing (Option 2)

Under option 2, health-care providers routinely offer pregnant women the option of HIV testing, counsel them about advantages and disadvantages of HIV testing, and leave the decision of whether to test to the women. Should a woman request to be tested and test positive, the choice of how to proceed with her pregnancy is her own: she may decide to continue her pregnancy without taking treatments aimed at reducing the risk of transmission to her child, she may take those treatments, or she may decide to abort.

Option 2 expands the offer of counselling and testing to all pregnant women, rather than only to those perceived to be at risk (option 1). As shown above, it has become official policy in some Canadian provinces, in particular in British Columbia and Québec. Professional associations such as the CMA, the Society of Obstetricians and Gynaecologists of Canada, the College of Family Physicians of Canada, the Collège des médecins du Québec, as well as community-based organizations such as the Coalition des organismes communautaires de lutte contre le sida (COCQ-sida), have approved of the concept of offering voluntary HIV testing to all pregnant women.[21]

There can be no doubt that, at this stage of the epidemic, this approach is preferable to an approach under which only women considered to be at risk are offered HIV counselling and testing. Several studies have shown that the latter approach fails to identify a high proportion of HIV-positive women.[22] Women are frequently not tested either because they are unaware of their risk for HIV infection or because they are reluctant to disclose potentially stigmatizing behaviour. In contrast, routinely offering counselling and testing will provide the benefits of counselling to all pregnant women and increase the number of women who will agree to be tested. In order to enhance the effectiveness of this approach, it should be accompanied by provision of information and education to physicians and other health-care providers about the importance of routinely counselling pregnant women and offering them HIV testing. For example, in Québec, physicians and other health-care providers will receive an information kit detailing the rationale for the program, standard procedures to follow, and referral resources.

Routine Testing (Option 3)

Under this approach, the HIV test would simply be added to the list of prenatal laboratory tests, but pregnant women would be given the option to refuse HIV testing by "opting out." Those who advocate for this approach argue that HIV should not be treated differently than other diseases for which prenatal tests are routinely undertaken, and that this approach would likely lead to an increase in the number of pregnant women being tested. However, as shown in *HIV Testing and Confidentiality: A Discussion Paper*, the new treatments notwithstanding, HIV is still very different from other diseases, requiring that HIV testing be undertaken only with the specific informed consent of the person being tested and only when pre- and post-test counselling is undertaken. There is no reason to make an exception to this principle in the case of testing of pregnant women. Indeed, it would seem that obtaining a pregnant woman's consent and counselling her before and after the test is particularly important. Testing is not a goal in itself: if it is to be beneficial, a pregnant woman testing HIV-positive will have to accept antiretroviral therapy for her own and – should she decide to continue her pregnancy – for the child's benefit. Under Canadian law, the decisions to interrupt or continue pregnancy, and to undergo treatment, are voluntary decisions. The sooner a pregnant women is informed about the advantages and disadvantages of testing and available treatments, the more likely she is to make decisions that will ultimately benefit herself and – if she continues her pregnancy – her child. In contrast, routinely testing without offering women the benefits of counselling may adversely affect the patient–provider relationship that is critical to the woman's ongoing care:

> The purpose of HIV testing is not to label a woman as infected, but to engage her and her

> child in appropriate health care. This is most likely to occur when a woman feels she has participated in decisions regarding her own and her child's health.[23]

In addition, several studies have shown that when pregnant women are informed of the benefits of HIV testing and when testing is recommended by their health-care providers, most accept it.[24] Routine testing may have few if any benefits, while it deprives pregnant women of the benefits of pre-test counselling and early involvement in decisions that are ultimately their own.

Mandatory Testing (Option 4)

> As treatment with ZDV cannot and should not be coerced, the 076 results do not compel involuntary testing without informed consent and abrogation of patient privacy.[25]

> Compulsory testing could drive women away from seeking prenatal care at all. If you want women to take AZT four times a day for six months, plus take it intravenously during labor, plus give it to their babies for six weeks afterward, is coercion the way you want to start?[26]

> Mandatory testing proposals will not work to improve the well-being of newborns living with or at-risk for HIV because they will not work to improve the well-being of their mothers. They undermine, rather than support, the provider–patient trust relationship that is essential to obtaining appropriate care and services.[27]

Under a mandatory testing regime, all pregnant women would be tested for HIV, without having the possibility of opting out. The arguments in favour of and against such an approach are substantially the same as those in favour of and against routine testing. Calls for mandatory testing are the result of the fact that treatments are available that can substantially reduce the risk of HIV transmission from mother to child. Thus, it is argued, every pregnant women should be tested for HIV and, if HIV-positive, should undergo treatment. In particular, some pediatricians and neonatologists are frustrated about the fact that many HIV-positive pregnant women have not been identified, thus forgoing their chance of taking AZT to reduce the risk of transmission from mother to baby:

> As a pediatrician who has been a part of this epidemic from the very beginning, I must admit that I am personally disappointed that there was not unanimous support for providing lifesaving treatment to as many infants as possible, as soon as possible.[28]

Proponents of mandatory testing point out that (1) in many jurisdictions in North America, pregnant women are already routinely screened for diseases that could jeopardize the health of the newborn, such as syphilis and hepatitis B,[29] and (2) only a mandatory testing regime will ensure that *all* pregnant woman will be tested for HIV. In 1996, proponents were joined by the American Medical Association, which abandoned its prior recommendation of routine counselling but voluntary testing, and now advocates mandatory testing of all pregnant women (but only where opportunities for counselling and treatment are available to those tested).[30]

However, the argument that routine screening is already being done for a list of other diseases and that this should serve as a precedent for adding HIV to the list, fails to address the question of whether the practice of routine screening in and of itself is justified. It may well be argued that mandatory prenatal screening of women is a violation of the rights of pregnant women.

Furthermore, as pointed out above, testing is not a goal in itself, and testing *all* pregnant women for HIV will not and cannot ensure that all HIV-positive women will undergo treatment to reduce the risk of transmission to their children: the decision to undergo treatment remains a voluntary decision that should be made by a woman herself, after she is made aware of the risks and benefits associated with treatment. As Bayer argues, pregnant women have a right to decide whether or not they will take medication even if the decision not to means that their babies will have a higher chance of being born with HIV infection. "I say that as a matter of moral principle. I don't think anyone ever have a right to force medication down someone's throat."[31]

Bayer continues by pointing out that there is also a practical issue:

> This AZT protocol requires that people take medication five times a day for almost two-thirds of their pregnancy. There is no way short of incarceration that you can make someone take medication five times a day if they don't want to take it. On practical grounds and on moral grounds, we would be on much stronger ground if we were to develop programs to encourage women at high risk to come in to get tested and urge them to start AZT treatment, not coerce them.[32]

In addition, mandatory testing may be counterproductive because, as pointed out above, it may adversely affect the patient–provider relationship that is critical to the women's ongoing care. Furthermore, women who do not wish to be tested may avoid prenatal care entirely if HIV testing is not clearly voluntary. As Cooper says,

> there is no data to indicate that mandatory testing programs will work to bring mothers and their newborns into care. In fact, past history reflects a resistance to mandated testing, name reporting, or undue governmental interference in the health care setting.[33]

Finally, while treatment has great potential benefits, it may have some unknown risks. As Lazzarini says, "we don't know all the wrinkles of AZT yet – its potential harm to the baby, its long-term effects on women who take it while pregnant, or its effectiveness on women at all stages of HIV disease."[34] Thus far, there have been no reports of adverse effects of AZT on the children in ACTG 076, but a database has been established to accumulate data on their development over the next twenty years.[35] In January 1997, new evidence that the offspring of mice given high doses of AZT during pregnancy are at risk for cancer raised concern about the use of the drug for HIV-positive pregnant women. The US

National Institutes of Health assembled a panel of AIDS and cancer patients to develop guidelines on the use of AZT during pregnancy. The panel overwhelmingly stated support for the old US guidelines encouraging the treatment of HIV-positive pregnant women and their babies to reduce the risk of HIV transmission from mother to baby. The panel pointed out that while high doses of the drug caused cancer in the baby mice, pregnant women take much lower doses.[36] The panel concluded that the theoretical risks represented in the study that provided the new evidence are far outweighed by the significant known reduction in risk of transmission from mother to baby. In addition, it recommended continued evaluation of the available data and re-evaluation of the programs currently in place to provide ongoing monitoring of children born to mothers who were treated with AZT.[37] Nevertheless, the concerns about possible limits and side effects of treatments persist.

Conclusions

> The legal and ethical background for HIV testing in Canada requires respect for the conditions of informed consent, pre- and post-test counselling, and confidentiality. As with any other patient, pregnant women and women who are intending to conceive need to fully understand the advantages and disadvantages of HIV testing before deciding to undergo the test. The discovery of a seropositive status has important implications for decisions to interrupt pregnancy, to take antiretroviral therapy should pregnancy continue, and to breastfeed – decisions which themselves are voluntary in Canada. The [Québec] provincial programme has been designed to meet the challenge of ensuring that all HIV-infected women who desire to continue a pregnancy are offered effective means to reduce the risk of HIV transmission to their babies while respecting the rights of all pregnant women, the majority of whom will not have HIV infection, to decide for themselves whether or not to be tested for HIV.[38]

Now that a treatment to lower the possibility of perinatal transmission has been found, the pressure to test pregnant women is great. In the rush to respond to this innovative therapy, there is a serious risk that the basic rights of the mother will be swept aside. As stated by Cooper, many of the proposed routine or mandatory testing programs may have been put forward with the best intentions, but they also reflect a confluence of the following factors:

> 1) people generally, and legislators in particular, are just plain tired of AIDS; especially in times of scarce resources, legislators look to take actions that, unfortunately, are not always positive; 2) the voices and needs of women generally ... are not sufficiently valued in the development of policy and the allocation of resources; 3) when children are involved, emotionalism prevails.[39]

Given the availability of treatment that can reduce the risk of perinatal transmission, there can be little doubt that pregnant women would be well advised to consider undergoing an HIV test. All pregnant women, and not only those considered at risk, should therefore routinely be offered HIV testing and counselled about the advantages and disadvantages of testing. Those provinces and territories that have thus far failed to implement a program of routine counselling and voluntary testing should follow the examples of British Columbia and Québec, and develop information kits detailing the rationale for the program, standard procedure to follow, and referral resources. At the same time, they should resist the temptation to make HIV testing a routine component of antenatal screening tests, or to implement mandatory HIV testing for pregnant women. Routine or mandatory testing is not justified. It is not the "least restrictive, least invasive, likely to be effective, reasonably available approach" because there is reason to believe that the vast majority of pregnant women will willingly undergo an HIV test when the risks and advantages of seeking such a test are fully explained to them: when properly informed and supported in their decision-making, pregnant women will do what is best for themselves and their babies without coercion. In addition, testing alone is not effective in achieving the goal of reducing HIV transmission from mother to child, and treatment cannot and should never be coerced.[40] Any mandatory intervention, including testing and mandatory treatment, would enormously interfere with the autonomy rights of pregnant women. It would predicate a voluntary treatment system on a mandatory testing program, an approach that is illogical and seems only to erode the likelihood that women can and will use the health-care system. In contrast, a voluntary system

> supports the provider–patient trust relationship, allowing a woman to make the best decisions for herself and for her family – regarding testing, use of antivirals, and treatment for herself and her newborn. This is the approach that deserves our support.[41]

The Broader Issues

Finally, while the debate about HIV testing of pregnant women rages and some Canadian provinces consider abandoning the principle according to which HIV testing should only be undertaken with the informed, specific consent of the person being tested, women who are not pregnant continue to find it difficult to access testing in their doctor's office. As the *Discussion Paper* points out,[42] one important barrier to women's access to testing is the misconception that women are not at risk of HIV infection. Of even greater concern is the fact that some women are dissuaded by their doctors from being tested. Counselling guidelines establish that counsellors should not attempt to talk people out of being tested, even when they – based on the discussions with the counsellor – appear to be at low risk.[43] Nevertheless, women have often been refused testing on the assumption that they are not at risk.[44] This raises important issues. As stated in the submission of the Canadian HIV/AIDS Legal Network to the Parliamentary Sub-Committee on HIV/AIDS,

> [o]ne striking feature of the debate on women and HIV/AIDS is its frequent preoccupation with women as mothers or as future mothers; it is comparatively rarely concerned about the women themselves and the many problems they face in dealing with HIV/AIDS. For example, while the issue of compulsory testing of pregnant women or of women of childbearing age is hotly debated, women who are not pregnant or of childbearing age still report that they find it difficult to access HIV testing. This raises the issue of whether there is less concern about the welfare of women than for that of their children or potential children. It will be necessary to ensure that women's needs and their "knowledge and ...

> varying life situations are systematically taken into consideration in the formulation of responses to the epidemic": so far, few, if any, policies and programs developed in response to HIV/AIDS "are related to women's real-life situations."[45]

If we are concerned about the welfare of the children of HIV-positive mothers, we need first and foremost to be concerned about the welfare of women – of HIV-negative women who are at risk of contracting HIV, and of HIV-positive women who often lack access to care, support, and treatment. Focusing on pregnant HIV-positive women because they risk transmitting HIV to their children means intervening too late and doing too little.

- *Ralf Jürgens*

> In all Canadian provinces and territories, all pregnant women – and not only those considered at risk of HIV – should be offered the opportunity to undergo an HIV test during pregnancy and counselled about the advantages and disadvantages of HIV testing. In contrast, coercive measures such as routine or mandatory testing of pregnant women involve an undue interference with the autonomy rights of pregnant women, and cannot be justified as a matter of law or medical necessity.
>
> - Conclusion 5, *HIV Testing and Confidentiality: A Discussion Paper*]

> The only time health officials pay attention to women is when they are pregnant. Why no special reports or plans to save local women with HIV?
>
> - Jennifer DePiero, ACT UP Philadelphia, 1997

> Women with HIV have challenging lives. We need housing, we need jobs, we need an end to the violence that plagues our lives and communities.
>
> - Anne Capone, Us Women, 1997

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[20]Communication with A Corveau on 27 August 1996.

[21]Québec Prenatal HIV Programme, supra, note 12 at 1-2.

[22]MB Barbacci et al. Human Immunodeficiency Virus Infection in Women Attending an Inner-City Prenatal Clinic: Ineffectiveness of Targeted Screening. *Sexually Transmitted Diseases* 1990; 00:122-126; LJ Fehrs et al. Targeted HIV Screening at a Los Angeles Prenatal/Family Planning Health Center. *American Journal of Public Health* 1991; 81: 619-622; D Gibb et al. Evaluating Antenatal HIV Testing in London, UK. Abstract Th.C.4615, presented at the XI International Conference on AIDS, 7-12 July 1996 (A survey of testing policies in London, England maternity units, showing that most maternity units offered HIV testing only to women considered at increased risk of infection or only on the request of the patient herself. Over a two-year period only two infected women were identified, while an estimated 154 HIV-positive women remained undiagnosed.) Meanwhile, in the state of North Carolina, a more aggressive approach was used to identify HIV-positive pregnant women and offer them treatment. By the end of the study, 90 percent of HIV-positive mothers were being identified before giving birth, whereas only 60 percent were being identified before. The rate of perinatal transmission was reduced from 21 to 9 percent (SA Fiscus et al. Perinatal HIV Infection and the Effect of Zidovudine Therapy on Transmission in Rural and Urban Communities. *Journal of the American Medical Association* 1996; 275(19): 1483).

[23]Rogers, Mofensen & Moseley, supra, note 6 at 81.

[24]MK Lindsay et al. Routine Antepartum Human Immunodeficiency Virus Infection Screening in an Inner-City Population. *Obstetrics and Gynecology* 1989; 74: 289-294; M Barbacci, JT Repke, RE Chaisson. Routine Prenatal Screening for HIV Infection. *Lancet* 1991; 337: 709-711. See also E Cooper. Mandatory HIV Testing of

Pregnant/Delivering Women and Newborns: A Legal, Ethical, and Pragmatic Assessment. Abstract We.D.491, presented at the XI International Conference on AIDS, Vancouver, 7-12 July 1996, with many references.

[25]CB Britton. An Argument for Universal HIV Counselling and Voluntary Testing of Women. *Journal of the American Medical Women's Association* 1995; 50(3&4): 85-86.

[26]Z Lazzarini, cited in S Abrams. Mandatory HIV Testing: The Search for a Quick Fix. *Harvard AIDS Letter* May/June 1995.

[27]Cooper, supra, note 24.

[28]A Ammann. Unrestricted Routine Prenatal HIV Testing: The Standard of Care. *Journal of the American Medical Women's Association* 1995; 50(3&4): 83-84.

[29]R Bayer, in: *HIV/AIDS: International Perspectives on Legal Issues and Human Rights*. Washington: National Council for International Health, 1995, at 33.

[30]American Medical Association Standard, adopted 27 June 1996. Members of the AMA agreed by a close vote in June 1996 to support mandatory HIV testing for pregnant women. That decision was reaffirmed by a wider margin later in 1996, after a committee of the AMA had asked for a new vote, hoping to reverse the initial decision. Dr WR Jones pointed out that the AMA also supports mandatory testing for people who donate blood, breast milk, organs, semen and ova, as well as for immigrants and military personnel, noting that HIV should be "depoliticized" and treated like other infectious diseases. In the US, voluntary testing continues to be supported by the Centers for Disease Control and Prevention, the American College of Obstetricians and Gynecologists, and other medical groups. See C Kent. AMA: Mandatory HIV Testing in Pregnancy. *American Medical News* 1996; 39(48): 6.

[31]Bayer, supra, note 29 at 33.

[32]Ibid.

[33]Cooper, supra, note 24. In addition, some have opposed mandatory testing schemes for pregnant women, saying that they would represent a waste of resources. They have suggested that money would be better spent on educational programs to prevent women from becoming infected in the first place, and that a mandatory testing regime would waste money on testing large numbers of expectant mothers who were never at any real risk of being infected. However, a US study that compared the cost-effectiveness of three approaches to prenatal testing (testing only those women perceived to be at risk of HIV infection; mandatory counselling of all pregnant women, with voluntary testing; and compulsory testing) concluded that compulsory testing would be the most economical approach. It was estimated that compulsory testing, by identifying more infected mothers, would prevent enough cases of perinatal transmission of HIV (thus avoiding the costs of caring for sick infants) to outweigh the costs of a universal testing scheme. The researchers cautioned, however, that the benefits indicated by their statistical model might be negated if a compulsory testing strategy brought about changes in the behaviour of the women to be tested, such as avoidance of medical services. See JW Thompson, ER Myers, KN Simpson. The cost-effectiveness of screening strategies to prevent vertical transmission of Human Immunodeficiency Virus. Abstract We.C.3590, presented at the XI International Conference on AIDS,

Vancouver, 7-12 July 1996.

[34]Cited in Abrams, supra, note 26.

[35]See J Fricke. A Conversation with Yvonne Bryson. *UCLA AIDS Institute: Perspectives* 1996; 4(1): 1 at 6.

[36]Panel to Review AZT Use During Pregnancy. *Washington Post* 1 January 1997 at A13.

[37]Recommendations Regarding Treatment of HIV-Infected Pregnant Women with AZT. PR Newswire, 14 January 1997.

[38]Québec Prenatal HIV Programme, supra, note 12 at 1.

[39]Cooper, supra, note 24.

[40]The state is generally not justified in interfering with the autonomy rights of pregnant women. While some very exceptional cases of abuse of the fetus may justify some interference, a case where a women merely refuses to consent to an HIV test and to treatment would present an even weaker case for intervening than the facts of a recent case in Manitoba in which a pregnant woman was pursuing an activity (drug use) that was actively and irreparably harming the fetus. Nevertheless, even in the Manitoba case the courts found that there were no lawful grounds on which the state could intervene (*Winnipeg Child and Family Services (Northwest Area) v D.F.G.*, Man QB, 13 August 1996, Schulman J, no CP 91-01-04256, unreported; rev'd, Man CA, 12 September 1996, no AH 96-30-02891, unreported; on appeal to SCC, no 25508). Merely refusing to consent to a diagnostic test and to treatment that may or may not ultimately benefit the fetus, presents only an indirect risk to the fetus, and is one that arises from nonfeasance, not malfeasance. The case for intervention would consequently be even weaker. Generally, Canadian law to date has determined that the fetus is not a person and is not entitled to legal recognition, making it very difficult to intervene in such cases.

[41]Cooper, supra, note 24.

[42]Supra, note 1 at 59ff.

[43]Ontario Ministry of Health. *HIV Antibody Testing: Guidelines for Pre- and Post-Test Counselling in Anonymous Testing*. Toronto: The Ministry, June 1992, at 3.

[44]Ibid at 3; communication with K Nallanagagam, Hassle Free Clinic (Toronto), on 23 August 1996; communication with J Cullingworth, Voices of Positive Women (Toronto), on 2 September 1996.

[45]R Jürgens. HIV/AIDS and Discrimination: A Brief to the Sub-Committee on HIV/AIDS of the House of Commons by the Canadian HIV/AIDS Legal Network. Montréal: Canadian HIV/AIDS Legal Network, 15 May 1996 (also available on the Network's website at http://www.aidslaw.ca), with reference to E Reid.

Gender, Knowledge, and Responsibility. In: JM Mann, DJM Tarantola, TW Netter (eds). *AIDS in the World*. Cambridge, MA: Harvard University Press, 1992, at 657–667.

Canadian HIV/AIDS Policy & Law Newsletter

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TESTING AND CONFIDENTIALITY

HIV Testing and Confidentiality: A Discussion Paper

As the last issue of the *Newsletter* announced,[1] **the Joint Project on Legal and Ethical Issues Raised by HIV/AIDS of the Canadian HIV/AIDS Legal Network and the Canadian AIDS Society released a 300-page *Discussion Paper* on HIV testing and confidentiality in March 1997.**[2]

This issue of the *Newsletter* provides a brief summary of the Paper and its conclusions, includes two articles on HIV testing of pregnant women, and – following the special feature on home testing in the last issue of the *Newsletter*[3] – reprints an article providing a consumer perspective on HIV home testing.

Why a *Discussion Paper* on HIV Testing and Confidentiality?

In Phase 1 of the Joint Network/CAS Project on Legal and Ethical Issues Raised by HIV/AIDS, over sixty individuals and organizations identified testing and confidentiality issues as one of eight "top priority" legal and ethical issues raised by HIV/AIDS in Canada. Most individuals and organizations consulted expressed the view that, although many documents were produced about testing and confidentiality issues in Canada in the late 1980s and early 1990s, the issues remain unresolved or need to be reexamined.

Background

Consensus

In Canada, a broad consensus emerged in the late 1980s that, except in a few well-defined circumstances, people should be tested only

- with their informed, voluntary and specific consent;
- when counselling and education before and following testing are available and offered; and
- when confidentiality of results or anonymity of testing can be guaranteed.

Lack of Consensus

Despite the consensus around these issues, opinion on several other issues related to testing has remained divided. In particular, there continues to be a lack of consensus regarding

- whether and, if yes, how positive test results should have to be reported to public health authorities; and
- whether and, if yes, how partner notification should be undertaken to warn partners of HIV-positive persons about their risk of having contracted HIV.

Unresolved Issues

In addition, there are a number of issues that, although in theory consensus was reached, in practice remain unresolved. For example, as raised by many of the individuals and groups consulted during Phase I of the Joint Network/CAS Project,

- although there is agreement that HIV testing should be easily accessible for all Canadians, access to testing remains a problem, particularly for women;

- testing for HIV without the specific informed consent of the person being tested is allegedly taking place more and more frequently;

- many people, whether they test positive or negative, often do not receive adequate counselling; and

- calls for mandatory or compulsory testing of certain groups of the population, such as sex offenders, prisoners, health-care workers, immigrants, and pregnant women, have continued.

New Controversies

Finally, new controversies over testing have arisen, in particular because of

- the availability of new and more promising treatments;

- the approval and marketing, in the United States, of the first HIV home testing kits; and, to a lesser extent,

- the shifting demographics of the epidemic.

What Does the *Discussion Paper* Contain?

The *Discussion Paper* contains a reexamination of the issues raised by HIV testing and confidentiality in Canada.

The main question addressed is whether new developments warrant a departure from the "general principle governing HIV antibody testing in Canada." In particular, the Paper examines the following questions:

- Is **specific** informed consent to testing still necessary, or should **general** consent suffice?

- Are anonymous testing facilities still required?

- Is pre- and post-test counselling still necessary?

- Should home testing for HIV be made available in Canada?

- Are any exception(s) warranted to the principle that testing always be voluntary? Is mandatory or compulsory testing, or testing of specific groups of the population (or under certain circumstances) justified?

- Are there any new exceptions to the principle that testing only be done when confidentiality of results or anonymity of testing can be guaranteed? Should an approach emphasizing partner notification be adopted?

What Is the Goal of the *Discussion Paper*?

The Paper does not provide definitive answers; this will be attempted in the *Final Report*, after individuals and organizations in Canada and internationally have had an opportunity to provide the Project with their input. Rather, the goal is to provide information and avenues for possible solutions that will encourage and contribute to a reasoned and informed process of making decisions about the future of HIV testing in Canada. Therefore, the conclusions in the *Discussion Paper* are preliminary conclusions that, it is hoped, will stimulate discussion on the many issues raised.

What Does the *Discussion Paper* Conclude?

General Conclusions

The Paper acknowledges that new testing technologies – in particular the availability of home testing kits – new treatments, and changing patterns of HIV infection force us to reconsider approaches to HIV testing and confidentiality. However, it urges that we not forget the lessons learned over the last fifteen years and keep in mind that HIV/AIDS remains different from other diseases. In particular, the new treatments constitute a huge step forward, but do not represent a solution to all problems faced by persons living with HIV or AIDS – problems that stem from the underlying problems of poverty and discrimination that are both a result and a cause of HIV infection. Therefore, while early detection of HIV infection has indeed become a pressing priority, a trend toward making HIV testing a routine or even mandated test needs to be treated with great caution. It would be a great mistake to dismiss the importance of respecting people's rights and the risk of discrimination, and it would be imprudent to rush the implementation of coercive measures when treatments are not accessible for many of those living with HIV, their long-term benefits remain unproven, and the efficacy of coercive strategies is at best questionable.

As Bayer has stated,

> [w]ere the end of HIV exceptionalism to mean a reflexive return to the practices of the past, it would represent the loss of a great opportunity to revitalize the tradition of public health so that it might best be adapted to face the inevitable challenges posed not only by the continuing threat of AIDS but also by threats to the communal health that will inevitably present themselves in the future.[4]

Testing policy will continue to require constant reevaluation as treatments and technology evolve, but a careful consideration of risks and benefits, informed by solid scientific research, that balances an individual's human rights and society's need to maintain public health must remain the basis of any legal and ethical approach to the threat posed by HIV.

Specific Conclusions

The Paper contains the following 15 conclusions:

1. Consent

1.1 Recent developments notwithstanding, the arguments for specific informed consent remain as pertinent as they ever were. As a general rule, HIV testing in Canada should only be undertaken with the specific, informed consent of the person being tested.

1.2 Hospitals should be encouraged to adopt policies on HIV testing specifying that HIV testing should only be undertaken with the specific informed consent of the person being tested.

1.3 Physicians should routinely offer information about HIV-antibody testing to all patients, but refrain from testing without specific informed consent, for two reasons: potential harms from testing, and respect for the autonomy of patients.

1.4 The general rule that HIV testing in Canada should only be undertaken with the specific informed consent of the person being tested does not apply to the testing of donors of blood, organs, semen, or similar bodily products. In all cases of donations, prospective donors should be informed before the performance of the test that an HIV-related test will be conducted, and given adequate information about the nature and purpose of the test.

1.5 The general rule that HIV testing in Canada should only be undertaken with the specific informed consent of the person being tested does not apply to testing performed as part of an anonymous (unlinked) HIV screening program for epidemiological or research purposes, provided the Guidelines on Ethical and Legal Considerations in Anonymous Unlinked HIV Seroprevalence Research are followed.

However, increased efforts must be made to reduce the potential for discrimination against groups or populations targeted by this research. In particular, before an anonymous (unlinked) HIV screening program is undertaken in a particular population, researchers and community leaders and members should undertake all necessary steps to ensure that communities understand the advantages and disadvantages of this type of research and take ownership of the research process and outcome so that the results can be usefully applied to programming and policy with respect to HIV/AIDS.

2. Access to HIV Testing

2.1 The availability of new treatments for HIV infection underscores the importance of providing easy access to HIV testing facilities to all Canadians. Barriers to testing, in particular for women, need to be removed.

2.2 Anonymous HIV testing facilities should be made available in various locations in each province and territory.

3. Counselling

3.1 While the availability of new treatments for HIV infection underscores the importance of removing barriers to access to HIV testing, pre- and post-test counselling should not be seen as barriers to HIV testing. Rather, they maximize the benefits from testing for the persons being tested and for society, while reducing potential harms. Therefore, as a general rule, testing should be undertaken only with quality pre- and post-test counselling consistent with existing counselling guidelines.

3.2 Counselling guidelines should be regularly updated and made widely available.

3.3 Health-care professionals need to be educated about the importance of providing counselling, and about proper counselling approaches, in basic and continuing education.

4. HIV Home Testing

4.1 Home test kits are devices with potential benefits for individuals, unproven benefits for society, and huge commercial interests behind them. Their introduction carries many risks that need to be better assessed before they are made widely available in Canada. Decisions about their introduction should not be based on the availability of the technology, but on sound scientific data and consultation with consumers, including persons living with HIV and AIDS.

4.2 Only home test kits that meet a set of criteria designed to minimize their potential harmful effects should ever be allowed for sale in Canada. In particular, manufacturers need to be able to demonstrate that their kits meet the technical standards set by existing approved tests and that counselling provided over the phone is adequate.

In addition, serious consideration should be given to implementing measures that would reduce the potential harms from making home test kits available, such as (1) addressing the risk of abuse by re-emphasizing the need for specific informed consent to HIV testing, by providing for support for those who are the victims of misuse of such tests by others, and by establishing severe penalties and quick complaint mechanisms in cases of violations; (2) renewing the commitment to the provision of free testing and counselling at a variety of state-sponsored testing clinics, advertising their services, and decreasing, as far as possible, delays at such clinics; and (3) renewing the commitment to prevention efforts that have proven successful, such as counselling, education, provision of wide access to preventive means such as condoms and sterile needles, and, generally, community-based efforts to prevent the further spread of HIV.

4.3 Serious consideration should be given to first offering home test kits on a limited trial basis and to requiring, as a precondition of approval, that post-marketing studies be carried out.

5. Testing of Pregnant Women

In all Canadian provinces and territories, all pregnant women – and not only those considered at risk of HIV – should be offered the opportunity to undergo an HIV test during pregnancy and counselled about the advantages and disadvantages of HIV testing. In contrast, coercive measures such as routine or mandatory testing of pregnant women involve an undue interference with the autonomy rights of pregnant women, and cannot be justified as a matter of law or medical necessity.

6. Testing of Newborns

At this time, in Canada, routine or compulsory testing of newborns is unwarranted. Rather, all pregnant women should routinely be offered voluntary testing and, if HIV-positive, be encouraged to consider taking treatment that will benefit them and reduce the risk of transmission to their infants (see conclusion 5).

7. Testing of Prisoners

There is no public health or security justification for mandatory or compulsory HIV testing of all prisoners. Rather, prison systems need to make anonymous testing accessible to prisoners, and make testing offered by prison health-care staff more accessible and acceptable to them, by offering them the option of non-nominal testing, training prison health-care staff in the delivery of pre- and post-test counselling, better protecting the confidentiality of medical information, and ensuring that HIV-positive prisoners will not be wrongfully discriminated against and will have access to care, support and treatment equivalent to that available outside.

8. Testing of Persons Accused and/or of Persons Convicted of Sexual Assault

Compulsory testing of persons accused and/or of persons convicted of sexual assault has few benefits for the survivor of sexual assault. Legislation authorizing such testing would do little to help the survivors, and divert attention from the real, underlying problems. What is required instead is a governmental response that answers the very real concerns of survivors of sexual assault and provides them with assistance. Therefore, Health Canada, the Department of Justice, Status of Women, and their provincial counterparts should develop, in consultation with non-governmental organizations, a best-practices model of counselling, short- and long-term care, treatment and other services that should be made available to sexual assault survivors. This should include

- access to anonymous HIV-antibody testing and counselling for all sexual assault survivors, provided by trained staff of sexual assault crisis centres or similar facilities;

- examination of the question of whether PCR testing should be made available to survivors of sexual assault;

- access to post-exposure prophylaxis for sexual assault survivors, accompanied by counselling about its effects;

- ensuring sensitivity to multiculturalism and societal diversity in the delivery of counselling, testing and support services; and

- assistance in the HIV/AIDS-related training of staff at sexual assault crisis centres and of other professionals who have contact with survivors of sexual assault.

9. Testing of Sex Workers

Mandatory or compulsory testing of sex workers and other coercive measures directed at them will do little to prevent the spread of HIV among sex workers and to clients. Rather than undertake such measures, policymakers must consult with sex workers to develop policies that will truly prevent and reduce the spread of HIV.

10. Testing of Health-Care Workers

Mandatory testing of health-care workers is not justified. Instead, all health-care workers who practise invasive procedures should regularly monitor their HIV status. If infected, they should seek advice about whether they need to limit their professional practice in order to protect their patients. Practice restrictions may be justified for "high-risk," exposure-prone invasive procedures (which should be clearly defined). At the same time, it is important to ensure that HIV-positive health-care workers are protected from unjustified discrimination and that information about their HIV status is not unduly disclosed.

11. Testing of Immigrants

For many reasons, Canada should not introduce mandatory HIV testing of prospective immigrants. In addition, the current system according to which immigration applicants who are found to be HIV-positive are assessed as "medically inadmissible" should be changed so that persons living with HIV/AIDS or other similar conditions will not automatically be excluded from immigrating. A new system should take the individual circumstances of each case into account, weigh the costs against the benefits of allowing a particular person to immigrate, and take humanitarian concerns into account.

12. Reporting

Reporting of both HIV and AIDS should always be non-nominal: nominal reporting is not warranted either for surveillance or for partner notification purposes. Provinces and territories that currently require nominal reporting should amend their public health acts and regulations accordingly.

13. Partner Notification

Limited provider-centred partner notification programs may further a vital public health objective, provided that such programs are specifically targeted at notifying persons who may otherwise be unaware that they may have been exposed to HIV. In order to encourage physicians to undertake partner notification upon request of their patients, fee schedules should provide for adequate remuneration of partner notification efforts. Only where a patient prefers that the notification be undertaken by public health authorities, or where a physician is unwilling or unable to undertake notification, should public health authorities undertake the notification. However, public health should not require that physicians divulge the name or personal identifiers of the index patient to them. Rather, non-nominal reporting should suffice. In addition, public health authorities need to ensure that identifying information about the persons to be notified will be deleted from public health files once notification is undertaken.

Generally, the importance of partner notification efforts should not be over-emphasized. For the populations most vulnerable to contracting HIV, targeted education and support through community-based programs remain essential. It would be dangerous to allocate increasing resources to partner notification programs without at least maintaining current funding levels for education and for support programs.

14. Disclosure

The disclosure of HIV/AIDS-related medical information to persons claiming that they have a need or right to know the serological status of HIV-positive individuals is seldom justifiable. In most situations, disclosure is unnecessary and its efficacy is questionable. In addition, disclosure is often counterproductive or harmful, in excess of any benefits or potential benefits that might result from it. Measures that can be undertaken to prevent exposure to and infection with HIV have to be undertaken regardless of whether a person is or is not known to be seropositive. To educate people about precautions that can prevent HIV transmission, and to make available to them the means necessary to prevent it, is essential if transmission of HIV infection is to be prevented. Only in rare, exceptional cases will disclosure be justified, when an individual assessment shows that disclosure is necessary, likely to be effective and the least invasive and restrictive means available to prevent harms that cannot otherwise be prevented. In all other situations in which claims for disclosure may arise, other means are often already available, would be less harmful than disclosure, are likely to be necessary and more effective.

15. Discrimination

Because of the limits of confidentiality and the difficulties of protecting it in practice, efforts to protect persons living with or affected by HIV/AIDS from discrimination need to be strengthened. This should include funding research on the extent and consequences of discrimination against those infected and affected, public education, strengthening anti-discrimination laws and policies and offering effective procedures for seeking redress.

The *Discussion Paper* has been sent to a broad range of individuals and organizations active in HIV/AIDS issues, and their comments and input have been solicited. In the summer of 1997, a final report will be written, providing a comprehensive analysis of the issues, and representing the full range of views expressed by those who commented on the *Discussion Paper*. The *Final Report* will provide a critical assessment of the issues and concrete recommendations.

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Copies of the *Discussion Paper* can be retrieved at the website of the Canadian HIV/AIDS Legal Network at http://www.aidslaw.ca or ordered through the National AIDS Clearinghouse. Tel: (613) 725-3434; fax: (613) 725-9826; email: aids/sida@cpha.ca

> "We know that the HIV test is an enormously effective public health tool, but it's only effective when deployed in ways that are socially, politically, and medically appropriate. If it's not, it can actually be a detriment to public health."
>
> - Prof A Brandt, Harvard Medical School, 1995
>
> "Although we know a lot about preventing HIV disease, we tend to focus our hopes on technological fixes. Many of these hopes have been disappointed and have prevented us from taking a look at the kind of social, behavioral, and preventive programs that could have a very positive effect right now."
>
> - Prof A Brandt, Harvard Medical School, 1995
>
> "Although circumstances of treatment and ongoing assessment may be changing, the circumstances necessary to ensure ethical observance of testing procedures have not. Physicians are ethically required to offer testing as an option for those who are concerned about their lifestyle history or state of health; the patient can and must still choose whether or not to be tested in the light of available information and their own situation."
>
> - D Miller, AJ Pinching, 1989

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ENDNOTES

[1] HIV Testing and Confidentiality Issues Re-examined. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 3(1): 1, 28-30.

[2] R Jürgens, M Palles. *HIV Testing and Confidentiality*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1997.

[3] M Palles, R Jürgens. Home Testing for HIV: Potential Benefits and Pitfalls. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 3(1): 30-37; R Bayer, J Stryker, MD Smith. Testing for HIV Infection at Home. Ibid at 37-40.

[4] R Bayer. Confidentiality and Its Limits. In: H Fuenzalida-Puelma et al (eds). *Ethics and Law in the Study of AIDS.* Pan American Health Organization Scientific Publication No 530, at 1504

Canadian HIV/AIDS Policy & Law Newsletter

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HIV Testing in Pregnancy: A Duty or a Choice?

HIV seroprevalence rates among women in Newfoundland are much higher than in other parts of Canada. Among other things, this leads to an increased risk that infants in the province will be born with HIV.

This article, written from a medical student's perspective, summarizes the results of a survey of family doctors and obstetricians in Newfoundland.[1] The survey was undertaken to assess attitudes and current practices regarding the HIV testing of pregnant women. The article then considers whether – in light of the higher seroprevalence rates among women in Newfoundland and the results of the survey showing that a relatively high number of physicians recommend testing only to women they consider to be at high risk – the health profession should urge routine or even mandatory HIV testing of pregnant women.

Background

It has been estimated that, worldwide, 40 percent of the total number of HIV-positive persons are women of childbearing age. In Canada, women represent a lower percentage of the total number of cases of HIV and AIDS, but the number of HIV-positive women continues to grow. In particular, HIV infections in women now represent a much higher proportion of new infections than earlier in the epidemic. In Newfoundland and Labrador,

- HIV prevalence among women is particularly high, reaching 135/10 000 in one area, Conception Bay North. This is one of the highest rates in North America.[2]
- Cases of AIDS among women and pediatric AIDS cases represent a much higher proportion of total AIDS cases than in the rest of Canada.
- The proportion of HIV cases among women due to heterosexual transmission, rather than injection drug use, is also higher than in the rest of Canada.

The Study

A group of medical students conducted a survey of 196 randomly sampled physicians and obstetricians from the six provincial health-care regions in Newfoundland in order to assess attitudes and current practices regarding the HIV testing of pregnant women. Physicians and obstetricians were asked whether they:

- always recommend HIV testing to pregnant women;
- only offer testing to those patients whom they perceive to be at high risk of HIV;
- believe that HIV testing should be mandatory; and
- would consider testing without consent.

Results

- 54 percent of the 95 physicians and obstetricians who responded to the questionnaire answered that they always recommend testing.
- 23 percent said that they recommend testing only to women they perceive to be at high risk.
- 54 percent were in favour of mandatory testing.
- 16 percent said that they would test without consent.

Other findings include:

- Female respondents were more likely than their male colleagues to always recommend testing.
- A significantly higher proportion (80 percent) of respondents who had been practising for over 20 years felt that HIV testing of pregnant women should be mandatory.

When asked why they might choose not to offer HIV testing to a pregnant patient, respondents tended to express their perception that their particular patient population was not at risk for HIV ("my patients won't get AIDS"), and/or say that they did not have time to provide the necessary pre-test counselling. Many felt that they would not have the time even if they had the option to refer their patient to a public health nurse to receive counselling. In addition, some respondents did not seem to be comfortable discussing the issue of HIV with their patients.

Issues and Questions

The results of the study raise many questions: Why is testing not recommended more often? Should pregnant women be routinely or mandatorily tested for HIV?

For a pregnant women, there are many benefits to knowing one’s HIV status. However, does this mean that the requirement that testing be undertaken only with the specific, informed consent of the person being tested should be abandoned? It is submitted here that the answer to this question is no. HIV/AIDS continues to be different from other diseases, a fact that needs to inform policy and medical practice. Testing HIV-positive can result in ostracism, loss of employment, loss of partner, discrimination, and great psychological distress. Given these social consequences and the seriousness of the illness, it is understandable that some people – the new treatments notwithstanding – say that they would rather not know than be tested.

What then should be done about HIV testing in pregnancy? Who should be tested or offered testing, and how? At the core of these questions is the conflict between two basic ethical principles, beneficence and autonomy. As health-care workers and as responsible members of the community, we believe in beneficence. We work to promote health and to do the best we can for patients – in this case, diagnosing HIV to delay progression of disease and to attempt to prevent transmission. However, because of the implications a diagnosis of HIV has, there are many reasons why a woman could refuse testing. To violate her decision is to deny her autonomy, another principle we are bound to respect. We cannot and should not presume to know better, and must therefore respect the mother's right to decide for herself whether she wants to be tested and, if HIV-positive, accept treatment. Anything else would be rank paternalism.

However, in order to encourage pregnant women to undergo HIV testing, we need to routinely offer all of them HIV testing and counsel them about the advantages and potential disadvantages of being tested, rather than offer testing only to those women we consider being at "high risk."

Conclusion

> An ethical person ought to do more than he is required to do but less than he is allowed to do (M Josephson).

We do not have the right to deny women's basic right to make reproductive decisions, to force them to accept treatment, or to subject them to mandatory testing. What we can do instead is offer women choices. We need to routinely offer every pregnant woman the option of HIV testing and to counsel them so that they can make their own, informed decisions, which we must respect.

- *Hasini Reddy*

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ENDNOTES

[1] B Blackie, H Reddy et al, 1995, unpublished. For more information, contact H Reddy at 5 Winthrop Place, St John's, Newfoundland A1A 3W7. email: hreddy@morgan.ucs.mun.ca

[2] Personal communication from Dr Sam Ratnam, Director of Public Health Laboratories

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A New World of HIV Testing: Experiences with Home Testing

The last issue of the *Newsletter* contained a "special feature" on HIV home test kits, examining some of the potential benefits and harms of such tests. In the United States, two home collection kits ("Confide" and "Home Access/Home Access Express") have been on the market since last year, opening up a new world of HIV testing – "to the applause of some and the dismay of many."[1] Are HIV home collection kits consumer-friendly? What is the packaging like? And, most importantly, how is the counselling? We reprint accounts of the experience of two young people who have used home kits in the US.[2]

"Your Result Is Negative..."

Heather Lusk, 25, is a training coordinator for the Training and Resource Centre of "Health Initiatives for Youth" (HIFY), a San Francisco–based non-profit agency dedicated to improving the health of young people. Heather first tested when she was 19 and tested negative again in January 1997. Her story and opinion follows.

Heather: Advertisements for HIV home tests depicted them as an easy way to find out the answer to a difficult and scary question. I was intrigued yet sceptical about taking my HIV test at home. I also wondered how the procedure would affect me as a young person.

The test kits are both excessively packaged, resulting in a two-foot-long spread of booklets, blood sample supplies, and return envelopes. I was feeling a tad overwhelmed, and appreciated Home Access' inclusion of a handy checklist/diagram of the kit's contents (especially for folks like me who had no idea what a lancet is). I was encouraged by both products' bilingual Spanish/English instructions but discouraged by the separation of the test instruction and HIV/AIDS information. Realistically, how many youth would take the time to read the separate HIV/AIDS booklets as I did? Neither book is particularly inviting in its vague and dry language. The text is cautious, non-youth friendly and without pictures. I was particularly perplexed by Confide's very broad definition of HIV risk behaviours, and pondered how puzzled I would be if this was my first introduction to HIV/AIDS information.

The instructions for both testing procedures were concise and pretty easy to comprehend. The tests' selling point of convenience is right on ... they supply you with everything you could ever need, from bandages to disposal containers to postage-paid return packages. I was ready to bleed. Gathering my blood sample was relatively painless, and soon I was bandaged and my blood was on its way to the lab. Home Access required me to register prior to sending my sample; I answered a short automated survey (age, who I have sex with, prior HIV tests, etc). I felt reassured that my future results counsellor would have some basic background information while maintaining my anonymity. Now I just had to wait.

The morning my results were available, (one week for Confide, three days for Home Access Express) I closed the door, took some deep breaths, and made the call to Confide. Initially, I was asked by an automated system to answer a survey very similar to the demographic questions I had answered before sending in my Home Access test. Despite my eagerness, I took the time to answer the questions, guessing their response rate would be pretty low considering the anxious period in which they are requesting information. When it was finally time to hear my results, an automated voice droned "Your test results are negative ... this means you do not have HIV ... unless you've been infected in the last six months." My entire pre- and post-test experience with Confide was completely automated (with an extremely vague definition of the window period). I listened as the recording went on in a monotone, basically reading verbatim the HIV/AIDS booklet included in the kit, for ten minutes before I had the opportunity to speak to a live counsellor.

I should have stayed with the computer. My "counsellor" was impersonal and vague as well. She didn't ask any clarifying questions to assess my age, needs, risks or knowledge. I also discovered she had no access to my previous survey answers, nor any awareness of the information I was forced to listen to before I had the opportunity to speak with her. I felt confused about her generic explanations to my questions, especially when she gave me wrong information. This traumatic counselling session ended with another plug for using Confide for my follow-up test since "only confidential testing is available in your area." Knowing this to be false, I pressed for a referral in San Francisco for anonymous testing. She gave me a number for the Department of Public Health, which (surprise) was a wrong number.

My experience with Home Access also began with a recorded voice telling me my results are negative. Unlike Confide, however, I received a clear concise definition of the window period, as well as an opportunity to speak to a live counsellor within seconds of receiving my result. A major difference was that my counsellor had my survey answers in front of her so she knew that I was a young adult, knew I had a prior negative HIV test, and had an idea of my risk behaviours. Overall, I felt much more comfortable with this counsellor, and she provided an overview of the continuum of risk behaviours, as well as more direct answers to questions I asked. Her plug for Home Access in my follow-up testing was a little inappropriate, but her referral to the San Francisco AIDS Foundation Hotline was much more helpful than any assistance I received from Confide.

My experience with Confide was appalling and I am nervous and scared when I think of other young people believing it is a safe and easy way to find out their HIV status. While Home Access was the lesser of the two evils, I am hesitant to promote its use without an accompanying counselling session from an outside source. Obviously home testing does not have the intervention quality that confidential and even anonymous testing may have on reducing the risk for HIV transmission. I'm not as concerned about that fact as I am about the possibility of a young person finding out their result in such an impersonal and potentially destructive manner.

"Your Result is Positive..."

Stefan Milenkovic, 24, a member of HIFY's Youth Services Team, first tested positive when he was 15. His story and opinion follows.

Stefan: I was originally tested for HIV in 1987 in England. I was 15 years old, HIV worldwide was about five years of age and was still very much the "gay plague." When I was given my result by phone I was very surprised to find that it was positive. I received no in-depth post test counselling and feel that the whole experience was a little – well – depressing. Things changed soon thereafter though; it became illegal in England to give results of this nature over the telephone. Nine years later when I was asked to write about the home kits, I jumped on the opportunity.

Upon opening the boxes, I found that the two tests vary only slightly. The information in both of them seemed to be aimed at a heterosexual of above average comprehension and education, but the instructions for the Confide test were more graphical and more easily explained the procedures involved. However, the Home Access test requires that you call in and answer demographic information at the time of drawing blood. That somehow made the experience much more tangible for some reason. Generally, I feel that the information was of high enough quality but was not designed for use by a young person.

The testing procedure is something I found very difficult and do not think it is something a young person could safely and privately achieve in all circumstances. The process of stabbing yourself with a lancet, squeezing blood into little circles, ensuring that the blood passes to the back of the card, etc. seems more than a little macabre. Further, I feel that the lancets included for drawing blood should be returned to the manufacturer for either recycling or disposal. These items, along with the rest of the packaging for that matter, are not things a parent would relish finding in the trash and could cause any number of questions to be asked.

Getting my result from Confide went like this.

"Do you have your 14 digit access Code?"

"01747905040785"

"I have to tell you that your test came back positive for the HIV antibody, this means you have the HIV virus, HIV is the virus that causes AIDS, HIV and AIDS are not the same thing. What did you expect your result to be?"

"..."

We got past the initial terror of the diagnosis and the resultant shocked silence very quickly. Ruth, our friendly operator, who incidentally hadn't asked for my name, began to read what sounded like a scripted counselling session. She was going to refer me to an appropriate agency as soon as possible whether I liked it or not. "The database," she told me, would like me to go to the Immune Enhancement Project for my primary care, as well as alternative therapies. (The Immune Enhancement Project does not provide primary care.) When I pointed out that I was a young person she referred me to the Balboa High Teen Clinic. I was uncomfortable with these referrals so she finally referred me to the Cole Street Youth Clinic. I feel that more appropriate referrals would have been possible had she had more accurate information, but still feel that she would not have the knowledge of services a local test clinic would have. The conversation finished with Ruth telling me that it seemed to her that I wanted to get off the phone.

Julie was my operator for the Home Access result. She had a much calmer manner and seemed to be willing to spend the time for me to process the way I was feeling before she launched into a counselling session. She passed on my result quite compassionately and made three referrals to local AIDS agencies. Again, these referrals were inaccurate, most notably that the San Francisco AIDS Foundation would provide me with primary health care.

When I tried to become maudlin about the information I had just received, she pointed out there were these "neat" new drugs which prolong people's lives now and that people don't get AIDS for ten years anyhow. I pushed the ten year AIDS prognosis to a degree by suggesting that because I am a young person that means I couldn't possibly have been infected long ago; therefore I wouldn't get sick soon. I was hoping that she would pick up on my age and suggest that I could have been infected as soon as I had my first sexual contact. Instead she told me that ten years was a good estimate and that lots of people get sick earlier.

My general view about both kits was that the counsellors did not have enough information about the virus, progression, the "neat new drugs" protease inhibitors, or local service. More to the point, it is not possible for these people to have local information unless they are to spend time working in the communities which they aim to profit from. The operators did not even attempt to ascertain my mental state prior to giving me the result. Neither of them determined that I was a young person, addressed issues such as testing for other STD's and hepatitis, vaccination against other diseases, or asked why I had initially decided to take the test.

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ENDNOTES

[1]For a Testing Controversy, Press 1. *Bridges* 1997; 3(1): 3-6 at 3.

[2]Reprint from *Bridges*, ibid.

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 2-3 - Spring 1997

Canada – Rapist Required to Submit to HIV Testing

Madam Justice Macdonald of the Ontario Court's General Division signed a court order on 23 September 1996 requiring that, at the request of six of his victims, serial rapist Paul Teale, also known as Paul Bernardo, be tested for HIV and other sexually transmitted diseases.[1]

The Case

No lawyers appeared for Teale to oppose the order. The plaintiffs had made a motion for an order pursuant to subsections 105(1), (2) and (3) of the *Courts of Justice Act*[2] and Rules 33.01 and 33.06 of the *Rules of Civil Procedure*[3] requiring Teale

> to undergo a physical examination by a health practitioner including all necessary tests to determine whether the Defendant, Paul Teale, ... is infected with the AIDS virus or other sexually transmitted diseases.[4]

According to the order of 23 September, Teale's blood samples were to be taken within 45 days at Kingston Penitentiary, where Mr Teale is serving an indefinite sentence.

One of the victims, who is suing for damages, said that the fear of contracting HIV was causing her "severe nightmares, continuing anxiety, depression, headaches, emotional instability, agoraphobia, poor concentration and an inability to work," and that this in turn has caused her "severe pain and suffering."[5] She was attacked on 22 December 1989 and has tested negative for HIV but, according to her lawyer, "wishes to send out a message to whoever cares to listen that people that are assaulted this way have valid fears about these types of diseases."[6]

No Precedent

The court order requiring Teale to be tested for HIV does not establish a precedent because Teale did not oppose the issuing of the order. Therefore, the larger question of whether there is a legal basis for compelling a person convicted of sexual assault to undergo HIV testing remains open in Canadian law.

- *Ralf Jürgens*

For a detailed discussion of whether individuals accused of (charged with) sexual assault; and/or individuals convicted of sexual assault should have to undergo compulsory HIV testing, see R Jürgens, M Palles. *HIV Testing and Confidentiality: A Discussion Paper*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1997, at 162-184.

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[1]*DC v Paul Bernardo et al*, Court File No 93-CQ-46124, unreported decision of 23 September 1996, Ontario Court (General Division), MacDonald J.

[2]Subsections 105(1), (2) and (3) of the *Courts of Justice Act* read:

105. (1) In this section, "health practitioner" means a person licensed to practise medicine or dentistry in Ontario or any other jurisdiction, a psychologist registered under the *Psychologists Registration Act* or a person certified or registered as a psychologist by another jurisdiction. 1989, c. 55, s. 18(1).

(2)Where the physical or mental condition of a party to a proceeding is in question, the court, on motion, may order the party to undergo a physical or mental examination by one or more health practitioners. 1984, c. 11, s. 118(2); 1989, c. 55, c. 18(2).

(3)Where the question of a party's physical or mental condition is first raised by another party, an order under this section shall not be made unless the allegation is relevant to a material issue in the proceedings and there is good reason to believe that there is substance to the allegation.

[3]Rules 33.01 and 33.06 of the *Rules of Civil Procedure* read as follows:

33.01 A motion by an adverse party for an order under section 105 of the *Courts of Justice Act* for the physical or mental examination of a party whose physical or mental condition is in question in a proceeding shall be made on notice to every other party. O. Reg. 560/84, r. 33.01.

33.06(1) After conducting an examination, the examining health practitioner shall prepare a written report setting out his or her observations, the results of any tests made and his or her conclusions, diagnosis and prognosis and shall forthwith provide the report to the party who obtained the order. O. Regs. 560/84, r. 33.06(1); 711/89, s. 21.

[4]*DC v Paul Bernardo et al*, Court File No 93-CQ-46124, Notice of Motion of 8 September 1996, at 1-2.

[5]D Downey. Bernardo to Take AIDS Test after Victims Make Request. *The Globe and Mail* 24 September 1996, at A7.

[6]Ibid.

Canadian HIV/AIDS Policy & Law Newsletter

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South Africa – National Policy on HIV Testing and Informed Consent Proposed

The South African Law Commission has been investigating aspects of law reform relating to HIV/AIDS since 1993.

Extensive research has been done, evidence was heard from interest groups, and a first discussion document was published for general information and comment during 1995. In 1996, certain aspects concerning HIV/AIDS which, according to the Commission, warrant urgent intervention – and which from a scientific, medical and legal viewpoint are relatively uncontroversial – were identified. These include, among other things:

- the statutory implementation of a national compulsory standard for condoms;
- a prohibition on the use of non-disposable syringes, needles, and hazardous material;
- the implementation, in relevant occupational legislation, of universal workplace infection-control measures (universal precautions); and
- the promulgation of a national policy on testing for HIV/AIDS.

A Discussion Paper was published, representing the preliminary views of the Commission's project committee.[1]

HIV Testing and Informed Consent

According to the Paper, it is indispensable that a national policy on HIV testing be adopted in South Africa, for many reasons:

- Voluntary testing for HIV with informed consent is recognized as indispensable in the care and support of persons with HIV, and to prevention efforts.
- According to members of the public, health-care workers and AIDS organizations, many patients are subjected to HIV tests without proper informed consent at public and private health-care facilities.
- Women of reproductive age face constant infringements of their constitutional rights to dignity, autonomy and privacy. The Paper cites from a WHO document, which states:

  > not only is it unethical to pressure or force women to make reproductive or breast-feeding decisions for any reason, including their HIV status, but those women most likely to be HIV-infected may try to avoid mandatory testing, precisely in order to avoid pressure in such decision-making. Such avoidance may have the additional unwanted result of discouraging pregnant women from attending antenatal services.[2]

- Testing infants for HIV without the informed consent of the *mother* is an invasion of the child's *and* the mother's individual constitutional rights. A mother may not want to know her HIV status because of the additional stress in caring for and supporting her family; she may fear emotional and physical abuse in the home; as with the vast majority of women diagnosed with HIV, she will not have access to full medical care and treatment because of costs; and she may face discrimination in the community, from her employers and other social services.

- Where the mother of the child still has a parental role, her consent should first be sought before the testing of the child.

The Paper suggests that adoption of a national policy will encourage "voluntary testing accompanied by pre- and post-test counselling with guaranteed confidentiality or anonymity at health facilities." It recommends that the Minister of Health exercise her statutory powers to issue such a policy.

Proposed National Policy on HIV Testing and Informed Consent

The proposed policy reads as follows:

Testing for HIV/AIDS presents serious medical, legal, ethical, economic and psychological implications [...] For these reasons, and, in accordance with the constitutional guarantees of freedom and security of the person, and the right to privacy and dignity, the following HIV testing policy shall be implemented nationally.

1 Informed Consent and Pre-Test Counselling Policy

1.1 HIV testing at all health care facilities will be carried out with informed consent, which includes pre-test counselling and with guaranteed confidentiality.

1.2 In the context of HIV/AIDS, testing with informed consent means that the patient has been made aware of the implications of the test. This includes benefits, risks, alternatives and the possible social implications of the HIV test.

1.3 This information has to be imparted in a language and in terms that the patient understands.

1.4 Pre-test counselling, a confidential dialogue between a trained HIV counsellor and patient, constitutes the most effective means of passing on information and gaining consent.

1.5 Where a health-care facility lacks the capacity to provide a pre-test counselling service, a referral to a counselling agency or another facility with the capacity to provide pre-test counselling by a trained HIV counsellor should be arranged before an HIV test is performed.

1.6 Where a patient presents with recognisable HIV/AIDS specific symptoms and where no facilities exist for adequate pre-test counselling, treatment for the specific symptom or illness may be undertaken without an HIV test. Referral to a specialist counsellor for pre-test counselling should be undertaken at the earliest opportunity.

1.7 Consent in this context means the giving of express agreement to HIV testing in a situation devoid of coercion, in which the client should feel equally free to grant or withhold consent. Written consent should be obtained where possible.

1.8 The use of posters, pamphlets and other media are encouraged to assist in making information on HIV/AIDS available but cannot be regarded as a general substitute for pre-test counselling.

1.9 A trained HIV counsellor should accept, after personal consultation, a client's decision to refuse pre-test counselling. Psychological competence in dealing with the diagnosis of a life-threatening condition, rather than educational or social status, should be the yard-stick for this decision. Such a decision should only be made on a case-by-case basis and be recorded in writing by the counsellor.

2 When Can HIV Testing Be Done?

2.1 Testing will be done only with informed consent under the following circumstances:

2.1.1 On individual request for diagnostic and treatment purposes; and

2.1.2 when clinically indicated on recommendation from a medical doctor.

2.2 Anonymous and unlinked testing for epidemiological purposes may only be undertaken by the national, provincial or local health authority or an agency authorised by any of these bodies.

2.4 Test results will be confidential.

2.5 No partially or wholly publicly funded health care facility may engage in any form of testing for HIV which is mandatory, or compulsory, or a pre-requisite for obtaining some benefit.

2.6 The rights of pregnant women and children to privacy, dignity and autonomy, should be observed by every health-care worker.

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ENDNOTES

[1]South African Law Commission. *Discussion Paper 68 – Project 85 (Aspects of the Law Relating to AIDS)*. Pretoria: The Commission, 1996 (ISBN: 0-621-17550-1).

[2]World Health Organization. *Statement from the Consultation on Testing and Counselling for HIV Infection*. Geneva: WHO Global Programme on AIDS, November 1992, at 4.

Canadian HIV/AIDS Policy & Law Newsletter

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CRIMINAL JUSTICE

Criminal Law and HIV/AIDS: Final Report Released

In recent years, the use of the criminal law to prosecute HIV-positive individuals for engaging in activities that may transmit HIV has attracted the attention of policy- and lawmakers in Canada. A handful of prosecutions across the country have received considerable media coverage, and in January 1995 the federal Minister of Justice declared that he was considering amending the *Criminal Code* to make it a crime to "knowingly communicate" HIV. In November 1996 the first appellate court decision regarding criminal prosecution for unsafe sex was released, and on 24 April 1997 the Supreme Court of Canada announced that it will hear the Crown's appeal of that decision. The release of *Criminal Law and HIV/AIDS: Final Report*[1] could not have been more timely.

Background

Individuals and organizations consulted during Phase I of the Project on Legal and Ethical Issues Raised by HIV/AIDS, undertaken jointly by the Canadian HIV/AIDS Legal Network (Network) and the Canadian AIDS Society (CAS), expressed concern about

- proposals to amend the *Criminal Code* to create an HIV-specific offence; and
- the use of criminal sanctions to prosecute persons who engage in activities that risk transmitting HIV.

Another common concern was that an HIV-specific criminal offence would further stigmatize

- HIV/AIDS and other sexually transmitted diseases; and
- persons living with the disease and some of the populations most affected by the disease, such as gay men, injection drug users and sex workers.

In addition, the individuals and organizations consulted raised the question of whether public health laws would not be better suited than criminal law to deal with those individuals who, knowing that they are HIV-positive, engage in behaviours likely to transmit HIV without using precautions and without previously informing their partners about their HIV status.

They suggested that the Joint Network/CAS Project examine these concerns and questions and make recommendations for legislators, policymakers, prosecutors and the judiciary about the appropriate use of criminal law in situations where HIV-positive persons engage in activities that may transmit the virus.

Activities Undertaken

The Discussion Paper

Work started in November 1995, when the Project Coordinator commissioned a discussion paper to identify the main legal and ethical issues raised by the application of the criminal law to HIV/AIDS. *Criminal Law and HIV/AIDS: A Discussion Paper*[2] was published in April 1996 and widely distributed for comment both nationally and internationally. A summary of the *Discussion Paper* and numerous articles addressing HIV/AIDS-related developments in the areas of criminal and public health law have been published in previous issues of the *Newsletter*.[3]

Key commentators provided detailed written comments on the *Discussion Paper*. These comments and the *Discussion Paper* itself formed the basis of a National Workshop on Criminal Law and HIV/AIDS held in Toronto in June 1996. In addition, comments on the *Discussion Paper* were received from both within and outside Canada and have been incorporated into the *Final Report*. Finally, an oral presentation on "Criminal Law and HIV/AIDS" was given at the XI International Conference on AIDS in Vancouver in July 1996.

The Final Report

The *Final Report* and its appendices

- review the cases of criminal prosecution that have arisen in Canada; the academic commentary; policy recommendations from various groups and organizations; proposed amendments to the *Criminal Code*; and the comments on the *Discussion Paper* received at the National Workshop, at the XI International Conference on AIDS, and from other commentators;

- summarize developments in the area of criminal law and HIV/AIDS in other jurisdictions;

- examine the arguments in favour and against criminalization of activity that risks transmitting HIV;

- consider whether measures available under public health legislation offer a preferable alternative to using the criminal law;

- analyze in detail the various provisions of the *Criminal Code* that have been used to prosecute people for conduct that transmits or risks transmitting HIV;

- consider whether the *Criminal Code* should be amended to create a new offence for HIV transmission or exposure and, if so, how such an amendment might be crafted; and

- make recommendations for legislators, policymakers, prosecutors and the judiciary.

New Developments

The *Final Report* incorporates new jurisprudence and policy developments that have occurred since the release of the *Discussion Paper* in April 1996.

- In the first decision by a Canadian appellate court in the area of criminal law and HIV/AIDS, the BC Court of Appeal dismissed the Crown's appeal, finding that the law of assault does not appropriately deal with consensual sexual conduct carrying a risk of transmitting HIV. As mentioned above, the Supreme Court of Canada will hear the case, following the Crown's appeal of the BC Court of Appeal's decision.

- In Ontario, in a case similar to cases previously seen only in the United States, an HIV-positive prostitute was charged with aggravated assault for biting a police officer and thereby allegedly endangering his life. The prostitute was sentenced to two years less a day in prison for the bite, although there was no risk of transmission. The sentence is under appeal.[4]

- In Montréal, a gay man was charged with four separate offences for allegedly engaging in unprotected sex with his lover without having disclosed his HIV-positive status.

- The Ontario Advisory Committee on HIV/AIDS held an extensive consultation to discuss the use of public health measures to respond to persons who are "unwilling or unable" to use appropriate precautions to reduce the risk of HIV transmission. A working paper with recommendations about the use of coercive interventions has been prepared and a final report on the issues will be released in 1997.

- Having prepared a working document on public health interventions to be used in cases of "unwilling or unable" persons, a working group of the STD/AIDS Control and Prevention Module of the Direction de la santé publique, Montréal, has developed a protocol for handling such cases.

Goals

The goals of this component of the Joint Project on Legal and Ethical Issues are to:

- provide a comprehensive review of the current state of Canadian criminal law relating to HIV/AIDS;

- assist people living with HIV/AIDS, their advocates and counsellors, health-care workers, AIDS service organizations and other service providers in understanding the criminal law issues that may arise for persons who engage in activities that transmit or risk transmitting HIV;

- assist legislators, policymakers, prosecutors, and the judiciary in appreciating the complexity of the issues; and

- contribute to a process of informed and rigorous discussion concerning the advisability of criminalization and the forms it may take.

Conclusions and Recommendations

General Conclusions

Whether ultimately advisable or not, and whether justified in all situations in which it has been applied, the criminal law will continue to be used to prosecute some individuals who engage in activity that transmits or risks transmitting HIV. The *Final Report* recognizes that, in some circumstances, criminal sanctions are appropriate. However, it emphasizes that

- cases of HIV-positive persons who deliberately infect others, or intentionally or recklessly put others at risk of contracting HIV, are extremely rare;

- the vast majority of persons living with HIV or AIDS pose no risk of HIV transmission; and, importantly,

- in general, both partners engaging in sexual or drug injecting activity have a responsibility to adopt precautions to prevent transmission of HIV and other infectious diseases – the responsibility does not lie only with the person who knows him/herself to be living with HIV or another infectious disease.

In general, arguments against criminalization (or in favour of limiting the scope of criminalization) outweigh the arguments that existing criminal offences or amendments to the *Criminal Code* offer a desirable response to HIV-transmitting or exposing conduct. In the vast majority of cases, public health measures offer a better alternative to criminalization. A coordinated response between prosecutors and public health officials is needed, one that attempts least intrusive and restrictive measures first and proceeds to more coercive interventions if these should prove necessary. The criminal law should be a measure of last resort; it is not, and cannot be, a sufficient response to conduct that risks infecting others.

Public policy aimed at criminalizing HIV transmission/ endangerment would appear to be getting tough with HIV and persons living with HIV/AIDS. In reality, it would do little or nothing to stem the spread of HIV and divert attention and resources from the policies that make a real difference and that Canadian provinces and territories and the federal government need to continue to pursue:

- delivery of focused education;

- easy access to voluntary testing, counselling, support services, treatments, and the means that allow people to protect themselves from contracting HIV; and

- action directed at redressing the causes that create people's vulnerability to HIV.

Specific Conclusions and Recommendations

The following are some of the major conclusions and recommendations reached in the Report.[5] [Note: the numbering in the following section reflects that of the conclusions and recommendations in the Report].

1.1 Legal and Policy Responses

Conduct that risks transmitting HIV is first and foremost a public health issue. Legal and policy responses should be concerned with promoting sound public health policy and initiatives that will have a significant impact on reducing risk activities and preventing further transmission.

1.2 Education

There is an urgent need to educate prosecutors and the judiciary about HIV/AIDS issues. [...]

1.4 Public Policy Arguments Against Criminalization

Public policy considerations militate against criminalization as a response to risky conduct, or at least are grounds for limiting the scope of criminalization. [...]

1.4.2 Detriment to Public Health Initiatives

Criminalization may not deter risky conduct but instead deter people at risk of infection from getting tested, and from accessing counselling and support services that could assist in modifying behaviour. Educational efforts will also be hampered.

In addition, criminalization runs the danger of further stigmatizing all people with HIV/AIDS, and those associated in the public mind with the disease, as potential criminals. This would be even more likely if an HIV-specific criminal offence were created.

Finally, criminalization may undermine the message that all people are responsible for protecting themselves against HIV infection, and encourage a false sense of security among those who believe themselves to be HIV-negative that the law will protect them by deterring HIV-positive persons from unsafe sex or needle-sharing.

1.4.3 Selective Prosecution

The criminal law may be used to selectively prosecute those already associated with HIV/AIDS, such as sex workers, injection drug users, and gay men.

1.4.4 Privacy Interests

The privacy of many persons' sexual relations may be unduly infringed in order to prosecute a small number of cases of risky sex.

1.5 Public Health Measures: A Preferable Alternative

Public health laws offer an alternative to criminal law in situations involving HIV transmission/endangerment. Indeed, in the vast majority of cases, their use is preferable to the use of the criminal law. Interventions by public health officials to effect changes in risk behaviours are more flexible, protect confidentiality better, are more consistent with a health protection and promotion focus, and more easily recognize that behaviour modification is a complex endeavour requiring a more flexible approach than that offered by the criminal law.

1.5.1 Safeguards

Provinces that have not developed public health policies addressing the issue of HIV transmission/ endangerment should follow the example of Ontario, Québec, Manitoba and British Columbia, and develop policies or guidelines to ensure a consistent, fair response that accords with sound public health policy. In particular, the following principles should apply:

- any intervention should be the "least intrusive, most effective" option;

- more coercive interventions should only be adopted after less coercive alternatives have been unsuccessfully attempted;

- before infringing personal liberty, there should be a clear danger that a person's conduct carries a substantial risk of harm to others;

- any coercive public health measures should carry full due process protections; and

- there must be a mechanism in place to automatically terminate any coercive intervention (such as detention) unless its continued validity can be established.

These policies or guidelines should be developed in consultation with a wide variety of interested parties, in particular persons living with HIV/AIDS.

Following the model used in Montréal, multidisciplinary teams should be established to assist public health in the application of the policies or guidelines, particularly in difficult cases. These teams should include representatives of community-based AIDS service organizations and persons living with HIV.

2. Application of Existing Criminal Offences

The use of the criminal law may be justified in limited circumstances. A number of the existing criminal offences can be used to prosecute in situations involving HIV transmission or risk of HIV transmission. However, charges are unlikely to succeed in situations involving consensual sexual intercourse or needle sharing that do not result in HIV transmission. [...]

2.3 Assault

It is arguable that assault could be used to cover situations where an HIV-positive person deliberately misleads his/her partner. However, stretching the offence in this way is problematic and the courts have refused such attempts: the offence is concerned with sexual force, not the withholding of information. [...]

2.6 Criminal Negligence

The existing provision in the *Criminal Code* that is best suited for prosecuting risk activities in the context of consensual sex or needle-sharing is "criminal negligence causing bodily harm." Although the imposition of criminal sanctions on the basis of objectively measured negligence is cause for some concern, this offence permits a better balancing of the responsibility of all participants in risk activities to protect themselves against HIV infection, and is consistent with the general rule that criminal sanctions are applied when conduct causes harm to others.

3. Should the *Criminal Code* Be Amended?

The *Criminal Code* should not be amended to create an offence of "HIV transmission" or "HIV exposure." First, past or current proposals to amend the *Criminal Code* to create such an offence are flawed. Second, creating a new offence is unnecessary. Existing criminal offences (specifically the offence of criminal negligence causing bodily harm) can be adequately used to address conduct that

- transmits HIV; and

- is justifiably brought within the realm of criminal law, in light of criminal law's functions and competing policy arguments.

Third, it is unlikely that a new offence would achieve any improvement in the body of criminal law that would outweigh the costs of making such an amendment. In particular, while a new offence could be created to cover consensual sexual or needle-sharing behaviour that risks HIV transmission but does not result in it, the costs of creating such an offence would outweigh its questionable benefits. In addition, in the vast majority of cases involving such behaviour, public health laws already offer a better alternative and should be used instead of using the criminal law. [...]

Appendix A of the *Report*

Although the *Report* rejects the creation of a new offence, Appendix A analyzes what a new offence should look like if a decision were ever taken in Canada to create one. Some of those providing input into the discussions leading to the preparation of the Report expressed concern that such an analysis could be misinterpreted as lending support to the creation of a new offence. Others, however, suggested that – the strong opposition to creating a new offence notwithstanding – it was important to engage in the discussion of what such an offence should look like if it was created. They felt that this would allow the Report to address some of the very serious concerns raised by statutes introduced in other jurisdictions and by amendments to Canada's *Criminal Code* that have been proposed in the past. The hope expressed was that addressing these concerns would help policy- and lawmakers to find a considered and measured response to the issues raised by criminalization in the context of HIV, should they ever decide to create a new offence.

The Appendix first analyzes whether any new legislation should be HIV-specific or whether it should also apply to other diseases. It then examines in detail what a new offence should look like. It concludes with a reminder that creating a new offence

- is unwarranted;

- would send out the wrong message that persons living with HIV are potentially dangerous individuals and that the law is needed to protect people from contracting HIV; and

- would be harmful to, rather than protect, the health of the public.

If a new offence were nevertheless to be introduced, the Appendix recommends that

- no criminal sanctions apply unless a person knew of his/her HIV-positive status and intentionally or recklessly exposed another to the risk of infection by engaging in "high-risk" activity;

- either disclosing one's HIV-positive status or taking precautions to reduce the risk of transmission be a sufficient defence to any criminal charge.

Next Steps

The Project will continue its efforts to avoid the damage to persons and public health that would be caused by poorly considered moves toward emphasizing a criminal law approach to activities that risk transmitting HIV, by undertaking efforts to ensure that the recommendations in the *Final Report* will be implemented.

For further information contact Ralf Jürgens, Project Coordinator, at (514) 987-3000 ext 8773#; fax: (514) 987-3422; email: ralfj@aidslaw.ca

Copies of *Criminal Law and HIV/AIDS: Final Report* can be retrieved at the website of the Canadian HIV/AIDS Legal Network at http://www.aidslaw.ca or ordered through the National AIDS Clearinghouse. Tel: (613) 725-3434; fax: (613) 725-9826; email: aids/sida@cpha.ca

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ENDNOTES

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

[2] R Elliott. Montréal: Canadian HIV/AIDS Legal Network and Canadian AIDS Society, 1996.

[3] See, eg, R Elliott. Discussion Paper on Criminal Law and HIV/AIDS. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 2(4): 9-12.

[4] R Elliott. Sex Trade Worker Sentenced to Two Years for Biting. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 3(1): 20-21.

[5] For the full list, see *Criminal Law and HIV/AIDS: Final Report*, supra, note 1.

Canadian HIV/AIDS Policy & Law Newsletter

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IMMIGRATION

Immigration Policy May Be Reviewed to Require Routine HIV Testing of Immigrants

Persons who wish to immigrate to Canada must meet the following medical criteria: they must not represent a danger to public health and safety, and their admission must not place excessive demand on Canada's health and social service systems.

Present Policy

At the present time, it is the policy of the Canadian government that persons living with HIV/AIDS who wish to immigrate do not represent a danger to public health and safety, but would place excessive demand on Canada's health and social service systems. Therefore, immigration applicants who are found to be HIV-positive are assessed as "medically inadmissible" and will not normally be allowed to immigrate to Canada.[1]

Detection of HIV-Positive Immigrants

Under the current system, some asymptomatic HIV-positive immigrants may not be detected because "a screening test for HIV is not required as a routine"[2] during the medical examination that applicants for immigration to Canada have to undergo to determine their health status.[3] However, according to the Director of Immigration Health Services, this policy may be reviewed within the next two years and HIV testing may become routinely required.[4]

Currently, the examining physician *may* require an immigration candidate to take an HIV test. Examining physicians *in Canada*[5] have been given instructions that "[c]ountry of origin, race, gender, and sexual orientation, by itself, is NOT a sufficient reason to warrant a screening test for HIV" (emphasis in original). HIV testing (after counselling) is required only when clinically indicated. The age of the applicant should be taken into account when assessing these indications for an HIV test – common sense and a realistic estimation of risk should prevail. A partial list of possible indications include:

> (1) The applicant has a history of receiving unscreened blood transfusions or blood products or the equipment used was reusable with inadequate sterilization
>
> (2) The applicant has unexplained significant weight loss
>
> (3) The applicant has used intravenous drugs at some point in the past – especially if the needles were shared
>
> (4) The applicant's history/physical examination is consistent with an AIDS defining condition
>
> (5) The applicant has X-ray evidence of a prior TB infection and is at risk of having acquired the human immunodeficiency virus (e.g. unprotected sexual intercourse with prostitutes)

> (6) The applicant's biologic mother is HIV positive
>
> (7) The applicant has taken part in unsafe sexual practices where the HIV status of the sexual partner was known to be positive (or where it was reasonable to assume that the partner was HIV positive)
>
> (8) The applicant has reason to believe that he may be HIV positive.[6]

In addition, any child for adoption should be tested "where there is a significant likelihood that the HIV status of the biologic mother was positive at the time of the child's birth." In contrast, applicants for a "short term temporary visa to Canada should be asked to undergo HIV testing only if signs of the acquired immunodeficiency syndrome are present."[7]

Determination of "Excessive Demand"

Under current medical inadmissibility regulations, immigration applicants who are found to be HIV-positive are seen as placing excessive demand on Canada's health and social service systems and, consequently, are assessed as "medically inadmissible" and will not normally be allowed to immigrate to Canada.

New regulations regarding medical inadmissibility have been under development for many years. If adopted, they could enable some people known to be HIV-positive to immigrate to Canada. A first draft of the new regulations, pre-published in August 1993, provided for a five-year "window of comparison" in assessing excessive demand:

> applicants for immigration would be medically admissible where, over five years, they would not cost the Canadian health care system more than the average Canadian citizen or permanent resident. Thus "early" cases of HIV would be admissible to Canada.[8]

A revised draft of the regulations was expected to be pre-published by the end of June 1995.[9] However, the determination of medical inadmissibility is ongoing and it now seems "unlikely" that the five-year "window of comparison" suggested in the first draft of the regulations will be maintained.[10] At the same time, there is some indication that some persons living with HIV, although technically medically inadmissible, have been allowed into Canada on compassionate humanitarian grounds.[11]

The Issues

Two questions need to be addressed if the current immigration policy is reviewed: (1) should all persons applying for immigration to Canada be tested for HIV?; (2) should all persons testing HIV-positive automatically, or only under certain circumstances, be barred from immigrating to Canada? These questions remain controversial. Opinion is widely divergent. Some, such as Reform MP Art Hanger, have issued a call for mandatory testing of all candidates for permanent residence in Canada, and denial of status to all candidates testing HIV-positive, including refugees. In addition, Hanger has demanded that temporary visitors living with HIV be barred from entering Canada.[12] A motion introduced by Hanger, proposing the HIV testing of all applicants for residence in Canada, was however defeated in the House of Commons in September 1994.[13] Then Immigration Minister Sergio Marchi stated that barring HIV-positive visitors was "going too far," but announced that he was reviewing the issue of whether immigrants should be tested.[14] Others, such as many AIDS activists and others working in the fields of human rights and disability rights, urge that would-be immigrants to Canada not be mandatorily tested and automatically rejected on the basis of their HIV status.[15]

Suggested Approach

Testing

For many reasons, Canada should continue its current policy of not automatically requiring HIV testing of all prospective immigrants. Somerville well set out these reasons:

> - [J]ust because a test is available does not mean that its use is acceptable or even more so that it should be used. Many tests that will become available probably should not be used for screening immigrants, or people in many other circumstances, because the harm involved, whether to those tested or to the values of our society, is not outweighed by compensating benefits.
>
> - Second, to institute such testing could appeal to and confirm the deepest prejudices of people who are opposed to anyone they perceive as unlike themselves, of whom immigrants are often considered to be a prime example.
>
> - Third, in an era when many countries are closing their borders to both immigrants and visitors on the basis of their HIV antibody status, Canada could stand out as an enlightened example to the contrary.
>
> - Fourth, there are technical–humanitarian concerns that support the argument against mandatory HIV testing of asymptomatic prospective immigrants. ... [An important] issue would be the effect on people identified as being HIV antibody positive who lived in countries with coercive legislation ...

Somerville concluded by saying that "[e]ven if it costs Canada some money for additional health care because some HIV-infected immigrants are admitted, what Canada could achieve by not requiring mandatory testing for HIV antibodies among asymptomatic prospective immigrants would far outweigh any losses that such testing involves."[16]

It is acknowledged that the opportunity to immigrate to Canada is a privilege and not a right, and that it is a legitimate criterion for immigration that a prospective immigrant be reasonably expected to contribute to Canadian society. It is further admitted that HIV-positive persons will impose costs on Canada's health-care systems. Nevertheless, as shown by Somerville, mandatory testing is unwarranted. Immigrants would be the first and – because of constitutional guarantees applying to Canadian residents that disallow involuntary testing except in very limited circumstances – probably only group of people for whom mandatory HIV testing would be imposed. This would heavily stigmatize all prospective immigrants and immigrants already living in Canada, who would be perceived as a group at high risk of HIV when there is no evidence that HIV is in fact overrepresented among immigrants to Canada. In addition, while mandatory testing of all immigrants would be the only way to identify *all* prospective immigrants living with HIV, immigrants are already being screened for HIV and many are asked to undergo HIV testing. Therefore, it is likely that a majority of immigrants living with HIV are already being identified, without mandatory testing of *all* immigrants. Finally, more and more tests are becoming available, particularly genetic screening tools, that "enable us, if we wish to use them, to predict with greater or lesser accuracy when and from which disease a given person will likely die."[17] If we mandate HIV testing, should we also use genetic tests on immigrants?

"Excessive Demand"

As mentioned above, Canada has been undertaking a review of its medical inadmissibility regulations. The language of a set of recommendations proposed in June 1992 by Employment and Immigration Canada[18] appeared to move away from the current blanket exclusionary policy with regard to people living with HIV/AIDS, but was vague and subject to much interpretation. Currently, the determination of medical inadmissibility is ongoing. Clearly, Canada needs a system that will not automatically exclude persons living with HIV/AIDS or other similar conditions from immigrating, but will take the individual circumstances of each case into account. With regard to HIV, the situation is changing rapidly: because of new treatments, people living with HIV lead longer and potentially very productive lives during which they can contribute a lot to Canadian society. At the same time, the costs of the new treatments are high. Assessing the potential costs and potential benefits from allowing a particular person with HIV to immigrate to Canada will not be easy, but must be attempted. In a considerable number of cases, the benefits will outweigh the costs, and persons living with HIV should be allowed to immigrate to Canada on that basis. In addition, in some cases, even when in purely monetary terms the costs would outweigh the benefits, persons living with HIV should be allowed to immigrate to Canada on compassionate grounds. Australia's system of assessing eligibility,[19] while not perfect, is certainly better than Canada's current system and could serve as an example. In any system it must also be ensured that HIV and AIDS are not treated differently from other diseases or situations with potentially high costs for Canadian taxpayers. Any rules about medical admissibility must be applied equally and fairly to all potential immigrants, including persons living with HIV. Finally, as a society, we also need to make a fundamental decision about how far we want to go in excluding potential immigrants. Should we hold persons of over 50 years of age medically inadmissible because they are unlikely to contribute significantly to Canadian society in monetary terms, but are likely to need costly health care relatively soon after immigrating to Canada? Should we screen for genetic disorders? It is submitted here that we should not. Immigrants as a group have and continue to contribute significantly to Canadian society. Recognizing this, the medical inadmissibility review process should allow for taking humanitarian concerns into account.

Conclusions

For many reasons, Canada should not introduce mandatory HIV testing of prospective immigrants. In addition, the current system according to which immigration applicants who are found to be HIV-positive are assessed as "medically inadmissible" should be changed so that persons living with HIV/AIDS or other similar conditions will not automatically be excluded from immigrating. A new system should take the individual circumstances of each case into account, weigh the costs against the benefits of allowing a particular person to immigrate, and take humanitarian concerns into account.

- *Ralf Jürgens*

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ENDNOTES

[1]See also Policy for Persons Living with HIV/AIDS. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 2(2): 14-15. The following text has been adapted from R Jürgens, M Palles. *HIV Testing and Confidentiality*. Montréal: Canadian HIV/AIDS Legal Network and Canadian AIDS Society, 1997, 207-225.

[2]Correspondence received from Dr GA Giovinazzo, Director, Immigration Health Services, Ottawa, on 13 February 1997.

[3]This examination is a screen. Its purpose is to determine medical and psychiatric conditions that may create an excessive demand on Canadian health or social services or that might reasonably pose a threat to public health or safety.

[4]Communication with Dr Giovinazzo on 13 February 1997.

[5]According to correspondence received from Dr Giovinazzo on 14 February 1997, it was intended to extend the instructions to the United States within "the next few months," but "there may well be changes to these instructions for overseas examining physicians."

[6]Supra, note 2.

[7]Ibid.

[8]WC Bartlett. *AIDS: Legal Issues*. Ottawa: Library of Parliament Research Branch, Current Issue Review 93-7E, 14 April 1994 (revised 19 April 1995), at 6. For more details, see S Wilson. Recent Developments in Immigration Law. *Canadian HIV/AIDS Policy & Law Newsletter* 1994; 1(1): 9-10.

[9]Bartlett, ibid.

[10]Communication with Dr Giovinazzo, supra, note 4.

[11]Ibid; see also in this issue of the *Newsletter*, R Carey. Challenging Ontario's Denial of Medical Care to HIV-Positive Immigrants.

[12]J Bryden. Marchi Considers AIDS Tests for Immigrants. *The* [Montréal] *Gazette* 26 April 1994, at B4.

[13] See House of Commons Debates, Official Report (Hansard), vol 133, no 96, 23 September 1994.

[14] Bryden, supra, note 12.

[15] Bartlett, supra, note 8 at 5.

[16] MA Somerville. The Case against HIV Antibody Testing of Refugees and Immigrants. *Canadian Medical Association Journal* 1989; 141: 889-894 at 893-894.

[17] Ibid at 892.

[18] Medical Inadmissibility Review. Recommendations prepared by Employment and Immigration Canada in consultation with Health and Welfare Canada, June 1992.

[19] See Australia: Allowing People with HIV Permanent Residence. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 2(3): 16-17.

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Challenging Ontario’s Denial of Medical Care to HIV-Positive Immigrants

The HIV & AIDS LEGAL CLINIC (ONTARIO) (HALCO) is a free law clinic for people living with HIV or AIDS in Ontario. One of the recurring problems seen by the clinic is the denial of access to free medical care by the Ontario Ministry of Health to certain classes of immigrants who are HIV-positive.

In Ontario, medicare is provided to the province’s residents pursuant to the Ontario Health Insurance Program (OHIP). In order to be eligible for OHIP, one has to meet the definition of "resident" set out in the regulations passed pursuant to the *Health Insurance Act*, RSO 1990, c H.6. Because of the way the provincial definition of "resident" in OHIP legislation interplays with the federal classification of immigrants under the *Immigration Act*, RSC 1985, c I-2, some HIV-positive immigrants cannot get access to free medical care in Ontario, whereas HIV-negative immigrants in exactly the same circumstances can.

The most common example HALCO deals with is the treatment of HIV-positive foreign spouses of Canadians in applications for permanent residency. In such applications, the Canadian spouse applies to sponsor the foreign spouse so that the foreign spouse can also eventually become a Canadian citizen. The HIV-negative foreign spouse becomes a "permanent resident" of Canada, which entitles that person to almost all the benefits of citizenship (except the right to vote) and the right to become a citizen within a certain period of time. The HIV-positive foreign spouse is refused permanent residence and is left in a form of limbo for five years. After five years the HIV-positive spouse is entitled to become a permanent resident despite the seropositive status, but during those five years the person is without the rights that go with permanent residence. In Ontario, one of those rights is free access to medical care.

Immigration

In Canadian law there are various "classes" of immigrants. The majority of immigrants come to Canada because they have close family members who are Canadian, and the family wants to be reunited and live in Canada. These immigrants are called family-class sponsored immigrants. As long as the Canadian relative is willing to support the immigrant relative when s/he arrives in Canada, Canadians have a right to be reunited with their close family from abroad. Sometimes the application is completed abroad, and the family member is granted the status of "landed immigrant" upon arriving in Canada. Having such status is extremely important for a number of reasons, the foremost of which is that the immigrant is accepted in principle for citizenship as a Canadian and simply has to serve a waiting period before applying to become a citizen. Landed immigrants are also called "permanent residents"; for the purpose of this article, the phrases are interchangeable.

When the federal Department of Employment and Immigration processes an application, a medical report is required (along with a criminal record check in Canada and in the country of origin). If a person is known to be HIV-positive, that fact will be reported. As a result of their HIV-positive status, these applicants are not treated in the same way as other applicants in the same class. This is because of section 19(1) of the *Immigration Act*, which says:

> No person shall be granted admission who is a member of any of the following classes: ... Persons who are suffering from any disease, disorder, disability or other health impairment as a result of the nature, severity or probable duration of which, in the opinion of a medical officer concurred in by at least one other medical officer, ... they are likely to be a danger to public health or to public safety, or ... their admission would cause or might reasonably be expected to cause excessive demands on health and social services... .

Immigration officials do not usually take the position that HIV-positive people are a danger to public health or safety, but they do take the position that anyone who is HIV-positive might reasonably be expected to cause excessive demands on health and social services.[1] As a result, HIV-positive immigrants are initially denied the right to become permanent residents. Instead, Immigration will issue family-class sponsored immigrants a Minister’s Permit. A Minister’s Permit gives a non-Canadian the legal right to be present in Canada. Section 38(1) of the *Immigration Act* says that after five years on a Minister’s Permit, an individual can be landed despite their ineligibility due to medical inadmissibility. In other words, the HIV-positive sponsored relative has to wait longer to become a citizen, and while waiting is not classified as a permanent resident and therefore has fewer rights than the HIV-negative sponsored relative. One of the rights taken away by this status is access to OHIP in Ontario.

Access to Medicare in Ontario

In 1994 the Ontario government changed the regulations to the *Health Insurance Act*, redefining "resident" for the purposes of eligibility for OHIP coverage. The changes to the regulations have meant that a growing segment of Ontario’s population is ineligible for OHIP coverage.

One of the populations affected by these regulation changes is immigrants living legally in Canada on certain kinds of Minister’s Permits. Not everyone with a Minister’s Permit will be denied OHIP. Minister’s Permits have on their face a number called a "casetype." The casetype code is basically an explanation of why the Minister's Permit was issued. Under Ontario Regulation 552 made pursuant to the *Health Insurance Act*, only certain casetypes will lead to ineligibility for OHIP, one of which is for family-sponsored immigrants who are medically inadmissible. Typically these are the people who contact HALCO. They have come to Canada to join their Canadian spouses and family. They often have Canadian children. And they happen to be HIV-positive.

The irony, of course, is that after five years on a Minister’s Permit in Ontario, without OHIP and without access to drug treatments (eligibility for the Trillium drug plan requires that the applicant be eligible for OHIP), there is a far greater chance that one will be a burden on health-care resources than if one had received treatments and drugs from the beginning. But after five years of waiting, one is automatically entitled to be landed. Therefore, the enforced five-year wait unnecessarily increases the probability that the HIV-positive immigrant will need costlier medical care.

The Charter Challenge

The discrimination in both the immigration procedures and OHIP is obvious. The HIV-positive relative sponsored by a Canadian is denied access to free health care for five years; the HIV-negative one is not. It is difficult to imagine that this aspect of the OHIP eligibility scheme will not be found to breach the guarantee of equal rights to benefits without discrimination on the ground of disability set out in section 15(1) of the *Canadian Charter of Rights and Freedoms.*

Legally, then, in the Charter analysis, the issue becomes whether or not the OHIP legislative scheme can pass the section 1 test of any Charter challenge: is this discrimination justifiable? What legislative objective does the discrimination serve to meet? Is that legislative objective valid? Is the legislated measure (denial of OHIP) the least intrusive way of meeting the legislative objective?

If someone is HIV-positive and asymptomatic, what justification could there be for denying that person access to health care? His/her demand for health services may well be similar to that of an HIV-negative person. For someone who is not asymptomatic, would providing medical coverage really be so expensive as to justify the discrimination? Has Ontario’s Ministry of Health done projections for the costs of health care for the small number of HIV-positive immigrants, or have they simply chosen to discriminate in the hope that no one will challenge them?

HALCO intends to find out by appealing the denial of OHIP to Ontario’s Health Services Board, using the Charter to challenge the exclusion of HIV-positive immigrants in the definition of "resident" in the Regulation.

For the purposes of the Charter challenge it would be helpful to hear from HIV-positive immigrants in other provinces: can you get health care through your provincial medicare plan? It would also be helpful to know from immigrants living with HIV in Ontario how not being able to access medical services affects your life. HALCO has a toll-free telephone number within Ontario (1-888-705-8889) and accepts collect calls. All contacts with HALCO are kept strictly confidential and are covered by solicitor–client privilege.

- *Ruth Carey*

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ENDNOTE

[1] For a comprehensive overview of immigration and HIV/AIDS in Canada, see R Jürgens, M Palles. *HIV Testing and Confidentiality: A Discussion Paper*. Montréal: Canadian HIV/AIDS Legal Network and Canadian AIDS Society, 1997, at 207-225.

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EUTHANASIA

The Case for Assisted Suicide and Euthanasia

This article continues our series on one of the most hotly debated legal and ethical issues: whether or not assisted suicide and euthanasia should be legalized.[1] **The article takes the position that (1) assisted suicide and active, voluntary euthanasia should be legalized for people in the terminal phases of a chronic disease or condition, and (2) legalization should be accompanied by appropriate safeguards to prevent abuse. In support of this position, the author argues that legalization would be consistent with the principle of individual autonomy, that the status quo discriminates against the disabled, and that the status quo leads to premature deaths.**

Following the introductory section, the terms used in the article are defined, and the current state of the law is discussed. The position is then restated and the supporting arguments developed. This is followed by a discussion of opposing arguments and additional considerations. Finally, the safeguards that should accompany legalization are listed.

Introduction

The debate surrounding decriminalization or legalization of assisted suicide and euthanasia rages on in Canada and in many other countries. At the centre of this debate is how society should respond to the suffering of individuals in the terminal phases of an illness.

Despite the fact that it is illegal, the practice of assisted suicide and euthanasia among people living with AIDS is believed to be widespread. Several studies put the number in the Netherlands at between 10 and 20 percent.[2],[3] In Amsterdam one study showed a rate of 26 percent and in British Columbia another study estimated the rate at between 10 and 20 percent.[4]

In many ways AIDS is *the* disease that makes the case for assisted suicide and euthanasia. An AIDS-related death is usually gradual, prolonged and complicated by infections that would normally be handled with ease. It is often a very difficult and painful death.

Terminology

For the purposes of this article, the following definitions will be used:

Euthanasia versus Assisted Suicide

Euthanasia is an act done with the intention of ending the life of another individual, and constituting an act of mercy to relieve that individual's suffering.

Assisted suicide is assisting an individual to take his or her own life, where the individual has requested assistance, and where such assistance is provided as an act of mercy to relieve that individual's suffering.

The difference between euthanasia and assisted suicide can be illustrated using the following examples:

- Where a person administers a lethal injection to an individual, the person has committed an act of euthanasia.

- Where a person provides the necessary medication, and the medication is then taken by an individual, the person has assisted in a suicide.

Both examples assume an act of mercy to relieve suffering.

Active versus Passive Euthanasia

Euthanasia can be active or passive, depending on the action involved:

- *Active* euthanasia involves the administration of a treatment or an act that induces death.

- *Passive* euthanasia involves the withholding or withdrawing of life-sustaining treatment or nourishment.

Voluntary, Non-Voluntary, Involuntary Euthanasia

Euthanasia can also be voluntary, non-voluntary or involuntary, depending on whether there is consent:

- Euthanasia is *voluntary* when done to a competent individual who has requested assistance to end his/her own life.

- Euthanasia is *non-voluntary* when done to an individual without knowledge of his/her wishes.

- Euthanasia is *involuntary* when done to a competent individual against his/her wishes.

Different Forms of Euthanasia

Some of the cases that made the headlines in Canada help to illustrate the different forms of euthanasia:

- Nancy B suffered from an incurable neurological disease that left her incapable of movement. She was kept alive by machines. She went to court to have the machines turned off and was successful.[5] This is an example of passive, voluntary euthanasia.

- Sue Rodriguez suffered from ALS, also known as Lou Gehrig's disease, an incurable condition that attacks the muscles and had robbed her of almost all movement. She asked the courts to allow her to obtain assistance to die because she knew that she would be incapable of killing herself when the time came that she no longer wanted to remain alive. Her request was denied.[6] She eventually obtained the assistance of a physician to die. The physician administered a lethal injection. This is an example of active, voluntary euthanasia.

- Robert Latimer put an end to the life of Tracy, his severely disabled daughter. She was considered to be incompetent – ie, not able to give consent. This is an example of active, non-voluntary euthanasia. Latimer was subsequently convicted of second degree murder. Recently, the Supreme Court ruled that his case had to be reheard.[7]

Current State of the Law in Canada

Suicide and *attempted suicide* were decriminalized in 1972. However, there is a specific provision in the *Criminal Code* against counselling, aiding or abetting a person to commit suicide — ie, assisted suicide. This provision has rarely been invoked.

Euthanasia is not mentioned in the *Criminal Code*. However, the Code:

- prohibits murder;
- prohibits a person from consenting to have death inflicted on him/her;
- places certain restrictions on the right to refuse treatment; and
- prohibits the acceleration of death even if the patient is already dying.

However, case law and civil law have evolved to the point where:

- the right to consent to, and to refuse, medical treatment is accepted; and
- the right to have treatment withdrawn or withheld is accepted.

Most provinces have enacted legislation allowing individuals to indicate through advance directives and living wills under what circumstances they want life-saving treatments withdrawn or withheld.

Therefore, for all practical purposes, the practice of passive, voluntary euthanasia is already legal in Canada.

Position and Supporting Arguments

Of the many types of assisted suicide and euthanasia listed above, three involve circumstances where the individual requests assistance to end his/her life:

- assisted suicide;
- active, voluntary euthanasia;
- passive, voluntary euthanasia.

As shown above, passive, voluntary euthanasia is, for all practical purposes, legal in Canada. It is submitted that assisted suicide and active, voluntary euthanasia should also be legalized and that legalization should be accompanied by appropriate safeguards to prevent abuse.

The Right to Choose

Legalizing assisted suicide and active, voluntary euthanasia would be consistent with the principle of individual autonomy — ie, the right to self-determination and the right to choose. This is an overwhelming argument in favour of legalization.

People have the right to make decisions about their own health care and to have their wishes respected in matters involving their own body. It is unfair to force people to continue to live when they no longer wish to do so. They should be allowed to choose to leave the world when they are satisfied that there is no quality of life left for them, or when their pain and suffering is too great.

For some people, a prolonged dying process can cause a loss of independence and control over their lives, and lead to a loss of dignity unacceptable to them. We have a moral duty to respect the wishes of people in this situation to choose the manner and timing of their deaths.

Our society already recognizes the principle of personal autonomy in some end-of-life decisions. We allow people to take their own lives — ie, suicide. We allow people to have life-sustaining treatment withdrawn or withheld — ie, passive, voluntary euthanasia. It is only logical, therefore, to allow people to request and receive assistance to die if they feel they require or desire such assistance — ie, assisted suicide or active, voluntary euthanasia.

There is very little, if any, distinction between passive euthanasia and active euthanasia, since the passive form still requires some form of an action. If a person is in the final stages of a terminal illness and does not want to endure the suffering any longer, is there any significant difference between a decision to withdraw a treatment, withhold a treatment, or administer a treatment if, in all three cases, death ensues? In each case, a decision to allow death to occur has been taken. It is only the means of attaining that end that is different.

Discrimination

In Canada, taking one's own life is allowed. As a result, people who are physically able can legally commit suicide. However, someone who is physically unable to commit suicide cannot legally receive assistance to die, if such assistance involves the administration of a treatment. This situation discriminates against the disabled and is in violation of the equality provisions of the Charter of Rights and Freedoms.

Premature Deaths

Opponents of the legalization of assisted suicide and active, voluntary euthanasia argue that these acts result in people dying "before their time." However, it should be up to the individual to decide when his/her time has come. In fact, if anything causes people to die "before their time" it is the fact that assisted suicide and active, voluntary euthanasia are not legal, which results in many people committing suicide prematurely, before they are truly ready and willing to die. They do so because they feel that they cannot afford to wait until they are physically incapable of taking their own lives, or because they do not want to ask their families, friends or health-care workers to commit an illegal act.

Discussion of Opposing Arguments

Those opposed to assisted suicide and active, voluntary euthanasia have advanced a number of arguments to support their position. The following are three of the most frequently used arguments.

Quality of Life vs Sanctity of Life

One argument advanced by opponents of assisted suicide and active, voluntary euthanasia is that life is so sacred and so intrinsically valuable that the state should not condone the taking of a life no matter how much the patient may be suffering. This is known as the sanctity-of-life argument.

In my opinion, society does not view life as an absolute value that transcends everything. Rather, society recognizes that there are some inherent limitations placed upon this value. For example, we allow

- people to commit suicide and to attempt suicide;
- killing in self-defence;
- people to refuse medical treatment;
- the withdrawal or withholding of life-sustaining treatments;
- the administration of pain medication to people in the end stages of life even when we know the dose of medication will be strong enough to cause death.

I submit that in the context of end-of-life decisions, quality of life is a legitimate consideration and that it is intrinsically more persuasive than the sanctity of life. As Chief Justice Antonio Lamer of the Supreme Court of Canada said in a dissenting opinion in the Court’s decision in the Rodriguez case:

> What value is there in life without the choice to do what one wants in life? ... For some, the choice to end one’s life with dignity is infinitely preferable to the inevitable pain and the diminishment of a long, slow decline.[8]

Palliative Care

Many opponents of assisted suicide and active, voluntary euthanasia argue that palliative care is the best and most effective method of addressing end-of-life situations, and that existing palliative care services should be improved.

Certainly, palliative care should be one of the options available. However, there is evidence that not all physical suffering associated with incurable illness can be relieved. In particular, some AIDS-related pain does not appear to respond well to opioid drugs.

Furthermore, it is often concerns other than physical pain that cause people to consider assisted suicide and active, voluntary euthanasia. These are:

- fear of loss of dignity;
- fear of an unacceptable quality of life;
- fear of lack of control over their body and bodily functions;
- economic or other burdens that may be experienced by family and friends; and
- fear of abandonment or isolation.

Palliative care cannot address all of these concerns. For example, there have been many cases where palliative care has been successful in controlling a person's physical pain, but this did not eliminate the individual's desire to end his/her life – eg, Sue Rodriguez and Nancy B.

As Svend Robinson, Member of Parliament for Burnaby–Kingsway, said in a debate in the House of Commons:

> At the end of the day, as even palliative care doctors will tell you, there is some indignity and some pain that no amount of palliative care can effectively respond to. ... Dr. Scott Wallace, in his brief to the Senate committee has pointed out that the process of dying can involve some of the most miserable and distressing sensations known to man, such as jaundice with intolerable itching, insomnia, hallucinations, constant unrelievable hiccups, the inability to swallow, paralysis of muscle groups requiring the insertion of multiple tubes, intense nausea and vomiting, incontinence of feces and urine, just to name a few. Not all of these can be controlled or regulated by even the finest palliative care. The wracking pain of bone cancer cannot in all cases be responded to by palliative care.[9]

Slippery Slope

Many opponents of the legalization of assisted suicide and active, voluntary euthanasia argue that allowing assisted suicide and active, voluntary euthanasia would inevitably lead to non-voluntary and involuntary euthanasia, and to situations where the elderly, the disabled and other vulnerable individuals would be forced or pressured to end their lives.

This "slippery slope" argument is a hypothetical argument, since we cannot know what will happen unless we legalize assisted suicide and active, voluntary euthanasia. However, experience in this area suggests that there is no reason to anticipate such dire consequences. We already allow suicide. We already allow passive, voluntary euthanasia — ie, the withdrawal or withholding of life-sustaining treatment at the request of an individual who wants to die. There does not appear to be any evidence that either of these measures has placed us on this "slippery slope."

The position being advocated here calls for the legalization only of assisted suicide and of active, voluntary euthanasia.

Non-voluntary euthanasia and involuntary euthanasia would remain illegal. Furthermore, the safeguards that would be enacted would protect against abuse.

Other Considerations

Back-Street Euthanasia

Assisted suicide and active, voluntary euthanasia are occurring regularly. Because these acts are illegal, they are performed entirely underground. Some patients are lucky; they are able to obtain the assistance of a physician and the act is done properly. However, many cases involve painful, botched deaths that result in terrible suffering for both the patient and the survivors. Legalizing assisted suicide and active, voluntary euthanasia would put an end to this.

Widespread Public Support

A majority of Canadians support the legalization of assisted suicide and active, voluntary euthanasia. Canadians have been polled on this issue every year since 1968.[10] They have been asked the same question each time:

> When a person has an incurable disease that causes great suffering, do you think that competent doctors should be allowed by law to end the patient's life through mercy killing, if the patient has made a formal request in writing?

In 1968, 45 percent said yes. By 1989, this number had reached 77 percent. Since 1989 it has remained between 75 and 78 percent. In 1995, 75 percent said yes and 17 percent said no.

Two Canadian studies among people living with HIV/AIDS show nearly unanimous support for the legalization of assisted suicide and active, voluntary euthanasia, providing adequate safeguards are put in place.[11]

Safeguards

Appropriate guidelines are required to prevent abuse and to ensure that requests for assisted suicide and active, voluntary euthanasia are rational and well thought out. These guidelines will need to spell out a process for requesting and carrying out assisted suicide and active, voluntary euthanasia. The guidelines should embody the following elements:

- Individuals must be suffering from an irreversible illness that is well-advanced.
- Individuals must have been informed of, and fully understand, their condition and prognosis, and the options available for their care.
- Individuals must receive counselling on the importance of their decision being rational, informed and free of coercive pressures.
- Individuals must make the request more than once, in writing if possible. A minimum time interval between requests should be established.
- Individuals must be informed of, and must fully understand, their right to change their minds at any time and to reverse the request.
- At least two health-care professionals must certify that the patient is mentally competent and capable of making a rational, informed decision; and that the proper process has been followed.
- Each case must be reported to the appropriate authority.

Conclusions

So far, the debate on assisted suicide and euthanasia has been carried out mainly by academics, pundits and editorial writers. It is time that we listen to those who are terminally ill and to those who have experienced terrible suffering and death in their own families. These people are telling us, in overwhelming numbers, that assisted suicide and active, voluntary euthanasia should be legally available to them, should they choose to go that route.

Legalizing assisted suicide and active, voluntary euthanasia would not impose anything on anyone. Nor would it encourage people to kill themselves. It would simply say to people that society accepts that assisted suicide and active, voluntary euthanasia are legitimate choices for the terminally ill. In the words of Sue Rodriguez:

> If I cannot give consent to my own death, whose body is this? Who owns my life?[12]

- *David Garmaise*

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ENDNOTES

[1]All references are to articles in the *Canadian HIV/AIDS Policy & Law Newsletter*: R Ogden. The Uncloseting of AIDS-Related Euthanasia. 1994; 1(1): 14-15; R Ogden. Euthanasia Law and Policy. 1995; 1(2): 9-10; Position Statement on Assisted Suicide Approved. 1995; 1(4): 11; T Lemmens. Legalizing Euthanasia. 1995; 2(1): 7-9; T Lemmens. Oregon's Measure 16 Declared Unconstitutional. 1995; 2(1): 9; R Ogden. Euthanasia: A Reply. 1996; 2(3): 20-22; T Lemmens. US Appeal Courts Rule in Favour of Assisted Suicide. 1996; 2(4): 1, 42-43; The Editor. Australia - Lenient Sentence in Euthanasia Case. 1996; 2(4): 25-26; The Editor. Dutch Study on Euthanasia in Gay Men with AIDS. 1996; 2 (4): 26; B Mongodin. Toward an End-of-Life "Treatment"? 1996; 3(1): 22-23.

[2]PJ van der Maas, JJM van Delden, L Pijnenborg, CWN Looman. Euthanasia and other medical decisions concerning the end of life. *Health Policy* 1992; 22(1/2).

[3]M de Wachter. In brief: the Dutch and the dying. *Hastings Centre Report* Nov/Dec 1991, at 2.

[4]RD Ogden. *Euthanasia, Assisted Suicide and AIDS*. Perogylphics Publishing: New Westminster, British Columbia, 1994.

[5]*Nancy B v Hôtel Dieu de Québec*, 69 CCC (3d) 450.

[6]*Rodriguez v British Columbia (Attorney General)*, [1993] 3 SCR 519.

[7]*R v Latimer*, [1997] SCJ No 11.

[8]A Lamer, dissenting opinion. *Rodriguez v British Columbia*, supra, note 6.

[9]S Robinson. *House of Commons Debates*. 21 Sept 1994: 5969.

[10]Gallup poll much the same as past years. *Dying with Dignity Newsletter* 1995; 12(4): 1.

[11]C Neron. Study on Euthanasia, Assisted Suicide and HIV/AIDS. Report prepared for the Canadian AIDS Society. Ottawa: The Society, May 1996; Ogden, supra, note 4.

[12]S Rodriguez, in videotape testimony, November 1992.

Canadian HIV/AIDS Policy & Law Newsletter

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US Study on Physician-Assisted Suicide and Patients with HIV

A survey of 228 physicians in the Community Consortium, an association of providers of health care to patients living with HIV in the San Francisco Bay area, showed that the physicians' acceptance of assisted suicide increased between 1990 and 1995.[1]

Methodology

Between November 1994 and January 1995, an anonymous, self-administered questionnaire was sent to the physicians. Among other things, the physicians were asked how they would respond to a request from a patient with AIDS for assistance in committing suicide, as described in the following case:

> Tom is a 30-year-old gay male computer programmer diagnosed with AIDS two years ago. He has severe wasting syndrome and painful oral ulcers, and responded poorly to treatment for his third episode of *Pneumocystis carinii* pneumonia. There is no evidence of neurological impairment, and it is clear that Tom is mentally competent. His mood is mildly depressed, but the depression is not pronounced given the seriousness of his condition. Tom has been in a primary relationship for eight years and worked until several months ago. As his personal physician since his diagnosis, you consider Tom a thoughtful, intelligent patient who does not appear to have any significant psychopathology. During Tom's biweekly clinic visit, he asks you to prescribe a lethal dose of narcotics for possible use at some future date.

The responses were compared with those in a 1990 survey of consortium physicians. Physician-assisted suicide was defined as "a physician providing a sufficient dose of narcotics to enable a patient to kill himself." Respondents were to "assume that the patient is a mentally competent, severely ill individual facing imminent death."

Results

118 questionnaires were evaluated. The researchers found that:

- respondents reported a mean of 7.9 "direct" and 13.7 "indirect" requests from patients for assistance in suicide.
- 48 percent of the respondents in 1995 said they would be likely or very likely to grant Tom's initial request for assistance, compared with 28 percent in 1990.
- 53 percent of the respondents in 1995 reported that they had "granted an AIDS patient's request for assistance in committing suicide" at least once.
- 50 percent of the respondents in 1995 and 49 percent of the respondents in 1990 reported that they had consulted with colleagues about helping patients with AIDS to commit suicide.

Four factors were found to be associated positively with whether a physician had ever assisted in a patient's suicide:

- a higher number of the physician's patients with AIDS who had died;
- a higher number of indirect requests from patients for assistance;
- a gay, lesbian or bisexual orientation on the part of the physician; and
- a higher "intention-to-assist" score.

Discussion

As the authors point out, previous surveys of physician-assisted suicide reported that seven to nine percent of physicians have complied with requests from terminally ill patients for assistance in suicide.[2] In contrast, in this survey, 48 percent of physicians reported assisting at least once in a suicide of a patient with AIDS, a "surprisingly large proportion." This confirms the results of another study indicating that rates of euthanasia and physician-assisted suicide among patients with AIDS may be higher than in the general population.[3]

Limitations

The authors acknowledge that a major limitation of the study is

selection bias, which limits the generalizability of the findings: physicians who had an interest in or experience with assisted suicide may have been more likely than others to respond to the survey. In addition, the study was conducted in the San Francisco Bay area, where attitudes are generally more liberal and where there is a higher incidence of HIV than in other regions of the US.

- *Louise Shap*

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ENDNOTES

[1] Lee R Slome et al. Physician-Assisted Suicide and Patients with Human Immunodeficiency Virus Disease. *Journal of the American Medical Association* 1996; 336: 417-421.

[2] MA Lee et al. Legalizing assisted suicide – views of physicians in Oregon. *New England Journal of Medicine* 1996; 334: 310-315; TR Fried. Limits of patient autonomy: physician attitudes and practices regarding life-sustaining treatment and euthanasia. *Archives of Internal Medicine* 1993; 153: 722-728.

[3] See PJE Bindels et al. Euthanasia and physician-assisted suicide in homosexual men with AIDS. *Lancet* 1996; 347: 499-504. For a summary, see Dutch Study on Euthanasia in Gay Men with AIDS. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 2(4): 26.

Canadian HIV/AIDS Policy & Law Newsletter

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Canadian Study on Euthanasia, Assisted Suicide and HIV/AIDS

In a small study published in 1996, Neron explores the views, attitudes, and experiences relating to euthanasia and assisted suicide of three groups: 13 persons living with HIV/AIDS; 11 persons who had assisted in AIDS-related deaths; and 9 persons with an interest in euthanasia and assisted suicide, such as a counsellor, bioethics experts, and a nurse.[1]

Group 1: Persons Living with HIV/AIDS

Nine of the 13 persons interviewed (69 percent) stated that they planned to have an assisted death:

> Many stated they felt relief after making the decision to plan an assisted death. Knowing assisted death was an option helped them manage the uncertainty related to future health deterioration and their death.[2]

Other findings include:

- Death through overdose of drugs was the most commonly cited method planned for assisted deaths.
- Those planning to have an assisted death all stated that they would end their lives when they felt they had reached the point in their illness when they had no chance of recovery.
- The decision to have an assisted death, and the planning associated with that decision, can occur at any stage of HIV and AIDS and is not unique to individuals whose illness has progressed.
- Depression did not appear to be a factor that affected the decision to have an assisted death, and none of the persons living with HIV/AIDS voiced concern that no one cared for them.
- Many were concerned about the loss of control related to future health problems and death, the fact that not all pain could be controlled, and the side effects associated with pain control:

  > "I don't want to spend my last days out of it," stated one PLWHIV/AIDS. "That's not quality of life to me."[3]

- The most frequently cited factor affecting the decision of a person living with HIV/AIDS to plan an assisted death was the witnessing of others dying of AIDS.

Group 2: Persons Who Have Assisted in AIDS-Related Deaths

Participants in this group assisted in at least 25 AIDS-related deaths, in most cases through assistance in suicide. Assistance was given in various ways: by helping to obtain and stockpile medication; by providing medication; by providing information, advice and support and/or assisting with plans for the death; and by administering medication to expedite death.

Other findings include:

- In the vast majority of cases, plans regarding the assisted deaths were discussed extensively beforehand.
- All deaths were expedited through the administration of medication.
- Several participants stated that they felt relief after the death and that, later, feelings of isolation developed as they were not able to discuss their involvement openly.
- Ten of the eleven participants had no regrets about assisting.

Group 3: Persons with an Interest in Euthanasia and Assisted Suicide

While nearly all the participants in the other groups supported legal changes related to euthanasia and assisted suicide, only two of the nine participants in group 3 were supportive of such changes. They expressed various concerns, including potential abuse of marginalized groups if euthanasia and assisted suicide were to be legalized, and stressed the need to increase palliative care services.

Neron comments about the differences between this and the other two groups as follows:

> Although some similarities did arise amongst the findings of the three groups, differences in attitudes, values, and perceptions related to euthanasia and assisted suicide emerged between those most directly affected by these issues (PLWHIV/AIDS and those who have assisted in deaths) and "experts" in the field, such as those working in bioethics and palliative care. While input from both groups is essential to the assisted death debate, in reality it is often the "experts" whose opinions are sought for legislative and policy changes, and who publish literature related to these issues. Efforts must be made to ensure that the voices of those most directly affected by these issues are considered in future policy development.[4]

- *Louise Shap*

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ENDNOTES

[1] Canadian AIDS Society. Study on Euthanasia, Assisted Suicide and HIV/AIDS. A Report Prepared for the Canadian AIDS Society by Carole Neron. Ottawa: The Society, 1996. Neron's study began as a qualitative study for CAS and was later expanded for academic purposes.

[2] Ibid at 3.

[3] Ibid at 5.

[4] Ibid at 11.

Canadian HIV/AIDS Policy & Law Newsletter

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DISCRIMINATION

European Study of Legal Services for Those Affected by HIV/AIDS-Related Discrimination

An interdisciplinary project about legal services for persons affected by HIV/AIDS-related discrimination is underway in Europe. The first stage of the project, funded by the European Commission, is aimed at developing best-practice standards and providing training recommendations. Its overall objective is to improve access to legal services and to reduce instances of HIV/AIDS-related discrimination across Europe.

In the longer term, the project hopes to be able to look at

- the type and range of discrimination experienced by those affected by HIV; and
- legal recourses.

This could lead to the development of training materials for legal professionals and advisers involved in HIV/AIDS discrimination cases in order to promote

- sensitive and effective case handling; and
- challenges to discriminatory behaviour.

The study is being coordinated in London, England, by Prof Avrom Sherr of the Institute of Advanced Legal Studies and Dr Lorraine Sherr of the Royal Free Hospital Medical School. It includes legal practitioners, legal academics and health professionals from seven European countries – France, Germany, Italy, Norway, Portugal, the Netherlands and the United Kingdom.

Conditions within Each Country

In each country, the project is collecting information on HIV/AIDS-related policy and social conditions. An analysis of the official policies on exclusion, screening and testing will be undertaken. In addition, the project is collecting information on

- the legal structure within each country; and
- specific and more general legislation that can be invoked in HIV/AIDS discrimination cases.

Factors felt to be important include:

- the range of legal help that is offered, including formal and informal legal services, generalist and specialist practitioners and legal centres; and
- the training lawyers receive on HIV-related case issues.

One premise for the research is that there may be characteristics of the legal system that may inherently restrict access, either directly or indirectly. Such issues include:

- the length of time it takes to bring cases through the legal system and the toll this may have on the health of the client;
- the lack of anonymity in legal cases in many of the countries concerned; and
- the availability of organizations that can champion a client's case without the client's identity being revealed to the public.

Although legal aid is available in all seven countries being studied, there are strong variations in the liability for costs of the legally aided party where they lose their case – a finding that is also considered to be important.

Identifying practices that work well in each of the countries studied will assist in the development of best-practice training and policy. In addition, a greater understanding of the interplay between specialist HIV organizations and private practice lawyers will open up access to legal redress for many more people.

Discrimination – Is It Viewed as a Legal Problem?

The research is also considering in more detail both HIV discrimination and unmet legal needs. Few HIV-specific cases have been brought to date within the seven countries, even where there is a constitutional right to equality and where legislation is in place that can be invoked by individuals affected by HIV. The project is considering whether, contrary to the general perception, discrimination is less acute than it used to be, or whether discrimination issues are not being translated into problems that may have a legal solution. To address some of these issues, an extensive research exercise is being carried out by way of questionnaire to two target groups:

- those living with, or affected by, HIV;
- legal professionals in law firms, law centres, specialist agencies and Citizens’ Advice Bureaux (CABx)[1] who may have come into contact with HIV/AIDS-related cases.

The first questionnaires, given to those affected by HIV in all seven countries in the research study, have focused on the types of discrimination that are being experienced and on whether legal action was taken pursuant to the discrimination. This includes asking what effect discrimination has had on the individual and whether the current system adequately serves those affected by HIV. It also aims to elicit information on the type of support that could improve access to justice and help to reduce instances of discrimination.

The second questionnaire, sent to 10,000 law firms, specialist agencies, CABx and barristers’ chambers in England and Wales, explores whether respondents:

- have been involved in HIV/AIDS-related cases, and if so of what kind;
- have had any specialist training in HIV issues, and if so from whom;
- feel that they would benefit from specialist training, and if so in what form.

Preliminary findings suggest that 40 percent of those who have responded to the second questionnaire have come into contact with an HIV-related case. However, few cases ever proceeded past the initial stages. Cases appear to cluster in the areas of family and criminal law, where the client has been thrust into the legal arena as a result of a criminal charge or due to a relationship breakdown or other family dispute. Few cases have been highlighted in the fields of employment, insurance or housing, although these seem to be the areas habitually covered by specialist agencies in the UK.

Further work relates to the way in which legal services are currently organized in each of the countries involved in the study. Each country in the study has a different ratio of specialist to generalist services, with very different functions. In Germany, for example, advice may be given by specialist agencies, but assistance may only be provided by a lawyer. This excludes the development of specialist law centres to act both as pressure groups and as first- and second-tier legal services, as they do in the UK. The Netherlands approach legal service through private practice provision, and treat HIV-discrimination cases in much the same way as they would any other discrimination case. They consider that there is no evidence of institutional discrimination in the Netherlands and that consequently specialist services are not required to level out inherent disadvantages in the system that operate against those affected by HIV. For each of the seven countries, the nature of legal service delivery is being considered, to draw upon elements that will inform the development of best-practice requirements in the field of legal services for those discriminated against on the basis of HIV/AIDS.

- *Lisa Webley*

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ENDNOTE

[1]In the UK, CABx provide free legal and other kinds of advice, and people often use them in order to find out whom they should to get further help. Many offer a limited representation service where legal aid is not available to allow solicitor representation.

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US – More than $400,000 Damages in HIV Discrimination Case

On 4 April 1997, the District of Columbia Commission on Human Rights issued a ruling awarding more than US$400,000 in damages and attorney fees and expenses in an HIV discrimination matter.[1]

John Doe was brought by ambulance to hospital after a suicide attempt. From comments he made, hospital staff decided he was gay and subjected him to an HIV test without his consent. After he tested positive, hospital staff refused to admit him to the psychiatric ward. His HIV-positive status was noted on his hospital chart without his knowledge or consent, as a result of which both his HIV status and sexual orientation were revealed to his employer, a government defense agency, when he signed a routine authorization for release of his medical records.

Doe charged disability and sexual orientation discrimination. In its decision, the Commission awarded $50,000 for indignity and emotional and psychological distress because of the non-consensual HIV testing, $50,000 for indignity and emotional and psychological distress because of the denial of psychiatric care, $8,920 for lost income, and $296,678 for attorney fees and litigation expenses. In addition, the Commission issued an injunction barring the hospital from "administering non-consensual HIV tests on the basis of sexual orientation."

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ENDNOTE

[1] *Estate of John Doe v Howard University Hospital*, No 89-095-PA(N), on remand from *Doe v DC Comm'n on Human Rights*, 624 A.2d 440 (DC 1993). Reprinted from *Lesbian/Gay Law Notes* May 1997

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PRISONERS AND HIV/AIDS

Methadone and Sterile Needles Soon in Canadian Federal Prisons? Parliamentary Sub-Committee Hears Witnesses

On 26 November 1996, two months after the release of *HIV/AIDS in Prisons: Final Report,*[1] the Parliamentary Sub-Committee on HIV/AIDS heard evidence about the extent of the problems raised by HIV/AIDS and drug use in the Canadian federal prisons system, as part of its hearings on HIV/AIDS, poverty, and discrimination.[2]

Six witnesses appeared before the Committee:

- Ole Ingstrup, Commissioner of the Correctional Service of Canada (CSC);
- Ralf Jürgens, Project Coordinator of the Joint Network/CAS Project on Legal and Ethical Issues Raised by HIV/AIDS, appearing for the Legal Network;
- Pat Sasakamoose-Tait, a counsellor and AIDS educator at the Katarokwi Native Friendship Centre in Kingston;
- Rick Lines, Prison Outreach Coordinator with the Prisoners with HIV/AIDS Support Action Network (PASAN) in Toronto; and
- Sébastien Brousseau, Coordinator of the Prisoners' Rights Committee of Québec (Office des droits des détenu(e)s du Québec)(ODD).

The full text of their presentations and of the question period that followed the presentations is available for browsing and retrieval at <http://www.parl.gc.ca/committees352/shiv/evidence/12_96-11-26/shiv-12-cover-e.html>

The following is a summary of some of the most important statements made at the hearing.

Presentation by Ole Ingstrup

Mr Ingstrup acknowledged that the number of federal inmates who are known to be living with HIV or AIDS increased by 46 percent between 1994 and 1996. He further acknowledged that, according to a CSC survey of 4,300 inmates, 26 percent of inmates engage in "risky practices" such as needle sharing, tattooing or unprotected sex. According to Mr Ingstrup,

> this is cause for concern. We are concerned about these things in the Correctional Service of Canada. I know there are many things that can be done ...

He provided examples of some of the activities CSC is undertaking in the area of HIV/AIDS: educational programs for inmates that deal with HIV and AIDS and high-risk behaviours; staff training, "which has been and will continue to be a priority"; and the inmate peer education pilot project undertaken at Dorchester Institution in New Brunswick,[3] which "demonstrates a benefit of inmate peer education." With regard to the latter project, he mentioned that it had been "quite well received and accepted by inmates and by staff, and by prison administration," and that he would "be looking at ways" of expanding it.

Referring to sex and drug use in prisons, he said that

> [o]ver the years the Correctional Service of Canada has been compelled to make some hard choices on the prevention and spread of HIV/AIDS. For instance, sexual activity among inmates is considered a disciplinary offence. It's not being condoned by the Service. However, in January of 1992 we did begin to make condoms available to offenders, in an attempt to prevent the spread of HIV and AIDS ... because we recognized that despite our best efforts we are unlikely to be able to eliminate high-risk behaviour completely.

He continued by saying that he knew "of no correctional system in this world that would be courageous enough to claim they had complete control, to the extent that all high-risk behaviour would be eliminated." Because high-risk behaviour cannot be eliminated, it is now "national Correctional Service of Canada policy that condoms, lubricants, dental dams, and bleach kits are available to all inmates in all our institutions."

He then admitted that "there is one area in the HIV/AIDS strategy where I believe the Correctional of Service Canada is still weak, and that is in our capacity to provide HIV/AIDS programming specific to the needs of both aboriginal people and women." He expressed his intention "to see to it that we develop specialized programs for these offenders as part of a major strategy.

With regard to methadone maintenance and needle exchange programs in prisons, he said that CSC was

> studying carefully what other jurisdictions are doing to prepare our best response to the recommendations of Dr. Jürgens [in *HIV/AIDS in Prisons: Final Report*[4]] in this area. In my view and in the view of my colleagues, Dr. Jürgens's report has provided us with valuable insights in this respect. I'll continue to seek his assistance, and work closely with him and with others in this area who can help us by sharing their expertise and by helping to guide our service.

Finally, he expressed the view that "giving inmates the knowledge and the means to protect themselves is safer and more effective than mandatory testing and segregation, from the viewpoint of both the individual involved and the communities to which they will eventually return."

During the question period, he promised that CSC would study all recommendations that would be made by the Parliamentary Sub-Committee, and said that the

> recommendations, comments and evidence to be found in the Jürgens report [*HIV/AIDS in Prisons: Final Report*, see endnote 1] are also very important to us. We take them seriously and once we are finished with our studies, we'll attempt to develop an overall strategy for AIDS and other diseases of this type within the Correctional Service of Canada.

He added that he hoped "very much" that CSC would be able to develop the strategy in the spring of 1997.

Presentation by Ralf Jürgens

Mr Jürgens summarized the recommendations made by the Joint Network/CAS Project in *HIV/AIDS in Prisons: Final Report*.[5] While he congratulated CSC for some of the positive initiatives undertaken – such as bleach distribution – he emphasized that the Service has failed to act on many of the promises it made and remains reluctant to face the reality of HIV and drug use in prisons. He urged that action be taken immediately, pointing out that rates of HIV infection among prisoners in Canadian prisons are already more than ten times higher than among the general population, and that studies show that at least every third prisoner is infected with the hepatitis C virus.

He concluded:

> Inmates return to the community. Caring for their health in prison is protecting society as a whole. Denying them access to preventative measures, imposing compulsory testing, and segregating HIV-positive inmates are unacceptable responses to HIV. No prisoner has received or deserves a sentence to contract HIV infection. No prison employee deserves to contract HIV in the workplace. Mandatory testing and segregation would not protect them, but public health measures that have proven successful in our community — and in many prisons around the world — will.

Presentation by Pat Sasakamoose-Tait

Ms Sasakamoose-Tait drew attention to the overrepresentation of first nations people in prisons: "Today we are 14 percent of the total population in federal prisons, though only two to three percent of the population of Canada."

She emphasized that, in its own directives, CSC promised that it would identify the needs of Aboriginal offenders, and develop and implement programs and services to meet those needs. However, according to her,

> [w]ith respect to HIV/AIDS and those prisoners infected or affected by this virus, with respect to the education of aboriginal prisoners about HIV/AIDS, and with regard to sensitive, informed counsellors for those faced with HIV and AIDS, this directive is an abysmal failure. In all of Ontario region, there is no HIV/AIDS programming entrenched into even the newest aboriginal prisoner programs. Where peer health teams are in place, they are without aboriginal representation. Peer training tools have been developed without either representation from or inclusion of first nations.

Presentation by Rick Lines

Mr Lines started his presentation by saying that, while he was "pleased that the Parliamentary Subcommittee on AIDS has recognized the importance of investigating the barriers faced by prisoners in accessing AIDS services," the very fact that "we're still discussing this issue today is testament to the failure of the Correctional Service to respond to the AIDS crisis in this country. He continued by saying that

> [f]or community-based AIDS service organizations across this country there's no question about what needs to be done. The recommendations already exist. The concrete proposals and programs already exist. The question we are asking is, why isn't the Correctional Service acting to implement these recommendations? Why aren't they acting rapidly to implement the recommendations of their own expert committee [the Expert Committee on AIDS in Prisons]? Why aren't they looking to European prison health projects as proof of the viability of those recommendations from the expert committee?

According to him,

> [t]he time for discussion and debate is long over. ... What is urgently needed now is action. We need the federal government to act to implement a comprehensive and coordinated HIV and AIDS strategy for the adult and youth prisons in this country. AIDS organizations have been running successful community-based HIV prevention and support programs across Canada for more than ten years. We need to make those same programs available for people in prison. Nothing less is needed and nothing less will do.

In addition, he urged the government to begin

to address the reasons why people end up in prison and what social structures and changes need to be made in law and society to provide people and communities with alternatives to prison. In his view, key to this process is a comprehensive reexamination of drug policies in Canada,

> which have done nothing at all to decrease the prevalence or use of drugs. The only accomplishment of our national drug policy has been the incarceration of thousands of non-violent offenders. These are people whose only crime is a dependence upon a proscribed substance.

According to him, the "sooner Canadian policy-makers begin to address substance use within a health care model rather than a law and order model, the sooner our society can begin to move toward the social goals that the war on drugs has promised yet has failed so dismally to deliver." He concluded:

> We must create social and medical supports for drug users other than incarceration. We need to expand the availability and access to methadone maintenance programs and other pharmacological replacement programs. We need to initiate scripting programs for drug users. We need to seriously examine the decriminalization of certain classes of proscribed drugs.

Presentation by Sébastien Brousseau

Mr Brousseau pointed out that, as early as 1988, his organization held a press conference in Montréal to alert the public and prison authorities to the fact that certain inmates with HIV or AIDS were victims of discrimination. He continued by saying:

> We thought that the situation would change quickly. Today, in 1996, here we are before the subcommittee and we've realized that the expression used by Mr. Jürgens, "too little and too slowly," correctly reflects the reality within the Correctional Service of Canada. I wouldn't be surprised at all to see us before a subcommittee again in five or ten years asking the same questions on the same issues.

With regard to preventing HIV in prisons, he emphasized that CSC has a moral and legal obligation to prevent the transmission of HIV: "This obligation results, among other things, from the constitutional guarantees of the Canadian Charter of Rights and Freedoms and international agreements concerning the rights and freedoms of individuals."

With regard to access to adequate health care for inmates, he stressed that, despite the widely recognized principle that inmates have the right to obtain health care that is equivalent to that provided to the general population, the reality is quite different:

> While in prison, people with AIDS have difficulty gaining access to specialized care and experimental treatment. They have trouble seeing a doctor on a frequent and regular basis. Moreover, the problems encountered during transfers between penitentiaries and the almost total lack of confidentiality are additional constraints that confront the inmate.

He suggested that it constitutes a clear violation of section 15 of the Canadian Charter of Rights and Freedoms to

> impose a double standard in the quality, quantity or accessibility of health care provided to the general population and that afforded to inmates. And yet, that is the reality.

Referring to the issue of compassionate release of terminally ill patients, he pointed out that "unfortunately, and often for security reasons, the National Parole Board is reluctant to approve such releases for people living with AIDS. He suggested that transition houses adapted to the needs of people living with AIDS be created:

> These establishments could be sufficiently secure to meet the standards of the National Parole Board, while being a better environment for people who are suffering. Moreover, by being outside the walls, inmates living with AIDS in transition houses could gain easier access to the specialized care that their state of health requires.

Follow-Up

The Parliamentary Sub-Committee

The Parliamentary Sub-Committee was to release a report with recommendations regarding issues raised by HIV/AIDS, poverty and discrimination in Canada, including a section on HIV/AIDS in prisons. However, because the report was not tabled in the House of Commons before the elections were called, it is currently unclear whether it will ever see the light of the day. The Standing Committee on Health of the next Parliament could decide to table the report after the elections, but does not have to do so.

A first draft of the report endorsed the recommendations made in *HIV/AIDS in Prisons: Final Report*.[6] In particular, it recommended that methadone maintenance treatment be made accessible in prisons, and that pilot projects for the distribution of sterile injection equipment be undertaken.

CSC and Health Canada

The Correctional Service of Canada and Health Canada are expected to respond to *HIV/AIDS in Prisons: Final Report* after the elections. It is hoped that, this time, a comprehensive, coordinated, long-term strategy will be adopted, replacing the current piecemeal approach to HIV/AIDS and drug use in prisons.

- *Jean Dussault*

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ENDNOTES

[1] R Jürgens. *HIV/AIDS in Prisons: Final Report*. Montréal: Canadian HIV/AIDS Legal Network and Canadian AIDS Society, 1996.

[2] House of Commons of Canada, 35th Parliament, 2nd session, Sub-Committee on HIV/AIDS of the Standing Committee on Health, meeting no 12, Tuesday, 26 November 1996.

[3] See infra, Inmate AIDS Peer Education Project: Final Report Released.

[4] Supra, note 1.

[5] Ibid. See also R Jürgens. Needle Exchange in Prisons: An Overview. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 2(4): 1, 40-42 at 41; Final Report on HIV/AIDS in Prisons Released. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 3(1): 13-14.

[6] Supra, note 1.

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Inmate AIDS Peer Education Project: Final Report Released

In February 1995, AIDS New Brunswick received funding from the Correctional Service of Canada (CSC) to develop, implement and evaluate an inmate AIDS peer education and support program at Dorchester Penitentiary. A Final Report[1] summarizing the main results of the project and a comprehensive Facilitation Manual[2] have now been released.

The following is a slightly edited excerpt from the Report's executive summary:

In sum, the evaluation of the Project supports the efficacy of inmate peer education models in relation to preventing the spread of HIV and other communicable diseases within prisons, as well as in providing support to those already infected. The Project has generally been very well accepted by inmates, prison administration and staff. Content and process evaluations of the training program strongly support its benefits in enhancing the knowledge, attitudes and skills of all participants. In addition to successfully delivering a variety of proactive initiatives, the Peer Education Team continues to meet the numerous information and support needs of a diversity of inmates.

Peer-led AIDS prevention and support programs are of utmost necessity to prevent the continued spread of HIV among prison populations, and to provide support to inmates living with HIV. The success and sustainability of such programs requires the integral and continued involvement of credible and "solid" inmates, the establishment of paid coordinator positions, as well as the widespread support of prison staff, administration and inmates. With the support of CSC, community-based organizations can also play an important role in helping prisons implement and sustain such programs.

The implementation of inmate peer education and support programs is an important step toward promoting and protecting the health of inmates and the communities to which they return upon release. The model developed for this project is adaptable for use in other correctional institutions across the country. As a tool to facilitate the implementation of inmate AIDS peer education programs in other institutions, a comprehensive training manual has been prepared to provide other organizations and prisons with guidelines regarding setting up, implementing, and sustaining peer education and support programs within correctional facilities.

For copies of the Report and/or the Facilitation Manual, or further information, contact the Health Care Services Branch, The Correctional Service of Canada, 340 Laurier Avenue West, Ottawa K1P 0P9. Tel: (613) 995-5058; fax: (613) 995-6277.

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ENDNOTES

[1] Correctional Service Canada. *Final Report: The "C.A.N." National Pilot Inmate AIDS Peer Education Project*. Ottawa: The Service, 1996.

[2] Correctional Service Canada. *Facilitation Manual: The C.A.N. National Pilot Inmate AIDS Peer Education Project*. Ottawa: The Service, 1996.

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Prejudice Feeds Spread of HIV in Prisons

The Joint United Nations Programme on HIV and AIDS (UNAIDS) recently reported that HIV is prevalent in the prisons of most nations.[1]

According to Stuart Kingma of UNAIDS, the prevalence of HIV and AIDS among prisoners is often ten times higher than among members of the general population. Kingma added that prisons offer ideal conditions for the spread of HIV, including intravenous drug use, tattooing, sexual tension, and an atmosphere of fear and violence. He concluded by saying that UNAIDS supports the distribution of condoms and syringes and needles in prisons.

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ENDNOTE

[1]Health: Prejudice Feeds Spread of AIDS in Prisons. *IPS Wire* 29 April 1997.

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More Needle Exchange Programs in Prisons

As demonstrated by the experience of a few prisons in Switzerland and Germany, where needle exchange programs were started as early as 1993,[1] such programs in prison can work. As a result of their success, and of the increasing realization of the risk of the spread of HIV and other infectious diseases among inmates and to the public, more and more prisons are starting such programs or announcing that they will soon do so.

In addition to the programs listed in *HIV/AIDS in Prisons: Final Report*,[2] the following new programs have started or will start soon:

> • The prison of Realta in the Swiss Canton of Grisons started making sterile needles and disinfectants available on 3 February 1997.[3] In the area leading to the cafeteria, there is an automated syringe-dispensing machine to which the prisoners have uncontrolled access. Prisoners have to get their first syringe from the institution’s physician and keep it, as well as exchanged syringes, in their personal medical hygiene package.
>
> Since 1990 Realta has been providing methadone prescription programs that are used by between 10 and 20 percent of inmates. In addition, upon arrival each new inmate is issued a personal medical hygiene package that includes bleach, and information and discussion evenings are organized for new inmates.
>
> • At the 3rd European Conference on AIDS and Drug Use in Prisons, held in Amsterdam in February 1997, Dr Jörg Pont announced that a needle-exchange pilot project would soon be undertaken in at least one prison in Austria.
>
> • At the same Conference, one delegate reported that a Spanish prison has recently been forced by a court ruling to start a needle exchange.

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ENDNOTES

[1] See, eg, R Jürgens. Needle Exchange in Prisons: An Overview. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 2(4): 1, 40-42; H Stöver, J Jacob, Needle Exchange in Prisons in Lower Saxony: A Preliminary Review, in this issue of the *Newsletter*.

[2] R Jürgens. *HIV/AIDS in Prisons: Final Report*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1996.

[3] See Offre de prévention pour les détenus toxicodépendants du pénitencier cantonal grison de Realta. *spectra* 1997; 7: 3.

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Germany - Needle Exchange in Prisons in Lower Saxony: A Preliminary Review

Since 1993, sterile needles have been made available to prisoners in an increasing number of Swiss prisons and, more recently, in some German prisons. This article provides a preliminary review of a needle-distribution pilot project undertaken in two prisons in Lower Saxony, a *Land* in Northern Germany.

The "Prevention of Infections in Penal Institutions" pilot project was initiated by the Lower Saxonian Ministry of Justice. The project includes innovative approaches such as needle exchange programs and prevention-oriented information and education programs. These approaches have helped to more effectively tackle the drug-related spread of infectious diseases in prisons. In addition, they have provided a basis for reorientation and a process of change at many levels: politics, prison policy, and public heath care.

Various groups are involved in the pilot project: political leaders, prison directors and staff, prisoners, and the social scientists who monitor the project.

Cooperation in the complex field of detention requires an integrative attitude. The participants need to be receptive to differing positions and consider the conditions unique to each penal institution. During the first few months of the project, communication and cooperation structures were developed that provided a sound basis for the project to move forward.

A preliminary report has been drawn up by the scientists monitoring the project. This report focuses on the first few months of the project's existence, describing the documents that have been produced and reviewing the project's development. An overview of the preliminary results follows.

Objectives

The objective of the pilot project is to improve prisoners' health status by offering prevention measures that have proven feasible and effective in reducing the number of infections among injection drug users (IDUs) outside prisons, to incarcerated IDUs in two prisons in Lower Saxony. In the women's prison in Vechta, a prison with approximately 170 prisoners, prevention measures including sterile syringes have been available since 15 April 1996; in the Lingen I men's prison, a prison with approximately 230 prisoners, they have been available since 15 July 1996. In both prisons, about 50 percent of the inmates once were or still are IDUs.

Prison doctors are following the pilot project closely, offering advice. The program, which is intended to run for two years, is also being monitored by social scientists at Oldenburg University, who will evaluate the project after its completion. In their evaluation, they will assess the following:

- the feasibility of the measures;
- their effectiveness;
- the degree of acceptance by all concerned; and
- the appearance of changed attitudes toward drug consumption and a healthy lifestyle.

HIV and Hepatitis Prevalence

There is conflicting evidence about HIV prevalence and the rate of seroconversions in prisons. Prison authorities often point to the relatively low number of prisoners known to be HIV-positive and to the fact that there are few documented cases of seroconversion in prison. In contrast, studies undertaken outside prison on the correlation between HIV infection and detention (and continued injection drug use) have yielded very different results. These studies have revealed considerably higher numbers of HIV-positive prisoners and shown that imprisonment increases the risk of HIV infection among IDUs.

In addition, there can be no doubt that hepatitis infections among drug users are on the rise, both inside and outside prison, a development that has been confirmed by studies undertaken in prisons.

High rates of infection among prisoners have devastating effects not only for the prisoners themselves but, in the longer term, will cause high costs for society due to the increasing demand on social and medical services. The implications for public health of these "infection risks in prisons" are clear. We need to pay more attention to the spread of infectious diseases among incarcerated IDUs and, generally, promote health care in prisons. One important step toward achieving these goals is the distribution of sterile syringes in prisons.

History of the Pilot Project

Prior to its initiation, the project was extensively discussed by the prison authorities involved. Expert knowledge on detention, administrative procedures, and on medical care, independent drug and AIDS support groups, as well as research provided by the experts of a commission set up by the Lower Saxonian Ministry of Justice, aided in an assessment of the risks involved in the project. Professionally recognized and practical models of preventing/coping with risks were developed. These models provided the basis for the political decision-making process regarding the handling of infectious diseases.

The prison staff was included in the preparation of the project and offered information sessions. In addition, the procedures for implementing the project were discussed in working groups in the prisons and at meetings with the initiators of the Swiss needle-distribution pilot project at Hindelbank institution.[1] Because groups at all levels were involved in the decision making process, decisions were not made in a hierarchical way (ie, political level / administrative level / institutional level). Instead, the process was basis-oriented, and considered the particular interests of each of the groups involved.

In both prisons, prisoners were asked about their readiness to participate in the project. In addition, they were asked to make suggestions regarding the method of needle distribution and, once the method was selected, to provide their views of it. Expert groups working outside prison, such as in drug and AIDS service organizations and in drug user self-help groups, also contributed to the conceptualization and implementation of the project.

Throughout the whole process, panels of experts at the political level and the politicians in charge were kept up-to-date about the development of the project, in order to foster wide-ranging consensus and support.

Implementation of the Preventive Measures

The two participating prisons chose different methods for the provision of sterile injection equipment. In the women's prison, equipment is distributed via machines; in the men's prison, it is manually distributed in a lounge area. In both prisons, needle distribution was incorporated into the support programs for IDUs that were already in place and became a part of the existing infection prophylaxis.

Health care cannot be promoted solely by making preventive measures accessible: it must be accompanied by communicative strategies at a more personal level. Therefore, education and information meetings are held in case of need and/or at regular intervals (for provision of adequate help in drug-related cases of emergency, to provide counselling on safer-sex/safer-use practices, etc). Such meetings help to foster acceptance of the project, not just among prison staff but also among prisoners, while increasing their knowledge of the health-related and social correlations between drug use and the spread of infectious diseases.

Acceptance and Use of the Needle Exchange Facilities

At the women's prison, a large number of prisoners expressed their interest in participating in the project even before the project started. At the men's prison, prisoners were initially more reluctant to use the facilities, but shortly after the start of the program the number of users rose, reaching a relatively constant level.

At the women's prison, 20 to 30 syringes are drawn from the 5 needle-distribution machines daily. The machines were installed in discreet locations throughout the institution so that the needles may be obtained anonymously. Alcohol swabs, ascorbic acid, plasters, etc, are also available at the machines. Approximately 50 women are currently participating in the needle exchange project.

At the men's prison, staff of the prison's drug counselling service have supplied approximately 800 sterile needles to drug-addicted prisoners. Staff have to maintain confidentiality and have been relieved of giving their opinion regarding relaxations in detention (vacation/leave) or premature release; participation in the needle exchange project should not entail any negative impact on the conditions of imprisonment. Currently about 25 detainees participate in the project.

Absolute anonymity, however, is not possible in prison. At the beginning of the project the participants were informed that the syringes had to be stored at a clearly specified site (on the washbasin console or in a lockable closet). This provision was not made in order to control prisoners, but so that prison staff searching the cells could avoid coming into contact with used needles.

Prisoners participating in a methadone program are not allowed to participate in the needle exchange project, as it is assumed that they do not need sterile syringes.

In general, most detainees have followed the rules regarding the supply of sterile needles (with the exception of a few cases at the women's prison in which women did not store the syringes properly). In both prisons, neither the controls exercised over cells nor the number of drug finds has increased.

Importantly, a great number of prison staff from both prisons have supported the first extensive social–scientific review of the project, reflecting their great readiness to actively participate in the project.

- *Jutta Jacob* and *Heino Stöver*

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ENDNOTES

[1]For more details, see R Jürgens. *HIV/AIDS in Prisons: Final Report*. Montréal: Canadian HIV/AIDS Legal Network and Canadian AIDS Society, 1996, at 52-65.

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The Netherlands: Court Orders Resumption of Methadone Maintenance

An increasing number of courts worldwide recognize that prisoners have the same right to health care as persons outside and order that prisoners dependent on drugs should be able to obtain methadone maintenance treatment in prisons, particularly if they already received such treatment on the outside.[1]

On 16 August 1996, a local court in The Hague (The Netherlands) issued a motion obliging the government to resume the provision of methadone to a drug-dependent prisoner being held in custody awaiting trial on a number of charges.[2]

The man was dependent on drugs and had already been imprisoned in the past. At that time and in other penitentiaries, he had received maintenance rations of methadone, after efforts to gradually reduce his consumption had failed. The man was now in a penitentiary where his methadone dosage had been systematically diminished and finally terminated. He requested that the government either resume methadone maintenance or relocate him to a penitentiary where this could be done.

The court ruled that one had to assume, until proof to the contrary, that in the case at issue there clearly were medical reasons to provide the prisoner with methadone. According to the court, the fact that in two other institutions a physician had prescribed methadone maintenance to the prisoner supported this argument. The court continued by saying that, while a more functional behaviour could be a positive side-effect of methadone prescription, the main reason for prescribing methadone in these institutions had been medical. On these grounds, the penitentiary had to resume methadone maintenance.

- *Trudo Lemmens*

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ENDNOTES

[1] For more information, see R Jürgens. Methadone Treatment in Prisons: An Overview. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 3(1): 14-16; Benoit Turcotte. Judge Orders Methadone Maintenance Treatment in Prison. Ibid at 16-18; C McLeod. Is There a Right to Methadone Maintenance Treatment in Prison? Ibid, 2(4): 22-23.

[2] ARR-Rechtbank's-GRAVENHAGE, 16 August 1996, rolnr 96/1122 (Mr Punt). *Kort Geding* 1996, Nr 291, 659-661.

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Australia - Not Giving Up the Fight: Prisoners' Litigation Continues

The New South Wales (NSW) Supreme Court recently had to deal with a legal claim for damages instituted by an inmate who claimed to have contracted HIV in prison as a result of negligence on the part of those responsible for administering and managing the New South Wales prison system – the NSW Government.

The Claim

The claim was lodged in July 1996. In late November 1996, the claimant, Richard Lynott, testified from his hospital bed at a pre-trial hearing that he had contracted HIV while under the control and custody of the NSW prison authorities.[1] Lynott – a former prisoner – instituted his negligence claim against the authorities for failing to provide him with access to condoms and sterile syringes while he was incarcerated.[2]

The Facts

Lynott had been incarcerated since the early 1960s, spending most of his adult life in several NSW prisons. There was evidence to the effect that he was known to the authorities as an addicted heroin user and bisexual male.[3] Lynott testified that he had engaged in unprotected anal and oral intercourse with other prisoners and that he could not use condoms because they were unavailable. Perhaps anticipating legal arguments that would embrace causation and contributory negligence issues,[4] he stated that had condoms been provided he would have used them. In addition, Lynott testified that he had an extensive intravenous drug habit while incarcerated and that he did not have access to sterile syringes – they too, like condoms, were prohibited in prison. According to Lynott, he could not remember the number of people with whom he had had unprotected sex and/or shared needles. However, he testified that in some circumstances the same needle was used for months.[5] Lynott tested positive for HIV in 1994.

Lynott died approximately one month after the commencement of the pre-trial hearing. Because he left no estate or dependants, the case ended with his passing.

Legal Issues

Negligence

In essence, the case embraced a simple matter. As his barrister put it:

> • had Lynott been treated like the rest of the community, with access to necessary protective measures such as condoms to prevent contraction of HIV, he would not have been in the position in which he found himself – dying of AIDS;[6] and
>
> • the non-provision of these measures was negligent.

However, in the course of providing his evidence, Lynott noted under cross-examination that he was aware of the risks associated with his conduct. The barrister handling the Government's case presented Lynott with comments he had earlier provided in an interview with a television documentary team concerning his life in the NSW prison system. In the documentary, Lynott had admitted that he had been aware that he was engaging in risky activity. Accordingly, the Government argued, among other things, that Lynott voluntarily assumed the risk of injury or harm through his consensual activity and that, as a result, he was precluded from seeking legal recourse.

Voluntary Assumption of Risk

Although one can only speculate on how the case would have been decided by the court, the prisoner's case would clearly have been difficult to win.[7] However, it should not be assumed as a foregone conclusion that engagement in risky activity will necessarily preclude recovery. In order to establish this defence, the Government would have had to show that the plaintiff

- knew of the facts constituting the danger;
- appreciated the danger of the situation; and
- freely and willingly agreed to encounter the danger.[8]

Having been asked why he used heroin, Lynott responded that he needed it and was not able to live without it.[9] This feeling of compulsion, a consequence of his addiction, arguably undermines the ability to satisfy one of the elements of the defence, that the risk was "freely and willingly encountered." Simply put, the addiction negates free will and volitional behaviour.

NSW as Defendant

This is not the first time the NSW Government has had to defend itself in actions for damages in the context of HIV/AIDS in prisons. In *Prisoners A to XX inclusive v State of NSW*, fifty prisoners claimed, among other matters, that the NSW Government was liable to them for its failure to provide condoms in prisons.[10] On appeal, the NSW Court of Appeal did not rule out the possibility of finding liability. However, the litigation ended as a consequence of the Government's decision to make condoms available in all prisons after evaluation of an initial, successful trial condom-distribution scheme in a few NSW prisons was undertaken.[11]

Purpose and Value of Instituting Proceedings

The question usually asked with respect to instituting a claim in negligence is: Will the complainant bringing the action succeed? But success in the traditional sense is not entirely the issue in this type of case. The purpose and value of instituting proceedings, and considering the possibility of judicial recognition of a duty of care and its breach, is not limited to the case of the unfortunate individual who actually suffers the damage that is the subject of the complaint. Rather, the educative function of these cases and tort law lies in the ability to set higher standards of behaviour, with a view to improving conditions of detainment.

To make a statement, some individuals – like Lynott – may be willing to endure the rigours of the litigation process, despite the fact that they presumably recognize that damages would be limited, both

- in the general terms of what money amounts can accomplish in reality (that is, how can the anguish and pain and loss arising from contracting HIV/AIDS ever be commodified?); and
- in terms of the potentially assessable amount in their particular case.

Negligence claims may provide a catalyst to reform. Litigating, or the threat of doing so, can be a fruitful way of effecting improvements. Even the failure or discontinuance of a particular action can have value; attention has been brought to the problem by means of extensive media coverage.

The Future

Lynott's case died with him, but this is not the end of his legacy. There are reports that at least seven more inmates or former inmates are commencing proceedings against the NSW Government for its negligence in not preventing their seroconversion while in custody. Barristers have warned that additional actions will be instituted until preventative measures are introduced in NSW jails. If a negligence action – or series of actions – can help demonstrate to the Australian public and authorities what could and should be done in prisons to prevent the spread of HIV, then instituting proceedings will have proven worthwhile.

As Lynott's barrister stated, despite the fact his client had not lived a "glorious past," Lynott was nevertheless prepared to litigate in order to promote certain principles:

- it is wrong for the entire prison population to be exposed to a major risk of serious harm to their health;

- there is no legitimate reason in terms of public policy or the protection of the community why a prison population should be treated as a forgotten population that is exposed to these hazards when the rest of the community is not.[12]

- *Ian Malkin*

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ENDNOTES

[1]*The Australian*, 28 November 1996.

[2]He also alleged that the defendant was careless for (1) failing to effectively treat HIV-positive prisoners and (2) failing to identify HIV-positive prisoners in order to keep them separate from the rest of the prison population. Many commentators and prisoners (some as litigants in other cases) would dispute the appropriateness of the latter allegation.

[3]C Bullock, reporter, Australian Broadcasting Corporation (ABC) *Radio National*, 22 December 1996.

[4]*March v E & M H Stramare Pty Ltd* (1991), 171 CLR 506.

[5]Bullock, ABC *Radio National*, 28 November 1996.

[6]Ibid.

[7]Other aspects of the action that would have proven particularly contentious, including a determination of breach, contributory negligence and possibly an illegality defence, are not discussed here. Because of the way in which the evidence was presented, the focus here is on the voluntary assumption of risk defence. For a detailed discussion of some of these issues, pre-dating the Lynott case, see I Malkin. Tort Law's Role in Preventing Prisoners' Exposure to HIV Infection While in Her Majesty's Custody. *Melbourne University Law Review* 1995; 2: 423. A shorter version of the paper can be found in the *Canadian HIV/AIDS Policy & Law Newsletter* 1995; 2(1): 19-22; and in R Jürgens. *HIV/AIDS in Prisons: Final Report*. Montréal: Canadian HIV/AIDS Legal Network and Canadian AIDS Society, 1996 (Appendix 1).

[8]See, eg, *Scanlon v American Cigarette Company (Overseas) Pty Ltd [No 3]* [1987] VR 289.

[9]*The Australian*, supra, note 1.

[10]*Prisoners A to XX inclusive v State of NSW*, Supreme Court of NSW, Dunford J, 5 October 1994. See also R Jürgens. Australia: Prisoners

Sue for the Right to Condoms. *Canadian HIV/AIDS Policy & Law Newsletter* 1994; 1(1): 5; Australia. Update on Prison Condom Case. Ibid, 1995; 1(3): 3.

[11] See, eg, D Smith. Unfair Punishment. *The Sydney Morning Herald*. 20 January 1997, at 11.

[12] Bullock, supra, note 5.

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Australia – Segregation of HIV-Positive Prisoners Illegal

The Human Rights and Equal Opportunity Commission has found the Western Australian Government in breach of the federal *Disability Discrimination Act* 1992 in respect of prison policies that segregate HIV-positive prisoners and have them imprisoned in maximum-security prisons.[1]

Until recently, Western Australia required that all male prisoners living with HIV or AIDS be imprisoned at a maximum- security prison and accommodated in the Infectious Diseases Unit of the prison infirmary. Responding to complaints from two prisoners, the Commission took evidence from a number of doctors on whether the regime was necessary and about the impact of the regime on the prisoners. It concluded that the "system of segregation must be condemned" and that "the segregation and close supervision of HIV positive prisoners is wrong because it denies those prisoners what should be seen as a right, namely, the right to medical confidentiality." In addition, the Commission held that "segregation and close supervision of HIV positive prisoners is wrong because it leads to affected prisoners being stigmatized."

The Commission ordered the State of Western Australia to pay the prisoners AUS$8000 and $3000 respectively, as compensation for having been unlawfully segregated.

After the ruling was released, Western Australia announced that it would from now on treat prisoners with HIV or AIDS on the basis of their security rating and behaviour rather than their HIV status.[2]

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ENDNOTES

[1] See: WA prisons discriminate against HIV positive prisoners. [Australian] *HIV/AIDS Legal Link* 1996; 7(4): 5.

[2] WA prison segregation ends. [Australian] *HIV/AIDS Legal Link* 1996; 7(4): 3.

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Ukraine – Isolation of HIV-Positive Inmates Proposed

Hoping to stop the spread of HIV in the prison system, Ukraine officials have proposed isolating HIV-positive prisoners in separate facilities.

According to a report by United Press International (UPI),[1] HIV has spread rapidly among inmates over the past two years, due to consensual and non-consensual sexual activity and to injection drug use. Officials say that 2100 inmates are infected, 70 percent of whom are male. If the government approves the proposal, HIV-positive prisoners would be moved to two existing prisons which "would be staffed by doctors and nurses trained in HIV care."

UPI's report did not specify whether protective measures such as condoms, bleach, and sterile needles are available in prisons in the Ukraine. Making such measures accessible to prisoners, rather than isolating HIV-positive inmates, is widely seen as the most effective way of curbing the spread of HIV among inmates and to staff and the public.

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ENDNOTE

[1] P Coumarianos. Ukraine Mulls HIV-Positive Prisons. United Press International, 26 November 1996.

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US – Prison Legislation Vetoed

For a second time, Rhode Island Governor Lincoln Almond vetoed legislation that would allow correctional officers to learn the name of adult prisoners living with HIV/AIDS.

Governor Almond said that testing prisoners for HIV and disclosing their HIV status to correctional officers would provide a false sense of security and "less vigilant application of common-sense precautions against transmission at a time when such precautions are needed most."[1]

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ENDNOTE

[1]Reported by Reuters Health Information Services. *HIV/AIDS News*, 20 September 1996.

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South Africa - Order against the Minister of Correctional Services

Since 1992 the South African AIDS Consortium has made the need for an effective HIV/AIDS prevention campaign in prisons - and the rights of prisoners with HIV - one of its focus areas for lobbying.[1]

The Charter of Rights on HIV and AIDS states that "prisoners should have the same access to education, information and preventative measures as the general population." A 1995 AIDS Consortium conference also took a resolution to step up the campaign around prisoners' rights.

On 22 November 1995, the Department of Correctional Services (DCS) Work Group on Health Care Services in South African Prisons released a report to the Commissioner of Correctional Services. The report highlighted the need for reforms in DCS health-care services. This included access to appropriate, understandable and continuing education on HIV/AIDS.

The work group also proposed that condoms and information about their use should be available to all prisoners on the same basis as in free society, and that the compulsory segregation of HIV-positive prisoners should be abandoned.

On 17 May 1996, the Minister of Correctional Services agreed and announced that segregation would end and condoms would be made available. A new policy has since been produced and recently had its first legal test: an order was handed down in the Supreme Court (Cape Provincial Division) against the Minister of Correctional Services and others.[2]

Based on the new policy, the matter was brought by 10 prisoners at Pollsmoor Prison in the Western Cape region of South Africa and the National Association of Persons Living with HIV/AIDS. One of the applicants was a gay male who had tested negative on entering the prisons system and had asked for condoms for more than a year. Every three months he had tested negative and after more than a year he seroconverted. Prisoners with HIV/AIDS at Pollsmoor were segregated and in 1995 had participated in a hunger strike to improve their conditions.

The order has far-reaching implications concerning all questions relating to HIV/AIDS in prisons. We reprint it in full:

In the matter between:

Applicant W [names omitted to protect confidentiality], the National Association of Persons Living with HIV/AIDS and others

and

The Minister of Correctional Services (First Respondent), the Commissioner of Correctional Services (Second Respondent), the Commander of Pollsmoor Prison, Tokai (Third Respondent), the Minister of Health and Welfare, Western Cape (Fourth Respondent)

Order

By agreement between the parties it is ordered as follows:

1. At Pollsmoor Prison the First, Second and Third Respondents and their servants shall, in accordance with the Department of Correctional Services' policy:

> 1.1 observe confidentiality about the status of all persons who are HIV positive or suffering from AIDS (hereinafter collective referred to as HIV positive prisoners or having HIV status);
>
> 1.2 protect, as far as possible, prisoners from stigmatisation on account of their HIV status or sexual orientation;
>
> 1.3 provide, or cause to be provided, condoms to all prisoners;
>
> 1.4 provide or make available the necessary and appropriate medical attention and treatment to HIV positive prisoners;
>
> 1.5 carry out and permit testing for HIV or AIDS only with the informed consent of the prisoners involved;
>
> 1.6 not deprive any prisoner of access to work solely on the basis of his or her HIV status;
>
> 1.7 not discriminate against HIV positive prisoners vis-a-vis other prisoners as far as the provision of accommodation and ablution facilities is concerned;
>
> 1.8 provide appropriate education and information about the HIV and AIDS condition to staff and prisoners.

2 First, Second and Third Respondents to pay Applicants' disbursements as taxed or agreed.

The South African AIDS Consortium was established in 1992. It focuses on human rights questions arising from HIV/AIDS and the need to propagate and enforce an anti-discrimination response. For more information, contact the AIDS Consortium at the Centre for Applied Legal Studies, University of the Witwatersrand, Private Bag 3, Wits 2050, South Africa. e-mail: 125mo2co@solon.law.wits.ac.za

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ENDNOTES

[1]Adapted from C Avant-Smith. Prisons Breakthrough. *The AIDS Consortium Newsletter* 1996(2): 1.

[2]In the Supreme Court of South Africa (Cape of Good Hope Provincial Division) before the Honourable Mr Justice van Deventer on Thursday, 20 June 1996 (case no 2434/96).

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South Africa – Corrections Department Required to Provide New Combination Therapies

The South African Constitutional Court has ruled in favour of two prisoners who sought an order against the South African Department of Correctional Services to provide the new combination therapies, based on a review of their individual medical situation.[1]

However, two other prisoners who applied for similar relief were turned down. According to an Internet posting by an attorney for the South African AIDS Law Project, the decision has proved controversial in South Africa, where many people living with HIV or AIDS outside prison do not have access to the new drugs. However, the attorney expressed hope that the judgment would ensure that the Department of Correctional Services "embark on formulating a policy on treatment for HIV infection in prisons coupled with a more serious approach to HIV prevention." According to the attorney, "[f]ailure to do so will result in more money being spent on treating the infection!"

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ENDNOTE

[1] See *Lesbian/Gay Law Notes* May 1997, at 66-67.

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INTERNATIONAL NEWS

Australia – Third National AIDS Strategy Launched

While Canada's governing Liberal Party only recently promised that, should the Party be reelected, it would renew the National AIDS Strategy for another five years, Australia's third National Strategy dealing with HIV/AIDS and other communicable diseases was launched on 18 December 1996.

The Strategy, titled "Partnerships in Practice: National HIV/AIDS Strategy 1996/97-1998/99, a strategy framed in the context of sexual health and related communicable diseases," was welcomed by AIDS organizations. In announcing it, the Australian Federal Health and Family Services Minister, Dr Wooldridge, emphasized that

> [u]nlike many other countries in the world, the vast majority of HIV infections in Australia remain among homosexually active men, although there is the potential for an emerging epidemic among Aboriginal and Torres Strait Islander people. As a result, the Third National Strategy places these two groups of people as the highest priority for continued education and prevention messages.

In addition, the Strategy targets other groups of people who are at high risk of infection because of behaviour and/or social circumstances: injecting drug users, sex workers, and people from diverse cultural and linguistic backgrounds. Five priority areas are identified:

- education and prevention;
- treatment and care;
- research;
- international assistance and cooperation; and
- legal and ethical matters.

In particular, the Strategy stresses the importance of a supportive legal environment to the success of initiatives undertaken in all priority areas.

[IN SMALLER PRINT:]

For more information, see: New National Strategy on HIV/AIDS. [Australian] *HIV/AIDS Legal Link* 1996; 7(4): 10-12.

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US – Priorities for Federal AIDS Policy Set

On 17 December 1996, the White House issued a statement from President Clinton setting six major goals for federal AIDS activities.

The goals are:

- developing a cure and a vaccine;
- reducing and eventually eliminating new infections;
- guaranteeing care and services for HIV-positive people;
- fighting HIV/AIDS-related discrimination;
- translating scientific advances quickly into improved care and prevention; and
- providing continued support for international efforts to combat HIV/AIDS.

Missing from the list was any specific reference to needle-exchange programs. As a result, AIDS activists in the US have pointed out that the administration continues to allow drug-war policies to get in the way of effective strategies to reduce HIV transmission among injection drug users.

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US – Puerto Rico Backs Away from Controversial AIDS Policies

Reacting to adverse testimony at a public hearing and a threat of a lawsuit by the American Civil Liberties Union (ACLU), the Commonwealth of Puerto Rico backed away from several proposed HIV policies.[1]

Under the policies proposed in early March 1997, patients who test positive for HIV would have had to send the health department a list of all their sexual partners, along with the partners' addresses and telephone numbers. Failure to comply would have resulted in a fine of up to US$5000. In addition, the policies would have authorized the health department to force any person they suspect of having a sexually transmitted disease, including HIV, to submit to a blood test. Finally, the policies would have resulted in the creation of a mandatory name-reporting scheme that would have required hospitals and medical laboratories to send HIV-positive laboratory results to the government.

If the policies had been adopted, HIV would have "spread more quickly in Puerto Rico," according to Michael Adams, a staff attorney with the ACLU's AIDS Project. Adams added: "Attacking the rights of HIV-positive individuals is an awfully misguided approach to public health. It will discourage people from being tested for HIV while doing nothing to help reduce the spread of AIDS."

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ENDNOTE

[1] See *Lesbian/Gay Law Notes* May 1997, at 66; ACLU press release of 19 March 1997, posted on hiv-law@web-depot.com

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US – North Dakota Authorizes Confinement

North Dakota has become the first jurisdiction to authorize confinement of people suspected of being HIV-positive.

On 10 April 1997, Governor Edward Schafer signed a new law that gives judges the power to detain a person suspected of being HIV-positive and ordering the person to submit to a blood test. The law provides that anybody who believes that another person has "significantly" exposed them to blood can get a court order confining that person for up to five days. During that time, the judge can rule on whether to order a blood test.[1]

The law goes into effect on 1 July 1997. It has been heavily criticized as "flying in the face of accepted medical and public health policy regarding HIV."[2]

The American Civil Liberties Union (ACLU) is considering filing a constitutional challenge to the law. For more information, contact Keith Elston of the ACLU of the Dakotas at (701) 255-4727.

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ENDNOTES

[1] Reprinted, in part, from the *Lesbian/Gay Law Notes* May 1997, at 66.

[2] K Lobel, Executive Director of the US National Gay and Lesbian Task Force, in a statement released on 18 April 1997.

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DRUG POLICY

Lost Lives, Lost Dollars: The Cost of US Government Inaction

At the Harm Reduction Satellite Symposium at the XI International Conference on AIDS in Vancouver in July 1996, Ernest Drucker, director of drug treatment at the Montefiore Medical Centre at New York's Albert Einstein University College of Medicine, presented the results of a study of injection-related HIV infections in the United States. The study was conducted with Peter Lurie of the Center for AIDS Prevention Studies at the University of California, San Francisco. Lurie and Drucker used modelling techniques to estimate the number of HIV infections associated with the US government's opposition to needle exchange programs (NEPs). They estimated that between 4,000 and 10,000 injection drug users in the US would not now be infected with HIV had they had access to sterile needles. Using the conservative estimate of US$119,000 for the lifetime cost of treating an HIV infection, the authors concluded that these infections have cost the US health care system US$250 to US$500 million.[1]

The model used was based on studies carried out in countries with needle exchange programs, such as Australia, Canada, the United Kingdom and the Netherlands. These studies have shown that NEPs provide clients with harm-reduction information and access to safer-sex and safer-injection supplies.[2] In communities with NEPs there is:

- a decreased rate of use of dirty equipment;
- a decreased rate of sharing of equipment;
- lower prevalence and incidence of HIV infection;
- a higher rate of self-referral to treatment services; and
- increased access to medical care.

In addition, and despite fears to the contrary, NEPs are not associated with an increase in the number of injectors or a decrease in the average age of injectors. NEPs have thus been shown to be a highly cost-effective means of reducing injection-related harms: The median annual budget of a NEP in North America is US$168,650. The average cost per syringe distributed is just US$1.35. Compared with the cost of inaction, these are very low costs.

In Australia, for example, early intervention with NEPs and rapid tenfold expansion of methadone treatment kept the HIV rate among injection drug users below two percent after 1988. The model used by Lurie and Drucker assumes that, as in Australia, as many as fifty percent of injection drug users in the US would use NEPs if they were available. Such usage could have reduced the level of infection by 17 to 33 percent (4,000 to 10,000 persons) in the US.

Since fifty per cent of new cases of HIV infection in the US now occur among injection drug users, the urgent need for harm-reduction measures is abundantly clear: Lurie and Drucker estimated that if NEPs were immediately increased to reach fifty percent of injection drug users each year, between 5,000 and 11,000 HIV infections could still be prevented by the year 2000. The authors concluded that "removing the US ban on NEP services and accelerating the growth of NEPs are urgent public health priorities in the USA."

Nevertheless, NEPs remain illegal in many states in the US and sale of needles to drug users without a prescription by pharmacists is still also illegal in a number of states. Although several reports have resoundingly endorsed NEPs as a cost-effective form of harm reduction that does not lead to an increase in the number of injectors, the US federal health authorities have remained firm in their opposition to NEPs and have banned by law the use of federal funds for them (even research on NEPs was banned until 1991). They maintain that harm-reduction program "give the wrong message." So what is the message that US officials wish to send - that the lives of drug users are not worth saving? The US government, fearing that a move toward harm reduction will be viewed as a "softening" of its stance on illicit drugs, remains committed to prohibition and all of the many harms, including death, that attend it.

- *Diane Riley*

The symposium "Harm Reduction Around the World" was a satellite of the International AIDS conference held in Vancouver in July 1996. The symposium was sponsored by the Canadian Foundation for Drug Policy, The Drug Policy Foundation and the International Harm Reduction Association.

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ENDNOTES

[1] P Lurie, E Drucker. An opportunity lost: Estimating the number of HIV infections associated with the US government opposition to needle exchange programs. Paper presented at the XI International Conference on AIDS, Vancouver, Canada, July 1996.

[2] The studies are reviewed in: Centres for Disease Control and Prevention. *The Public Health Impact of Needle Exchange Programs in the United States and Abroad*. Rockville, MD, 1993; Drug Policy Foundation. *Health Crisis*. Washington, DC: The Foundation, 1995.

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ACCESS TO CARE AND TREATMENT

Compassionate Access to Investigational Therapies: Part II

From December 1995 to May 1996, the House of Commons Sub-Committee on HIV/AIDS organized a series of National Round Tables on the issue of compassionate access to investigational therapies. In October 1996, it released a report containing eight recommendations aimed at ensuring "a more liberalized form of compassionate access that is acceptable to all those concerned,"[1] and asking the government to table a comprehensive response to the recommendations and the report.

The last issue of the *Newsletter* contained a summary of the report and two of the presentations made at one of the round tables organized by the Sub-Committee.[2] The following texts, by Maggie Atkinson and Trudo Lemmens, provide an analysis of and commentary on the report and its recommendations, from two different perspectives: that of an HIV-positive AIDS treatment activist and that of a university-based ethicist.

Summary of the Report and Recommendations

The Sub-Committee's report contains sections on the concept of catastrophic rights; access to unapproved drugs; the case for compassionate access; concerns surrounding compassionate access; consensus on the need for compassionate access; proposed mechanisms to compel or encourage compassionate access to investigational therapies; ethical aspects; the role of Health Canada in making new therapies available; liability; and responsibility.

Eight recommendations are made:

> 1. The Sub-Committee recommends that the Governor in Council make whatever changes are necessary to the regulations of the Food and Drugs Act in order to require that pre-investigational new drug submissions and investigational new drug submissions include a statement of the pharmaceutical manufacturer's intention with respect to the compassionate provision of the investigational agent(s).
>
> 2. The Sub-Committee recommends that Health Canada, in cooperation with representatives of the Pharmaceutical Manufacturers Association of Canada and treatment activist groups, develop compassionate access guidelines. These guidelines are to include, but not necessarily be limited to, criteria to judge whether a pharmaceutical manufacturer's offer of compassionate access to an investigational therapy is fair and reasonable; and provisions to accommodate the flexible nature of consumer demand and the availability of an investigational therapy. These guidelines should be developed in all due haste and be available for decision-making purposes no later than 1 June 1997.
>
> 3. When a pharmaceutical manufacturer, in the absence of a clinical trial in Canada, establishes a compassionate access program to provide Canadian patients with an experimental therapy, the Sub-Committee recommends that the Drugs Directorate of Health Canada conduct the evaluation of the new drug submission for that therapy as expeditiously as possible.
>
> 4. The Sub-Committee recommends that the Governor in Council amend the regulations of the Food and Drugs Act that pertain to the Emergency Drug Release Program to give Health Canada the authority to

require pharmaceutical manufacturers to account for a refusal to provide compassionate access to a therapy not approved for sale in Canada.

5. The Sub-Committee recommends that Health Canada review and strengthen the mandate of the National Council on Bioethics in Human Research to clearly establish the objective of promoting harmonized national standards of ethics in research involving humans.

6. The Sub-Committee recommends that Health Canada move with all due haste to put into effect, no later than 1 June 1997, a conditional approval process for drugs designed to treat life-threatening illnesses.

7. The Sub-Committee recommends that the Government of Canada study the future direction of drug regulation in Canada. This study should investigate, but not necessarily be limited to, the cost benefits of the present system, the advisability of phasing out the Canadian system, the efficiency and effectiveness of the new drug evaluation system in the European Community, and the possibility of applying this model to NAFTA partners.

8. The Sub-Committee recommends that the federal Minister of Health propose to the Conference of Ministers of Health the establishment of a consultative mechanism to facilitate the timely adoption of new drugs on provincial formularies.

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ENDNOTES

[1] House of Commons Canada. *Compassionate Access to Investigational Therapies. Second Report of the Standing Committee on Health - First Report of the Sub-Committee on HIV/AIDS*. Ottawa: The House, October 1996 (Second Session, 35th Parliament), with reference to House of Commons, Minutes of Proceedings and Evidence of the Sub-Committee on HIV/AIDS of the Standing Committee on Health, Meeting No 19, 6 December 1995, at 2.

[2] The Editor. Compassionate Access to Investigational Therapies. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 3(1): 1, 41-43; T Lemmens. Compassionate Access to Experimental Drugs: Balancing Interests and Harms. Ibid at 43-44; B Freedman. Compassionate Access to Experimental Drugs and Catastrophic Rights. Ibid at 44-46.

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Maggie Atkinson: A Response to the Parliamentary Sub-Committee's Report and Recommendations

I have been struggling with the issues around compassionate access to experimental therapies both personally and as a representative of the HIV-positive community since 1993, when I joined the Steering Committee of the Canadian HIV Trials Network (CHTN), an organization that facilitates the conduct of clinical trials in Canada. As a member of AIDS Action Now! (AAN) I have advocated for improved access to drugs with both government and pharmaceutical representatives.

I was pleasantly surprised when I first read the recommendations in the Report on Compassionate Access to Investigational Therapies. Many of the recommendations were originally made by Brian Farlinger of AAN in March 1995 when he appeared before the Subcommittee on HIV/AIDS. While I have concerns about a number of the submissions relied upon by both the Report and the Reform Party Dissenting Report, in this review I will limit my comments to the recommendations set out in the Report.

Improved and Expedited Access to Drugs

The Report recognizes that what is needed by people with catastrophic illnesses is not just compassionate access but improved and expedited access to drugs, from the initial phase of development to the point of approval and release to the general public. We need

- access to new therapies as soon as possible;
- to speed up the drug review and approval process;
- to have reasonable compassionate access until approval; and
- coordination of federal and provincial approvals so that there is reimbursement by third-party payers without delay.

The recommendations address all these issues.

Statement of Intention and Compassionate Access Guidelines (Recommendations 1 and 2)

Although the Report does not go so far as to recommend mandatory compassionate access, it does recommend that a statement of intention with respect to compassionate access be required of a manufacturer making an investigational new drug submission to carry out a clinical trial in Canada (recommendation 1). The Health Protection Branch would then assess the reasonableness of the statement in deciding whether to grant approval of the trial. To ensure that the decision-making does not appear arbitrary, the Report further recommends (recommendation 2) that Health Canada develop a set of guidelines that would include criteria against which the fairness and reasonableness of an offer of compassionate access could be judged. The development of the guidelines is to be done in cooperation with representatives of the Pharmaceutical Manufacturers Association of Canada (PMAC) and treatment activist groups.

These two recommendations will encourage the practice of compassionate access by companies who wish to run clinical trials in Canada. In 1994, the CHTN put forward a similar request: that pharmaceutical companies provide information to the CHTN regarding how they plan to make compassionate access available in their applications for protocol review. This request did help to raise the profile of the issue of compassionate access, but companies do not need CHTN approval to run a clinical trial in Canada. However, they do need HPB approval and for this reason the Sub-Committee's recommendations should have some real effect.

Is Government Regulation Needed?

On a more general level, the recommendations raise the issue of whether compassionate access needs to be regulated at all and, if so, whether government intervention will provide the most effective means. PMAC has argued that there is no need to regulate this area because all PMAC member companies endeavour to provide compassionate access. This is a difficult argument for PMAC to maintain: if PMAC members are already providing compassionate access, why should they object to a requirement that they continue to do so?

In addition, although progress has been made in achieving a limited acceptance by drug companies of the necessity for some kind of compassionate access program, there have nonetheless been cases, as recently as 1996, in which companies have denied individual requests for compassionate access without providing any reason or justification for their refusal. Unless organizations like AAN threaten action against such companies, individual patients do not have the power to force companies to respond to their requests.

The history of compassionate access speaks volumes about the need to regulate. Without regulation it is left to a handful of activists, many of whom have AIDS themselves, to negotiate with large multinationals who continue to threaten to stop running trials in Canada if life is made "too difficult for them." However, in saying that we need regulation, I am not suggesting that there should be mandatory provision of compassionate access in every trial: it is probably most appropriate to look at trials on a case-by-case basis to determine the reasonableness of a requirement for compassionate access.

Expedited Review of New Drug Submissions (Recommendation 3)

The third recommendation put forward by the Report encourages provision of compassionate access by companies seeking regulatory approval of their drugs in Canada, in the absence of clinical trials in Canada. Under the recommendation, such companies would be offered an expedited review of their new drug submissions if they have established a compassionate access program.

Therapies Not Approved for Sale in Canada (Recommendation 4)

Some manufacturers outside Canada do not seek regulatory approval of their drugs for distribution in Canada. Recommendation 4 would bolster the Emergency Drug Release Program (EDRP) by giving Health Canada the authority to require manufacturers to account for a refusal to provide compassionate access to these drugs.

It is important that Health Canada increase its role in the administration of the EDRP; it is more likely that a manufacturer will pay attention to a request from Health Canada than from an individual. For this reason we have argued against the development of the new Special Access Program, which would reduce the role of government to a monitoring one.

Conditional Approval Process (Recommendation 6)

The Report recommends that Health Canada introduce a conditional approval process for drugs designed to treat life-threatening illnesses. If such drugs received conditional approval after Phase II trials, indicating an acceptable degree of safety and efficacy, the drugs could then be prescribed and the companies reimbursed. This would provide earlier access to the drugs. The US Food and Drug Administration (FDA) has implemented a conditional approval process; however, our system does not currently allow for it. The Drugs Directorate has drafted a proposal for a conditional licensing framework which should soon be made available. AAN has supported the concept of conditional approval as a means to expedite access. However, there are some concerns:

- post-marketing monitoring of adverse effects would be extremely important to protect consumers;
- in addition, it would be essential that the provincial health authorities and other third-party payers such as insurance companies recognize the conditional approval for reimbursement purposes.

The Future Direction of Drug Regulation (Recommendation 7)

In its seventh recommendation the Report addresses some of the problems of the Canadian drug regulatory process, asserting that the Government of Canada must study the future direction of drug regulation in Canada. The Report questions whether Canada should continue to have an independent system of drug review or whether it could integrate its system with that of its NAFTA partners.

Clearly, the Sub-Committee took our complaints regarding the delays and inefficiencies of the current system seriously. It is obvious that Health Canada cannot review drug submissions as quickly as the FDA unless more money is allocated to that area. It is questionable how valuable it is for Canada to continue to replicate reviews already done by the US. At the very least, Canada should follow the German model and introduce a mechanism that recognizes FDA approval and allows the prescription and reimbursement of a drug approved in the US, even though it has not yet been approved here.

Provincial Reimbursement (Recommendation 8)

The eighth and final recommendation deals with the issue of provincial reimbursement. It recommends that the federal Minister of Health propose to the Conference of Ministers of Health the establishment of a consultative mechanism to facilitate the timely adoption of new drugs on provincial formularies.

The harmonization of federal and provincial approvals of drugs is long overdue. Currently, it can take up to a year after federal marketing approval for a province to approve a drug for inclusion on the formulary. This delay means that people with AIDS who receive social assistance are denied access to the drug because they depend on the provincial formulary. Many people with private insurance are also denied access because approval by insurance companies is often tied to inclusion in the provincial formulary. I realize that under the Constitution health care is a provincial matter; however, I would argue that there should be a national formulary. Regardless of whether a person lives in Alberta or Newfoundland, if s/he has a catastrophic illness like AIDS s/he will require access to the same drugs.

Conclusion

In general, I am pleased with the Report's recommendations because they represent a step in the right direction by providing earlier access to new therapies. Although it remains to be seen how the government will respond, the Report, at the very least, has validated our arguments and provided us more with ammunition to continue to fight for improved equitable access to therapies.

- *Maggie Atkinson*

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Trudo Lemmens: A Response to the Parliamentary Sub-Committee's Report and Recommendations

In its Second Report on "Compassionate Access to Investigational Therapies," the Parliamentary Sub-Committee summarized the arguments made at the various round tables and formulated specific recommendations for governmental policy. In this comment, I will argue that the Sub-Committee's recommendations, although rather vague, are laudable and merit further consideration. The arguments put forward in the Report, however, often lack balance and contain extravagant interpretations of research ethics principles. They undermine the value of the recommendations. Two issues, in particular, should be criticized: the Report's arguments on the notion of "catastrophic right" and the discussion on the conditions for including terminally ill people in clinical trials.

As discussed in the previous issue of the *Newsletter*, the Report deals with the question whether and how people suffering from a catastrophic illness could obtain faster access to investigational drugs.

Current Ways of Obtaining Investigational Drugs

In Canada, investigational drugs can currently be obtained through participation in clinical trials, through the Emergency Drug Release Program (EDPR), or through importation from other countries.

The Emergency Drug Release Program

Traditionally, the EDRP has been used in emergency cases, when drugs approved elsewhere are necessary to treat a disease rarely occurring in Canada. Over the last decade, it has become one of the most important ways to obtain new investigational drugs that are not yet approved in Canada. However, the paperwork involved, the loss of time due to the obligation to obtain permission from the Drug Directorate, and the individual character of each permission have been criticized.

Clinical Trials

In Canada, most people living with HIV/AIDS become, at one time or another, participants in a clinical trial in which promising new drugs or treatments are tested. Clinical trials aim at testing the safety, toxicity and efficacy of an investigational new drug.[1] In order to do so, the new drug is compared with either standard treatment or placebo (where no standard treatment exists). Very often, these novel drugs or treatments are not available outside a clinical trial and many people participate in a trial with the desire to improve their health and to contribute to the development of a cure. There are some problems, though. Trials require time, not all people can participate, and of those who participate many receive only the control drug or placebo instead of the investigational drug. For these reasons, demands for early release of promising new drugs have often been made in the context of HIV/AIDS. This is understandable because many people living with HIV/AIDS have had to experience how time was running out on them while promising new drugs were being developed and available only in clinical trials. As a result, people living with HIV/AIDS have lobbied to obtain access to new drugs outside a trial. Their desire to obtain access to new drugs has compromised some clinical trials; trials have been delayed and trial results invalidated because participants wanted to make sure they obtained the drug under investigation rather than the control drug.

The Recommendations

The Report discusses these problems and makes some interesting recommendations. There is, for example, a clear recommendation to implement a new system of conditional approval for drugs designed to treat life-threatening conditions and to develop guidelines for compassionate access to investigational therapies before 1 June 1997.

Other recommendations remain vague, but they could be the basis for further regulatory intervention. For example, many recommendations call for participation of drug manufacturers or suggest that they *could* be held accountable for refusing to provide compassionate access (however, they do not specify what the result of this accountability would be, and do not clarify the manufacturers' duties). It seems reasonable to ask manufacturers to provide details about how they will provide compassionate access to new drugs, for example to those who cannot participate in a clinical trial or have to be withdrawn from one. It also seems right to develop guidelines to judge whether any such compassionate access program is "fair and reasonable." This leaves room for assessing, among other things, (1) the risks and the potential benefits of a new drug, as indicated by preliminary findings and studies on animals; and (2) whether enough participants have been found to conduct a clinical trial.

Interestingly, the Report also recommends that the mandate of the National Council on Bioethics in Human Research (NCBHR) be reviewed and strengthened. What the Report does not mention is that NCBHR could play an important role in the development of a renewed compassionate access program in Canada. The organization could function as a rational buffer between vulnerable patients and powerful pharmaceutical companies who, by their commercial nature, are in the business of selling hope to people.

The Supporting Arguments

While most of the recommendations in the Report, taken alone, are acceptable, some of the "supporting arguments" provided for them are seriously flawed. Overall, insufficient attention has been paid to the serious danger of providing uncontrolled access to investigational new drugs, the majority of which prove to be unacceptable after clinical trials are conducted. The irony is that, while the Report may seem to adopt many of the arguments made by advocacy groups for persons living with HIV/AIDS, the real beneficiary of the proposed new system would be the pharmaceutical industry, which would be able – under the proposed system – to sell drugs before obtaining approval. As a result, people living with HIV/AIDS would become the victims rather than the beneficiaries of the new liberalized policy.

Two points in the Report merit special attention: the recognition of a "catastrophic right" and the argument that a clinical trial is unethical if a drug is not available outside the trial. They indicate a misunderstanding of the reason for conducting clinical trials and put into question the entire drug-approval system. Both points are related to the importance and necessity of conducting clinical trials for unproven therapeutic agents. The Report missed the occasion to discuss at greater length why drug assessment and clinical trials are not necessarily a burden on people suffering from life-threatening diseases, but are on the contrary an essential aspect of their protection.

Catastrophic Rights

The Report suggests that all people who are catastrophically ill have the right to elect any therapy whatsoever provided it does not cause harm to others. It claims that participants at the round tables agreed upon the existence of such a catastrophic right; this is, however, not correct. All the participants probably agreed that the Health Protection Branch should be more flexible in releasing new drugs for treatment of terminally ill people, if these drugs could be life-saving. But this is not the same as recognizing a catastrophic right. Some of the participants at the round tables clearly rejected the proposition that people have an absolute right to choose a non-approved drug or therapy. Moreover, the Report contradicts itself by admitting that the concept of "catastrophic right" is not recognized under Canadian law. Furthermore, it states that "this right is only operational when the physician agrees with the choice of therapy" and that "the release of a therapy should only be considered when ‘an acceptable balance between efficacy and toxicity’ has been demonstrated." In short, while suggesting that a "catastrophic right" should be recognized, at least as an ethical principle, the Report recognizes that there is no such thing as complete freedom to choose a potentially harmful and unproven therapy, without assessment of harm. Put another way, clinical trials are so important precisely because they aim to establish whether there is an acceptable balance between efficacy and toxicity.

Coercion

A lack of appreciation for clinical trials is also reflected in the Report's assertions regarding the problems of voluntariness in connection with using terminally ill people as research subjects. Ordinarily, when one talks about coercion or problems of voluntariness in the context of clinical trials, it is to argue that people should have the choice not to expose themselves to the risks of a new drug. The research ethics literature points out that people who are terminally ill are vulnerable and may be tempted to take any new drug, even if it involves major risks without reasonable hope for cure. Researchers and research ethics boards have to make an additional effort to verify whether patients really understand the risks of participating in a drug trial. They have to inform participants that there is no guarantee that the new drug will be helpful and that it may cause harm. They have to point out that the best *proven* therapy or treatment is available outside the trial. Standard treatment should not be made conditional on participation in the trial. Patients should know that they can always withdraw from the trial and obtain further standard treatment. The idea is that vulnerable people warrant special protection and that their search for a cure should not be used to convince them to participate in trials in which they may be harmed.

Surprisingly, the Report holds that people who are catastrophically ill cannot freely consent to participate in clinical trials if there is no compassionate access program that allows them to have the ‘investigational therapy’ outside the trial. The Report suggests, in other words, that there is coercion when the only way of obtaining *unproven* new drugs or therapies is to participate in a trial. To support this argument, it invokes ethics guidelines that warn, on the contrary, that people who are in a vulnerable position should be protected against the temptation to take whatever drug is available, without realizing it might harm them seriously. MRC guidelines[2] and the draft document of the Tri-Council [3] certainly do not support these claims of the Report, which invokes the Tri-Council's argument that "special provisions must be made for the protection of the rights and welfare of vulnerable people." But the Tri-Council's suggestion calls precisely for a system of drug approval based on valid clinical trials, to ensure that people who are in a vulnerable position are protected against unlimited promotion of non-validated therapies.

The Role of Clinical Trials

If a trial involved a drug with proven efficacy and safety, it would be unacceptable and coercive to require participation in the trial in order to obtain the drug, in particular if the trial tested the proven drug against placebo or an inferior control drug. However, clinical trials are conducted precisely because there is no certainty whether the new drug is superior to standard treatment or placebo. There is, in other words, a risk that the new drug is inferior, both as to efficacy and safety. It is in no way sure that participants can benefit from the new drug. On the contrary, trial participants could be seriously harmed. The informed consent process aims at providing sufficient information about the risks and potential benefits so that participants can assess these risks. The essence of a clinical trial is that it starts off with a situation of uncertainty and aims at resolving some of this uncertainty.

In clinical trials of a new drugs for HIV/AIDS, the risk lies more in receiving the new drug and less in receiving no drug or standard treatment if there is one. Obviously, the problem is that standard treatment does not offer the prospect of cure and that patients see the new agent as their only hope. HIV/AIDS is not the first disease that evokes this dilemma. The ethics literature has extensively debated the same dilemma with regard to Phase I oncology trials, testing the toxicity of anti-cancer agents in terminally ill patients.

The Report, however, focuses only on the element of hope in trials for HIV/AIDS. It treats new drugs as if they were the only treatment, and suggests that there is coercion because participation in trials is the only way to obtain this form of treatment. It ignores *why* new drugs are not available outside the trial – because of lack of proof of their efficacy and safety and to protect people who are sick and therefore vulnerable in their dealings with the powerful, commercial forces interested in promoting these drugs.

Suggesting, as the Committee does, that it is no longer "socially and ethically acceptable" to run double-blind clinical drug trials in a population of terminally ill patients without offering them the possibility to take the drug outside the trial, is problematic. It gives the wrong impression – that investigative new drugs are accepted treatment – and risks creating increased suffering as a result of an increased consumption of potentially harmful new drugs. It might also deprive research of its essential tool for establishing whether a drug is efficient and safe. Based on a false belief that a new drug will save their lives and on an understandable but potentially dangerous hope to have found life-saving medication, people may be tempted to ask for compassionate access to the new drug rather than to participate in clinical trials. Researchers could have problems finding enough trial participants. Taken to the extreme, it could be possible that hundreds of patients obtain investigational new drugs over a period of months or years although their safety and efficacy has never been established, simply because the drugs have been "launched" as a promising new treatment, while clinical trials cannot be conducted because of a lack of participants.

Drug approval is based on the process of verifying safety and efficacy through clinical trials, which involve comparing the new drug with standard therapy or placebo. They are a precondition for commercializing drugs and are essential to protect people living with HIV/AIDS and the public against the marketing of inefficient and/or highly toxic drugs.

By confusing accepted treatment and investigational drugs, the Report undermines the rationale of the drug approval system; surely that cannot be the goal of the drafters of the Report.

Special Rules for Catastrophically Ill People

Is there no place, then, for special rules in the context of "catastrophically ill" people? Certainly there is. It seems reasonable to allow terminally ill people to take certain risks that we do not want others to be exposed to.

- If a promising new treatment is being developed and a clinical trial is being conducted, compassionate access could be provided to those who could not be included in the trial.

- Considering the threat to people's lives, it is important to switch people more quickly from one arm of the trial to the other if there are indications that this might improve their situation. As soon as a significant statistical difference in favour of the new drug has been determined, participants in the control arm should be allowed to shift to the drug. Considering the urgent need for treatment, statistical support in favour of the new drug could be weaker than in other studies.

- The requirements for scientific assessment of safety and efficacy could be lower in the case of life-threatening conditions. This is also why a procedure of conditional approval of new investigational drugs is acceptable in these circumstances, and less so when there is no immediate threat to people's lives.

- Special procedures should be established for approving drugs that have already been submitted to rigorous studies in other countries. The recommendation in the Report to study the harmonized European system of drug approval and to study the feasibility of collaboration for drug approval in the context of NAFTA merits special attention. Conditional approval procedures should take into consideration studies undertaken in other countries.

Conclusion

One can conclude that, while the initiative of the Sub-Committee on HIV/AIDS has been laudable and constitutes an important step in developing specific procedures for the particular case of people suffering from a life-threatening condition, the Report is disappointing as a result of inconsistencies in its reasoning. Many of the recommendations can be supported, but they lose their force because of the unbalanced arguments used in their support.

- *Trudo Lemmens*

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ENDNOTES

[1] See T Lemmens. Compassionate Access to Investigational Therapies. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 3(1): 41.

[2] Medical Research Council. *Guidelines on Research Involving Human Subjects*. Ottawa: Minister of Supply and Services, 1987.

[3] Tri-Council Working Group. *Code of Conduct for Research Involving Humans* (draft document). Ottawa: Minister of Supply and Services, 1996.

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PUBLICATIONS REVIEWED

François Dadour. *Le phénomène du SIDA et le droit criminel: impacts et enjeux!* Montréal: Éditions Thémis, 1996.

In his book, Dadour, a member of the Québec bar, reviews the ethical and policy issues that have characterized the legal landscape (up until 1994) in the areas of

- criminal prosecutions for HIV transmission/exposure;
- coercive measures under public health legislation; and
- mandatory HIV testing, prison practices, and sentencing.

Social Context and HIV/AIDS

Before embarking on his analysis of public law measures such as penal and public health law, Dadour first cautions that any discussion of the law must necessarily consider the social context in which law is shaped and applied. The symbolism of AIDS has been laden with judgmental and stigmatizing notions that people living with HIV/AIDS are to blame for their own condition: "presently, a diagnosis of AIDS can become a diagnosis of social marginality."[1]

Drawing our attention to several cases in which judicial homophobia, misinformation about HIV/AIDS, and other uninformed views about the "guilt" of persons living with HIV/AIDS have led to the abuse of state powers when responding to HIV, Dadour points out that since judicial policy lies at the heart of common law, there is a very real risk that judicial prejudices influence the search for justice that is at the heart of criminal proceedings.

Traditional Criminal Offences

Dadour's discussion of coercive state measures first canvasses the use of traditional criminal offences and public health legislation to respond to conduct that exposes others to, or actually transmits, HIV. Dadour suggests that the former criminal offence of "the transmission of venereal disease" could have been amended to cover HIV/AIDS had it not been repealed by Parliament, and questions whether public health authorities will in fact be more effective than the criminal law in this matter.

In considering other existing *Criminal Code* offences, Dadour concludes that charges of "murder," "attempted murder" or "administering a noxious thing" offer an inadequate solution to conduct placing others at risk of infection. Only in the rarest of cases will it be possible to prove the requisite subjective intent on the part of the accused: "having sex or sharing needles is a highly indirect *modus operandi* for the person whose purpose is to kill."[2]

In Dadour's view, prosecutions for "criminal negligence causing bodily harm" are more likely to succeed in addressing HIV-transmitting conduct, but he echoes the concern expressed by numerous commentators that applying an objective standard in determining criminal negligence may allow for discriminatory applications of the criminal law to stigmatized minorities, and uncertainty as to what conduct will be deemed negligent.

In "assault" prosecutions for risky conduct, the prosecution argues that the accused's failure to disclose his/her status to a partner constitutes fraud vitiating the consent given by the complainant. Reviewing the early jurisprudence in this area, and the *Lee*[3] and *Ssenyonga*[4] decisions that specifically addressed this issue in the HIV/AIDS context, Dadour concludes that assault provisions, as they are currently interpreted, do not provide a response to unprotected sex exposing others to risk of infection. In his view, a different conclusion than that reached in the above decisions was possible and warranted, and Canadian courts are to be criticized for maintaining a rigid, dated conception of fraud that strips it of any substantive meaning.

Contrary to numerous commentators, Dadour argues that the offence of "common nuisance" is well-suited to prosecuting those who put others at risk of HIV infection. In light of the "proportionality" approach adopted by the courts, Dadour suggests that the slightest risk of HIV transmission could appropriately be considered a common nuisance (ie, that it endangers the health or safety of the "public") because the harm that may result is of such consequence. Furthermore, Dadour argues that this offence relieves the Crown of proving actual harm and a causal connection between that harm and the accused's conduct because it criminalizes the taking of risk. However, as is the case with criminal negligence charges, Dadour reiterates the concern that an objective *mens rea* standard for culpability will lead to excessive stigmatization of already marginalized conduct.

Public Health Law

Dadour adverts to the historical misuse of public health powers to stigmatize and target prostitutes, immigrants, and other socially marginalized populations, but argues that past misuses should not necessarily prevent current, careful uses of public health powers to address risk behaviours. However, he agrees with the majority of commentators that "soft" public health measures such as education, prevention and support are preferable alternatives to coercive uses of public health powers (which raise many of the same concerns as traditional criminal offences).

HIV-Specific Criminal Offences

Dadour concludes that because both traditional criminal and public health laws have proved unsatisfactory, legislators have frequently turned to implementing HIV-specific penal legislation. He reviews several statutes from US jurisdictions and concludes that most such statutes are poorly and irrationally drafted, generally overbroad and arguably unconstitutionally vague.

Dadour notes that there is overwhelming agreement among commentators that actual knowledge of one's HIV-positive status, and knowledge of the risk of transmission, should be required before criminal liability is imposed for risk behaviour.

He also recognizes that opposition to HIV-specific penal legislation is based both on principle and on pragmatic grounds. Not only will such coercive measures actually be counterproductive to the more important, longer-term public health measures that promote voluntary testing and the use of precautions when engaging in risk activity, but HIV-specific legislation unfairly stigmatizes all persons living with HIV and those belonging to so-called "high-risk" groups, and is a serious entrenchment on sexual privacy that will cast the net of surveillance too widely and will discriminate against groups such as gay men, sex workers and injection drug users.

In light of these concerns, Dadour ultimately concludes that, while they are not ideal, traditional criminal offences suffice to impose liability on the conduct he describes as truly "criminal."

Conclusions

Dadour notes that the US experience, including judicial support of "anti-sodomy" legislation, is a clear warning of the danger that criminal law will be used for ideological and prejudicial ends. He joins the majority of commentators in reiterating that HIV/AIDS is first and foremost a health issue. Because of its grave social implications, any solution to the legal and ethical difficulties HIV/AIDS presents must be the result of social compromise that protects the rights of those affected and groups such as hemophiliacs, gay men and IDUs and does not pit the uninfected against the infected. Social investments in education, prevention, support services, access to treatment, and research will do the most to achieve respect for the rights of persons living with HIV/AIDS and to prevent the further spread of the virus. Dadour concludes that, in those rare instances of individuals who willingly infect others, existing criminal offences offer an adequate response, and that adopting HIV-specific legislation would only reinforce and entrench prejudices and misinformation surrounding AIDS, to the detriment of the infected and uninfected.

- reviewed by *Richard Elliott*

For more information, or to order a copy, contact Éditions Thémis, Faculté de droit, Université de Montréal, CP 6128, Succursale Centre Ville, Montréal, Québec H3C 3J7; tel (514) 739-9945; fax (514) 739-2910.

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ENDNOTES

[1]J Dolgin. AIDS: Social Meanings and Legal Ramifications. *Hofstra Law Review* 1985-86; 14: 193.

[2]KM Sullivan & MA Field. AIDS and the Coercive Power of the State. *Harvard Civil Rights – Civil Liberties Law Review* 1988; 23: 139 at 163.

[3](1991), 3 OR (3d) 726.

[4](1993), 81 CCC (3d) 257.

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Barry D Adam and Alan Sears. *Experiencing HIV: Personal, Family and Work Relationships*. New York: Columbia University Press, 1996.

The structure of *Experiencing HIV: Personal, Family and Work Relationships* reflects the experiences of people living with HIV and AIDS. From the opening chapters, which focus on issues surrounding the context in which testing occurs and the effect a positive diagnosis has on one's identity, to later chapters which deal with access to health care and HIV/AIDS in the workplace, the authors examine how a positive diagnosis can challenge assumptions about our roles at home and work.

Throughout the text, a broad spectrum of participants candidly discuss their situations and the ways in which, as the authors point out, they cope "adequately or inadequately with the difficulties posed by the syndrome." Both authors choose to deftly navigate between these voices, pausing only to draw the reader's attention to the larger patterns that emerge from the participant's stories. Such a structure, relying heavily upon individual voices, resists any single understanding of HIV/AIDS, lending itself to an open-ended and complex understanding of how the pandemic plays itself out in individual lives.

Having recently returned from a workshop on legal and ethical issues raised by HIV testing and confidentiality, I read the section on testing with great interest. The experiences outlined by the participants in Adam and Sears's study confirm the need for clear and respectful policies regarding HIV testing. "Three participants in this study were diagnosed as HIV-positive through mandatory testing in prisons or the armed forces." Another participant was tested while pregnant, without specific informed consent. One participant described how regulations regarding informed consent, already in place at the hospital, were not observed: "I was scheduled to have an operation and they tested my blood . ... The doctor refused to operate ... I had no counselling; was handed a couple of pamphlets and that was it."

Issues surrounding the tensions between disclosure and access to services were also paramount to the participants. "At the moment when their need for basic services was greatest, they felt at greatest risk of losing their children and so tended to avoid social service offices." One participant, Crystal, describes how many women fear that their HIV status and history of drug use will prompt child protection workers to "snatch up their children," and therefore avoid such workers altogether.

Another participant's story urges a broader understanding of confidentiality, one both comprehensive and practical. In Devon's case, he needed to provide his workplace with documentation in order to justify an absence: "So my doctor, not thinking, sent my entire medical record to my director, who was a [nurse], and it had HIV written all over it." Further, participants describe how HIV-related symptoms are being "red-flagged" by private insurance companies, prompting an immediate reassessment of candidates' access to coverage. Clearly, these stories are telling us that we need to reassess our understanding of the scope of "privacy." Our policies and laws regarding confidentiality need to reflect the practical experiences of persons living with HIV and AIDS.

With Canadian hospitals closing their doors, and "current government budgetary crises threaten[ing] the continuation of public, universal health care in Canada," the chapter on health care is especially ominous. Though the book is binational, and includes both Canadian and US participants, this section expressed the first real divergence based on national identity. As the authors point out, the voices in this section are those of Americans. But these voices hold a lesson for Canadians as well, for whom access to health care is not yet, in these narratives, an issue. In the US, "a major portion of the distress suffered by people with HIV has been inflicted by (rather than alleviated by) the health care system itself." The privatization of insurance has resulted in a profit-oriented health-care system, which works against those with costly and chronic conditions. Having come to know these voices, having listened to their stories of lives interrupted, having borne witness to the difficult process of rebuilding an integral sense of self, one must reject the validity of any system that denies basic needs to a person when s/he is most in crisis. This book should be required reading for all those involved in the making of policy and legislation that impacts upon the lives of those affected by HIV/AIDS.

- reviewed by *Anne Stone*

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HIV/AIDS, Human Rights and Public Health

The following text is an excerpt from the Guidelines on HIV/AIDS and Human Rights adopted at the Second International Consultation on HIV/AIDS and Human Rights.

Several years of experience in addressing the HIV/AIDS epidemic have confirmed that the promotion and protection of human rights is an essential component in preventing transmission of HIV and reducing the impact of HIV/AIDS. The protection and promotion of human rights is necessary both to protect the inherent dignity of persons affected by HIV/AIDS and to achieve the public health goals of reducing vulnerability to HIV infection, lessening the adverse impact of HIV/AIDS on those affected and empowering individuals and communities to respond to HIV/AIDS.

In general, human rights and public health share the common objective to promote and to protect the rights and well-being of all individuals. From the human rights perspective, this can best be accomplished by promoting and protecting the rights and dignity of everyone, with special emphasis on those who are discriminated against or whose rights are otherwise interfered with. Similarly, public health objectives can best be accomplished by promoting health for all, with special emphasis on those who are vulnerable to threats to their physical, mental or social well-being. Thus, health and human rights complement and mutually reinforce each other in any context. They also complement and mutually reinforce each other in the context of HIV/AIDS.

One aspect of the interdependence of human rights and public health is demonstrated by studies showing that HIV prevention and care programmes with coercive or punitive features result in reduced participation and increased alienation of those at risk of infection.[1] In particular, people will not seek HIV-related counselling, testing, treatment and support if this would mean facing discrimination, lack of confidentiality and other negative consequences. Therefore, it is evident that coercive public health measures drive away the people most in need of such services and fail to achieve their public health goals of prevention through behavioural change, care and health support.

Another aspect of the linkage between the protection of human rights and effective HIV/AIDS programmes is apparent in the fact that the incidence or spread of HIV/AIDS is disproportionately high among some populations. Depending on the nature of the epidemic and the legal, social and economic conditions in each country, groups that may be disproportionately affected include women, children, those living in poverty, minorities, indigenous people, migrants, refugees and internally displaced persons, people with disabilities, prisoners, sex workers, men having sex with men and injecting drug users - that is to say groups who already suffer from a lack of human rights protection and from discrimination and/or are marginalized by their legal status. Lack of human rights protection disempowers these groups to avoid infection and to cope with HIV/AIDS, if affected by it. [note deleted]

Furthermore, there is growing international consensus that a broadly based, inclusive response, involving people living with HIV/AIDS in all its aspects, is a main feature of successful HIV/AIDS programmes. Another essential component of comprehensive response is the facilitation and creation of a supportive legal and ethical environment which is protective of human rights. This requires measures to ensure that Governments, communities and individuals respect human rights and human dignity and act in a spirit of tolerance, compassion and solidarity.

One essential lesson learned in the HIV/AIDS epidemic is that universally recognized human rights standards should guide policy-makers in formulating the direction and content of HIV-related policy and form an integral part of all aspects of national and local responses to HIV/AIDS.

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ENDNOTE

[1] J Dwyer. Legislating AIDS Away: The Limited Role of Legal Persuasion in Minimizing the Spread of HIV. *Journal of Contemporary Health Law and Policy* 1993; 9: 167.

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Human Rights and the HIV Paradox

Faced with the grave challenge to public health presented by HIV infection, governments are obliged to "do something." One response, which often finds favour with the general public, is to enact laws that criminalize the activities of certain target groups. However, such laws marginalize individuals in these groups and have very little impact on containment of the epidemic. It is far better to introduce measures that protect the rights of people most at risk of infection and thereby encourage and sustain behaviour modification.

This text, by Justice Michael Kirby of the High Court of Australia, is reprinted in full from the *Lancet*.[1]

For centuries people like me have been sentencing and locking up other people in the social groups which are now most exposed to HIV infection – sex workers; homosexuals and bisexuals; drug users; adulterers; promiscuous people. The effort has been only partly successful. Resolutely, in their quest for pleasure and their pursuit of happiness, the targeted groups have often ignored social sanctions. They have defied the law and its punishments. They have run risks and largely gone on doing what they wanted. Some were deterred by the awful pronouncements of people in black robes. But most were not.

Behaviour modification is hard to achieve at the best of times. It is harder to sustain where people's pleasures are involved. This product of judicial experience teaches that we cannot place much store on law enforcement as an effective and immediate means of achieving behaviour modification to help contain a pandemic such as that involving HIV.

Yet ... the pace of developments in the search for a cure and a vaccine has been so disheartening that unprecedented attention is now being paid to behavioural and social change and how, in practice, to produce it. For the foreseeable future, these uncertain and imperfect strategies will be essential to effect HIV prevention programmes everywhere. Whilst in developed countries some progress has been made in HIV prevention by mobilising political commitment to saving lives and by taking courageous and controversial decisions (eg, syringe exchange), in most developing countries, which carry the greatest share of the global burden of the pandemic, the prospects of effective interventions often appear very bleak. They run headlong into deeply entrenched social phenomena such as:

- Religious and other impediments to the education of children in schools and colleges and in the media about sexual transmission
- Disempowerment of women, so that they cannot defend themselves against unprotected sex
- Prohibitions, by law and social convention, on homosexuals, on injecting drug users, and on sex workers
- Unavailability of affordable and suitable condoms
- Lack of clear political commitment to take the radical steps necessary to save lives.

Reflection on the current stage of the HIV pandemic, the progress, or lack of progress, towards really effective treatment and a vaccine, and the problematic nature of promoting and sustaining behaviour modification are enough to engender a feeling of despair and even desperation.

Against this background it is essential that we place the efforts of enlightened elements in the international community to respond effectively to the HIV pandemic in the context of universal human rights. This is not just theory. It is a matter of placing our debates in a conceptual and historical framework from which people in the know can seek to argue for action by people with power who are ignorant and often obstructive.

Although the international human rights movement has a long history, its global manifestations really only gathered pace after the terrible suffering and revelations that followed the Second World War. The *Universal Declaration of Human Rights 1948* and the *International Covenants on Human Rights* 1966 incorporate fundamental principles, which are now part of international law. They uphold the dignity and entitlements of each human being on earth [see panel 1].

Many citizens – and most political leaders – will question what human rights have to do with a successful strategy to contain the spread of HIV. It is here that the HIV paradox arises for consideration. However imperfect our understanding of the tools of behaviour modification, this much at least seems clear. To have a chance of penetrating into the mind of an individual, so that he or she secures the knowledge essential to change behaviour at a critical moment of pleasure-seeking, it is imperative to win the trust of that individual. Only in that way will their attention be captured in a manner that will convert words and information into action. Pamphlets and posters, homilies and sermons are only of minor use in this regard. What is needed is the direct supply of information by a source regarded as trusted, impartial and well intentioned, so that, by repeated messages of this kind, a general awareness about the existence of HIV can be translated into individual daily conduct.

The paradox is that laws which criminalise particular target groups (sex workers, homosexuals, injecting drug users, &c) may appear to be a suitable response. They are often attractive to the public and therefore to distracted politicians who are anxious to be seen to be doing something in the face of the grave challenge to public health that HIV presents. But experience teaches that such responses have little impact on the containment of an epidemic of this nature. They actually tend to have a negative impact on behaviour modification because they place targeted groups beyond the reach of the requisite information. They undermine the creation of the supportive social and economic environment in which effective strategies can be prosecuted.

Thus the HIV paradox teaches, curiously enough, that one of the best strategies of behaviour modification which will actually work to reduce the spread of HIV, by enhancing and sustaining self-protection, is to be found in measures that positively protect the targeted groups and uphold the rights of individuals within them. In those countries where there has been a measure of success in achieving and sustaining behaviour modification, and thereby reducing the spread of HIV infections, such strategies have been adopted [see panel 2].

To those who find the HIV paradox unconvincing or even offensive, two answers may be given. The first is that of practicality. No other strategy has been shown to work. Without effective behaviour modification HIV will continue to spread rapidly, causing enormous personal suffering and devastating economic and human loss. By 1987, most informed health officials, led by the World Health Organization, had come to recognize the force of the HIV paradox. However, their endeavour to supplement public campaigns and health prevention efforts with attention to human rights has only been partly successful. The effort must continue.

The second justification for the strategy which I have described takes me back to fundamental human rights. They are important, not because they are contained in the international constitutions or laws. Their importance lies in the fact that such rights are basic for every human being for no reason other than the humanity and unique individuality of each of us. I once explained, to a law school in the USA, the practical reasons for supporting a strategy protective of the rights of individuals especially at risk of HIV infection. A young law student rebuked the judge. He told me that I had forgotten the main reason. This was that we accord every human being that person's human rights because it is our duty and their right. When epidemics are about, human rights tend to go out of the window. But even in times of epidemic, departures from respect for fundamental human rights must be controlled by law. They must be limited to measures that are strictly proportional and necessary. They must be compatible with the other objectives of a democratic society.

In the struggle against HIV/AIDS we need to learn again the lessons that were taught nearly a century ago when syphilis presented as a major challenge to public health in some ways similar to that now presented by HIV. The manifestations of symptoms were delayed. The condition was often, ultimately, fatal. The drug therapy then available was incompetent and had serious side-effects. The social stigmas were substantial and they arose largely from the sexual modes of transmission. This was a time before advanced therapy. It was only when syphilis was treated in a way which accepted its reality, applied strategies to promote non-transmission, and respected the rights and dignity of the patient, that any real progress was made toward containment.

HIV shines the spotlight of human rights on medical practice, epidemic control, and our social responses to aspects of human sexuality and drug-taking. Only by re-learning the lessons of the past, and by studying such successful endeavours as exist in the present, will we avoid the mistakes that beset most of the present strategies against HIV. The problem is extremely urgent. The obstacles are many. The apathy, indifference and hypocrisy that attend such terrible suffering are appalling. Teaching the HIV paradox to frightened communities is by no means easy. Yet we must persist in our attempts to do so.

Let me therefore lay it on the line: the most effective strategies that we have so far found to help promote reduction of the spread of HIV involve the adoption of laws and policies which protect the rights of people most at risk of infection. This may seem surprising. It is a paradox. But it is so. The appalling neglect and denial, especially in developing countries, should be reversed in their own economic interests and in the interests of the rights of their people. We should take this course because it is all that is likely, at this stage, to be effective in changing the behaviour we need most urgently to change. But we should also do it became it is right.

- *Michael Kirby*

Panel 1: **Human rights**

Rights to healthcare, which include preventive health education and self-protection

Rights to privacy (now held to extend to rights to sexual privacy and to one's sexual orientation)

Rights to shelter and housing

Rights to employment without discrimination

Rights of children to be given basic information necessary for their protection, health, and life

Rights of women to the dignity of their person and to protection from violence, including unconsensual sexual conduct

Rights to protection against oppressive laws and policies of the state

Panel 2: **Strategies to contain HIV infection**

Introduction of systems for the exchange of sterile needles

Legalisation or decriminalisation of adult, consensual, private homosexual conduct where this has been illegal

Decriminalisation of prostitution and other activities of sex workers and legalisation of brothels

Facilitation of school education and public information in frank and direct terms, including by imaginative use of the public media

Publicity concerning condom use and the free distribution of condoms in selected venues

Involvement of representative community groups and leaders in programmes designed to sustain behaviour-modification campaigns

Provision of the best affordable medical care and up-to-date information to persons living with HIV

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[1] *Lancet* 1996; 348: 1217-1218.

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Guidelines on Ethical and Legal Considerations in Research on HIV/AIDS and Drug Use at the Community Level

Background

The spread of HIV among injection drug users continues to be one of the most volatile aspects of the HIV/AIDS pandemic. In Canada, research activities involving drug users at the community level are expanding to include participatory studies, cohort studies, the monitoring and evaluating of outreach programs, and multi-agency epidemiology networks on drug use. The direct involvement of drug users in community level, HIV-related research is now seen as essential. Such studies have an immediate impact on study participants, and involve a better balance between traditionally-defined scientific merit and practical outcomes. It is important to recognize that the need for services for drug users may outweigh the need for research.

The Working Group

A multi-disciplinary Working Group was convened by the HIV/AIDS Prevention and Community Action Programs, Health Canada, on March 27, 1996. Working Group Participants included those representing drug users, law, ethics, public health, research, theology, needle exchange programs, provincial and federal governments, law enforcement, and national non-governmental organizations.

Purpose

The Guidelines are intended for use by all parties involved in HIV-related research with drug users at the community level. The primary intent is to prevent and reduce harm to study participants as individuals and as populations. This will, in turn, protect researchers, participating agencies and the overall integrity of research efforts.

The Guidelines must not be perceived as a substitute for rules or regulations, nor should they encourage researchers to over-simplify complex situations and decisions. The Working Group recommends that the Guidelines be used as a frame of reference to be integrated by researchers, review committees, and funding agencies into their work.

Legal Context

The range of options that exist for research on AIDS and drug use is limited by the legal context. For example, there are a variety of federal and provincial laws that place restrictions on data collection, and it is not yet possible to conduct pilot studies on medical access to heroin, or the impact of de-criminalization of narcotics on the spread of HIV.

All research is to be conducted within the legal requirements defined by laws on privacy and confidentiality. Guidelines have also been developed in the related areas of testing and contact tracing.[1] There may be special situations where collecting information on HIV and drug use has implications with respect to a professional duty to warn, or a duty to notify public health authorities. Those involved in research are obliged to have a good understanding of these requirements.

Recommended Approach

Researchers have a moral duty to continually assess study practices to ensure that they are ethical. For example, including minors who are using drugs in a study requires a careful analysis of the legal context and the balance of benefit against potential harm. Researchers also have a moral duty to monitor the implications of their findings and facilitate their use in policies and programs.

Researchers must make every effort to anticipate, and minimize the negative impact that studies might have on individuals, communities and service providers. Ensuring that a study is ethical involves an ongoing process of anticipating and monitoring the balance of harm and benefit. This process is complicated and involves a good deal of ambiguity.

Anticipating and protecting against harm

- Community-based studies should link drug users with existing health and social services.

- Research must take into account that users of illicit drugs and their communities are exceptionally vulnerable to stigmatization.

- Study participants can be harmed and/or wronged (e.g. privacy breached without their knowledge), and researchers must protect against both.

- Research involving drug users at the community level must be sensitive to cultural diversity and special needs (e.g. ethnicity, poverty, mental illness).

Participation of drug users

- Participation of drug users throughout the research process is crucial to identify potential harms and resolve moral ambiguities.

- Researchers must engage in realistic negotiations with individuals and groups to be studied, and jointly develop mechanisms to ensure that studies are ethical.

- It is recommended that an active advisory group be established that represents study participants/affected communities. The advisory group should play a central role in the design and implementation of studies, and in resolving issues concerning data ownership, interpretation and dissemination.

Data collection and use

- The use (including record linkage) of nominal data without specific informed consent is not acceptable.

- The use of non-nominal data for purposes other than those originally identified to study participants must be assessed carefully to protect privacy, and to ensure that benefit outweighs potential harm to individuals and groups.

- Protection of study participants must also consider the implications of post-research use of findings as well as stringent security measures during data collection and analysis. There are many instances where individual records may be of interest to a third party, e.g. insurance, child custody, child welfare disputes.

Consent and Coercion

- When a study requires informed, voluntary participation of individual drug users, discussions with potential study participants at the outset must reinforce that they can withdraw from the study whenever they choose to do so.

- The consent of communities to be studied should be obtained. It may be difficult to identify who can effectively represent disenfranchised populations, or whether anyone has the authority to provide consent.

- Researchers must guard against both real and perceived coercion of drug users to participate in studies. There is a difference between inducement and coercion in this context. For example, payment of drug users for their time is respectful, but it is not acceptable for study participation to be a condition for access to a previously-available treatment or services. Payment and other forms of compensation should not encourage study participants to take risks that they otherwise would not have taken.

Ethics Approval

- Study protocols must be reviewed and approved by an ethics committee.

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For additional copies of these guidelines, contact the National AIDS Clearinghouse. Tel: (613) 725-3434; fax: (613) 725-9826; e-mail: aids/sida@cpha.ca

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ENDNOTE

[1] Federal/Provincial/Territorial Advisory Committee on AIDS. *Guidelines for Practice for Partner Notification.*