# Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

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## Contents

## Volume 3 Number 4 & Volume 4 Number 1

**Discrimination**

**HIV/AIDS Legal Clinics**

**Return To Work**

**Confidentiality**

## Canadian News

## International News

## Drug Policy

## Prisoners and HIV/AIDS

## Criminal Justice

**Euthanasia**

**Immigration**

**Internet News**

**Publications Reviewed**

---

Top of this page

Return to Home Page

---

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# Current Issues in HIV/AIDS and Insurance

**Insurance was at one time rarely a concern of Canadians with AIDS. In the early days of the epidemic, the short and painful course to death generally precluded any consideration of legal problems outside estate planning. With the advent of early diagnosis and improved treatment, more people living with HIV/AIDS are confronting issues around insurance.**

**In this two-part series, we will explore some of the current issues through two fictional scenarios and make suggestions for reforms. The first scenario, presented here in Part I of the series, focuses on obtaining insurance. The second scenario, to be presented in Part II of the series, focuses on obtaining benefits once one is insured.**

## Scenario One – Access to Insurance

Bill is a gay man. He was diagnosed with HIV in 1988. Bill has three insurance policies:

- The first is an individual life insurance policy that was obtained in 1985. At the time, no questions about HIV/AIDS were asked.
- The second is an individual disability insurance policy, obtained in 1988. At the time, Bill had noticed that he had swollen glands. He had decided that he should be tested for antibodies to HIV, but – "just in case" – had applied for the insurance before he obtained his HIV test results. There was a question about HIV/AIDS, but Bill answered "no."
- The third is a group life insurance policy provided through the company for which Bill works. No question was asked about HIV/AIDS when Bill joined the company in 1987.

Bill has a same-sex partner, Stephen. Stephen applied for insurance in 1990. At that time, Stephen was not aware of his HIV status. He was required to take an HIV-antibody test as part of his insurance application. He was surprised to be turned down by the insurance company because he had "tested positive for AIDS." Prior to this rejection by the insurance company, Stephen had received no post-test counselling to advise him of the outcome of his HIV test.

Stephen is currently considering two offers of employment: one from the AIDS Committee of Metro (ACM), the other from V & G Trust Company (VGT). ACM tells him that they are very interested in hiring him, but have no group benefits for HIV-positive persons. VGT brags about how good their plan is and assures him that "your wife and kids will have the best coverage around."

Bill and Stephen also have a mortgage that they took out in 1995 and for which they obtained life insurance. There was no question asked about HIV/AIDS, but they are worried about whether they will be covered.

## Discussion

Three important questions need to be looked at when examining insurance issues involving HIV/AIDS.

- The sequence of the events: was the application made before or after the applicant knew that s/he was HIV-positive or was aware of a condition deemed to be caused by HIV?
- The period during which the application was made: was the application made before or after it became routine to require applicants to be tested for HIV antibodies?
- The nature of the insurance policy: is it an individual or a group policy?

As was noted by the Supreme Court of Canada in the leading case of *Zurich Insurance v Ontario*,[1] there is a fundamental tension between human rights law and insurance practice. Human rights law requires that certain innate personal characteristics be ignored, while insurance is in the business of classifying risk using probabilities based on innate personal characteristics.

## The First Insurance Policy

Bill's first insurance policy was secured at a time (1985) when there was still considerable debate about the propriety of testing for HIV antibodies or asking about HIV-antibody test results. Some American jurisdictions actually banned the use of the test.[2] However, in a 1986 Report, the Canadian Bar Association – Ontario AIDS Committee found that the test was sufficiently reliable and actuarially significant that it could properly be the subject of inquiry by insurers.[3]

Bill was diagnosed with HIV in 1988. When he applied for the first policy in 1985, he did not know whether or not he was HIV-positive. (Whether Bill was in fact HIV-positive in 1985 may be impossible to determine.) Bill was certainly not required to disclose that he was a gay man. Discrimination on the basis of sexual orientation is prohibited under federal and most provincial human rights codes.[4] Exceptions for insurance policies do not extend to the grounds of sexual orientation. This policy will be valid.

## The Second Insurance Policy

By 1988, questions about HIV/AIDS had become commonplace on individual insurance applications. A positive answer would result in denial of insurance. There may be little difficulty in concluding that the swollen glands were a symptom of HIV infection, and inferring that this prompted the test. A close review of the insurance application will be called for when the policyholder in a case such as this applies for benefits. It is quite possible, however, that the question on AIDS is sufficiently broad to cover this symptom, or that there is a general health question or "basket clause" which may catch this medical presentation.

This situation demonstrates the principle of *uberrimae fidei*, or utmost good faith. Traditionally, insurers had to rely on the proposed insured to tell the truth about his or her habits and health in order to assess the risk they were accepting by underwriting the policy. Failure to disclose a material risk on the part of the insured rendered the policy void.

Sadly, some think that if you are tested anonymously or non-nominally this means you need not disclose your true status on an insurance application. You must. If you do not do so, and you are caught, the policy is void. While it is impossible for the insurer to gain access to anonymous test information, the timing of the testing is often subsequently recorded on a treating physician’s chart. This chart is subject to scrutiny by an insurer who is investigating a claim made on a policy. As a result, in those circumstances and in the case of non-nominal or confidential testing, an insurer is not prevented from subsequently obtaining information about when you were tested.

The interesting question raised in this scenario is the fact that swollen glands are a non-specific condition that might be caused by a number of benign conditions, such as a tonsil infection or flu unrelated to HIV infection. The application may not have a specific question that calls for disclosure of the swollen glands, or it may be that they were not considered important because of their transitory association with a minor illness or condition. It is not uncommon for persons to forget to disclose minor items of this sort.

Transitory conditions that might be overlooked or forgotten are generally saved by what are known as "incontestability clauses" in the contract of insurance or in applicable legislation, such as the *Ontario Insurance Act*. These clauses provide that after a certain period of time, a misstatement or omission on an application for insurance does not render the policy voidable or void, except in the case of fraud.[5] However, the manner in which "fraud" has been interpreted in this situation has been very favourable to insurers. As a result, incontestability clauses often provide cold comfort to most people. Real or suspected conditions of a more serious nature generally are not excused by these clauses on the legal principle that such misrepresentations amount to "fraud" in the insurance setting.[6]

### The Group Life Insurance

Bill’s group life insurance was obtained in 1987, before he tested positive. It will be secure. It was unusual to ask questions about HIV/AIDS in group insurance settings at that time, and even today it is still not unusual to find large groups where no questions are asked about HIV/AIDS. Even if his group policy contained a "pre-existing condition clause," and if Bill was indeed HIV-positive in 1987 (which is not known), most such clauses do not have any impact after one or two years. In addition, the principle of *uberrimae fidei* ought to have little or no application in the group insurance setting, where the insurer should look to the characteristics of a pooled group.

### The Mortgage Insurance

The only joint policy that Bill and Stephen hold is the mortgage insurance. This is a special type of group insurance known as "group creditor" insurance. It pools together the borrowers of the creditor and spreads the risk among them. It is uncommon, and perhaps legally unjustifiable, to find a question regarding HIV/AIDS in applications for insurance for such large groups. Nonetheless, there can be a clause in the fine print that purports to exclude claims based on HIV/AIDS-related causes. The BC Superintendent of Insurance has ruled that such clauses are too broad and constitute an unfair practice under the law of British Columbia.[7] However, the primary concern of the Superintendent in that case was that the clause was broad enough to catch even people who became infected *after* they had obtained the insurance. In the case discussed here, both Bill and Stephen were HIV-positive *before* they obtained the insurance. Therefore, the case is different. Should a clause excluding claims based on HIV/AIDS-related causes exist, the real question would be the applicability of the human rights exemption for insurance companies.

### Pre- and Post-Test Counselling

The manner in which Stephen learned his HIV status – without pre- and post-test counselling – is disturbing but not necessarily unusual.[8] In Canada, it is generally recognized that HIV testing should only be undertaken with the specific informed consent of the person being tested, pre-test counselling about the nature and implication of the test, and post-test counselling.[9] Failure to observe this definitely taints the ethics of the testing, but, at least in some cases, may have no impact on its legality.[10]

Clearly, while insurance companies are entitled to require testing for HIV antibodies of persons applying for individual insurance policies, they are not well-equipped to provide the necessary pre-test and post-test counselling.

### Insurance for Persons Living with HIV or AIDS

At least one insurer in South Africa and one in the United States now offer limited and expensive insurance policies for "healthy" people with HIV. This is a positive development, and it may be that in the future the validity of totally excluding persons living with HIV/AIDS from insurance policies will be questioned more generally.

### Access to Group Benefits for HIV-Positive Persons

Stephen's dilemma – choosing between a "friendly" workplace that offers no benefits and a more hostile environment in which being out about his sexual orientation and HIV status is problematic if not impossible – clearly demonstrates two important problems: the problem of persons who are HIV-positive obtaining access to group benefits; and, generally, the stigma associated with AIDS.

ACM is an AIDS service organization (ASO). Many ASOs have encouraged PHAs to apply for positions with them. For persons living with HIV/AIDS, this represents an opportunity to work in a positive employment environment and to make a contribution in fighting the disease. However, many ASOs find themselves unable to offer group benefits because of the way group benefits are handled today.

Group insurance differs in principle from individual insurance policies. Individual policies are based on underwriting, where there is an assessment of the individual risk. In theory, an assessment of individual risk should not be required with group insurance. Large pools are insured. The risk is not the individual one, but the average risk within that pool. Within the pool, there will be some who are at greater risk than others. People with HIV should be in no different a position in this regard than women who carry the gene for breast cancer or people who are heavy smokers.

In fact, pools have tended to become smaller. Employers with small groups are often "experience rated," an industry euphemism meaning that all costs of the particular group plus an administrative fee are re-captured without pooling with any larger group. As a result, principles of individual risk assessment have begun to creep into the group setting. The presence of a PHA in a pool of five persons clearly can affect the viability of the notion of "spreading the risk." This "pooling" problem has resulted in many ASOs being unable to obtain group benefits or being forced to deny coverage to persons living with HIV/AIDS.

In addition to the problems caused by small pools, there has been some blatant discrimination based on the nature of HIV/AIDS.[11] As Marcosson notes,[12] we tend to believe insurance is for "us," not "them." Given the stigma associated with AIDS and the groups it has most affected, it is not hard to see why some employers and insurers see PHAs as "them," persons who should not be allowed to join "us" in the group. However, this does not provide legal justification for discrimination against PHAs.

However, it must be acknowledged that treatment of PHAs is not just based on irrational prejudice, but also on genuine concerns about the financial impact of including PHAs within a group. There has been great fear on the part of insurers that HIV/AIDS would devastate the insurance industry. In particular, it was thought that gay men would engage in "anti-selection," that is, that they would take out insurance knowing they were likely to develop AIDS.

In fact, these fears have proved to be exaggerated. There is no doubt that some gay men bought insurance for fear of HIV/AIDS. However, one must ask how that is different from anyone else who buys insurance because of fear of premature death. This is precisely the business insurers are in: assuming risk in exchange for payment of money.

### Stephen's Choices and Rights

Stephen could accept the offer of VGT, which appears to have a good plan that offers important financial security to a PHA like Stephen. However, he may be working in an environment that is less welcoming of him as a gay man. He must consider how VGT will deal with his claims for drugs or his need for compassionate leave if Bill falls ill.

As a preliminary matter, Stephen will have to determine whether there will be an HIV question or test as part of his application for group insurance. He cannot be refused employment because of his HIV status or his sexual orientation. Can he be denied access to the insurance benefits?

Even in the absence of a question about his HIV status, Stephen needs to be aware of the problem of pre-existing condition clauses. In group settings where individual underwriting does not take place, insurers use pre-existing condition clauses to limit their risk. Pre-existing condition clauses are very common, and their validity was considered in the context of HIV in the leading case of *Thornton v North American Life Insurance Company*.[13] Thornton was HIV-positive and had received treatment before obtaining employment at the Clarendon Foundation. Within a few months of starting work, he fell ill and applied for long-term disability benefits. The pre-existing condition clause in his case – typical of the clauses used – provided that claims were excluded for conditions for which treatment had been received within 90 days of commencing employment, where the claim was advanced within one year of commencing employment. The Board of Inquiry held that, although discriminatory, the use of such clauses was reasonably justifiable on actuarial grounds and thus saved by the exemption contained in sections 22 and 25 of the current *Ontario Human Rights Code*.[14] The test to be applied to determine if the insurer's requirement is legally valid is from the *Zurich* case:[15] is the use of the distinction made by the insurer – in this case between HIV-positive and HIV-negative persons – bona fide and reasonable? Bona fide means not for the purpose of defeating the rights under the Code; reasonable means in accordance with sound and accepted insurance practice where there is no practical alternative. The Board found that the evidence supported the contention that, given that there was no individual underwriting in group insurance, insurers required these clauses to limit risk, and especially the risk of anti-selection. This decision was eventually upheld by the Divisional Court.

It is likely that Stephen will find himself without coverage if he falls ill soon after joining VGT.

Can VGT’s insurer ask questions about Stephen’s HIV status or require that he be tested? This raises a very difficult question. There are, as noted, exemptions in human rights law for bona fide and reasonable insurance questions that discriminate based on physical disability (but not based on other types of distinctions, including race and sexual orientation). The bona fides or reasonableness of this question has both factual and legal frailties. Factually, the recent improvements in treatment have meant that persons living with HIV/AIDS are leading longer and more productive lives. The medical landscape has changed since *Thornton*, which in any event was concerned with pre-existing condition clauses. *Thornton* is actually a case that can be used to fight such a requirement: the industry justified the use of such clauses as necessary in *group* situations where they do not assess individual risk. How can they also insist on testing to eliminate *individual* risk?

In addition, there is a real question about why HIV/AIDS is being singled out. Is there sound evidence that supports the contention that HIV/AIDS is different? Frequently, some illnesses are viewed as more worthy than others socially. Even among people with HIV, children and other so-called "innocent victims" elicit more public sympathy than those who contract the disease through "voluntary" behaviour, especially gay sex and injection drug use; yet, we do not exclude those who fall ill through other voluntary behaviours, such as smoking, poor nutrition or sedentary lifestyles.

An important recent case on this point is *Gibbs v Battlefords & District Co-operative Ltd*.[16] Although not an AIDS case, it deals with another illness that carries social stigma and seems to attract special attention from the insurance industry: mental illness. In that case, the Supreme Court of Canada considered the legality of a clause in a group benefits plan that purported to impose requirements on the mentally ill that were not imposed on the physically disabled. The Court ruled that once an employer chose to offer benefits, it could not discriminate on the basis of types of disabilities in the absence of compelling actuarial reasons. The special requirements imposed on mentally disabled claimants were found to violate Saskatchewan’s human rights legislation and were not saved by the exemption.

In this regard, Marcosson alerts us to the need to be vigilant about attempts to present the simplistic defence that HIV/AIDS does impose greater-than-average costs and that distinctions based on HIV/AIDS are therefore "reasonable" and "actuarially sound." In a pooled situation, the extra financial burden distinction will be true of many diseases. Legally, the question must be a comparison with other costly diseases that might occur in the pool, such as cancer or multiple sclerosis. Ethically, the question must be why persons with HIV should be excluded from the group, from "us". The whole point of this type of insurance is that some will need the insurance more than others, and that the ones who do not need the insurance bear no unfair burden: they are the lucky ones. Once the group starts down the slippery slope of excluding some as more risky, more costly, or "less deserving," the notion of group insurance becomes a mockery. It becomes a process of paying a reduced premium for the privilege of being identified with the safest possible group. It is not spreading the risk, it is pushing the risk onto the shoulders of the most vulnerable members of the group.

- *Douglas Elliott*

Part II of this article, to be published in the next issue of the *Newsletter*, will give consideration to problems in obtaining insurance benefits or preserving them for persons who are or believe that they are insured. In addition, it will make suggestions for reform.

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Top of this page

Return to Table of Contents

Return to Home Page

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ENDNOTES

[1] [1992] 12 CCLI (2d) 206 (SCC) at 224.

[2]JE Stengel, C Brown. The Impact of AIDS on the Canadian Life Insurance Industry. *Canadian Insurance Law Reports* 1992; 2: 95 at 100; B Shatz. The AIDS Insurance Crisis: Underwriting or Overreaching? *Harvard Law Review* 1987; 100: 1782 at 1792.

[3]Canadian Bar Association – Ontario. *Report of the AIDS Committee*. Toronto: The Association, 1986.

[4]The exceptions are Alberta, Prince Edward Island, the Northwest Territories, and Newfoundland and Labrador. The latter is in the process of amending its human rights legislation following a court ruling that the absence of protection against discrimination for gays and lesbians is unconstitutional. Alberta's Court of Appeal reached the opposite conclusion regarding the *Individual Rights Protection Act*. The judgment has been appealed and has been heard in the Supreme Court of Canada. The Northwest Territories are currently considering amendments. For more details, see A Vassal, J Fisher, R Jürgens, R Hughes. *Gay and Lesbian Legal Issues: The Impact of Discrimination on the Spread of HIV: A Discussion Paper*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1997.

[5]See, eg, section 184, *Insurance Act*, RSO 1990, c I-8.

[6]See, eg, *Kiernan v Metropolitan Life Insurance Company*, [1925] SCR 600; *McArthur v Prudential Insurance Company of America*, [1969] 2 OR 689 (HC); *Kruska v Manufacturers Life Insurance Company*, (1984), 6 CCLI 299, aff'd (1985), 11 CCLI 197 (BCCA).

[7]British Columbia Ministry of Finance. *Information Bulletin*. Bulletin number INS-95002 (16 January 1995).

[8]See, eg, the testimony of Mrs Joan Drew before the Commission of Inquiry on the Blood System in Canada, 31 March 1994, at 5037-5040.

[9]For more details, see R Jürgens, M Palles. *HIV Testing and Confidentiality: A Discussion Paper*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1997.

[10]See *Canadian AIDS Society v Ontario* (1995), 25 OR (3d) 388 (Gen Div). The facts of the case were unusual. The Court ruled that testing of blood donors without consent did not invalidate the reporting requirements under public health law in the circumstances, a decision that was sustained by the Court of Appeal. The Supreme Court refused leave to appeal. For more information, see PA LeFebour, D Elliott. Ontario Court Rules on Notification of Blood Donors. *Canadian HIV/AIDS Policy & Law Newsletter* 1995; 1(2): 13-14; PA LeFebour, D Elliott. Further Update on Blood Donor Notification Case. *Canadian HIV/AIDS Policy & Law Newsletter* 1995; 2(1): 5-7.

[11]It appears that this is less common in Canada, with its socialized medicine system. In the USA, private health insurance is very important and has been the main area of contention. See, eg, Marcosson, infra, note 12, and Stengel, supra, note 2.

[12]S Marcosson. Who Is "Us" And Who Is "Them" – Common Threads And The Discriminatory Cut-off Of Health Care Benefits For AIDS Under ERISA And The Americans With Disabilities Act. *American University Law Review* 1994; 44: 361.

[13](1995), 28 CCLI (2d) 4 (Ont Div Ct).

[14]RSO 1990, c H-19.

[15]Supra, note 1.

[16](1990), 40 CCLI (2d) 1 (SCC).

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

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# Focus on HIV/AIDS and Injection Drug Use

**On 22 May 1997, the National Task Force on HIV/AIDS and Injection Drug Use released its Action Plan.[1] Pointing out that Canada is in the midst of a public health crisis concerning HIV/AIDS and injection drug use – over 50 percent of new infections currently occur among injection drug users, a dramatic shift from only a few years ago – the Task Force identified priority issues and first steps to help stop the spread of HIV among injection drug users.**

This issue of the *Newsletter* contains:

- a summary of the Action Plan;
- reactions to the Plan by two of Canada's foremost experts on drug policy;
- an article attempting to explain why, its numerous failures notwithstanding, the "War Against Drugs" continues, making harm-reduction measures aimed at reducing the spread of HIV and other harms from drug use more difficult, if not impossible; and
- a short review of websites containing new information on HIV/AIDS and drug policy.

## The National Action Plan on HIV/AIDS and Injection Drug Use: A Call for Action

The Plan begins with a call for action, emphasizing the urgency of the situation: while *new cases of AIDS* are decreasing in Canada, *HIV rates* are still increasing, largely due to the huge number of new infections among injection drug users (IDUs):

> Canada is in the midst of a public health crisis concerning HIV and AIDS, and injection drug use, as the infection continues to spread in vulnerable populations, showing little respect for geographical boundaries. Those becoming infected are younger and younger,

> with the median age of new infection having dropped from 32 years to 23 years. Incarceration constitutes a risk for HIV, with limited innovations being implemented to improve the situation. Aboriginal peoples are over-represented in groups at high-risk for HIV infection. Women represent an increasing percentage of new HIV cases. The number of new HIV infections among injection drug users is increasing dramatically, with Vancouver now having the highest reported rate in North America.[2]

## The Importance of the Issue

The Action Plan emphasizes the rate at which new cases of infection among IDUs are occurring, the costs related to infection, and the human suffering involved:

> While the direct and indirect costs associated with these HIV infections are still being calculated, early indications suggest they will no doubt justify a dramatic increase in investment to keep this epidemic under control. It is not only the absolute numbers one must take into account, but the alarming and consistent rates of increase, as well as the toll in dollars and human suffering.[3]

It stresses that people who inject drugs do not usually continue to do so all their lives and that

> when they successfully stop injecting, society wants them to have years of productive life ahead of them. For this to happen, we must keep them healthy, HIV free, and alive.[4]

In addition, the Plan points out that IDUs do not live in a vacuum, but are members of our community:

> Both during and after the periods of their lives which involve the injection of drugs, they form intimate partnerships and have children. Although epidemiologists agree that this epidemic is unlikely to ignite within the broader community to the same extent it has among injection drug users, it will nonetheless touch many lives, infecting and affecting many people who have never used drugs.[5]

## The Recommendations

The Plan urges that "immediate action is required at all levels of governmental and community leadership." The recommended actions and implementation strategies have been grouped under five headings:

- policy and legislation;
- prevention and intervention;

- treatment;
- aboriginal peoples; and
- women.

## Policy and Legislation

The Plan acknowledges that current Canadian drug laws and policies limit our ability to address HIV/AIDS in the injection drug using population, and, "in fact, may contribute to the situation or make it worse." The document cites the following examples:

- given the illegal status of many drugs, those who inject often opt for the most efficient and fast means of introducing the substance into their bodies – injection drug use – in an attempt to maximize a speedy effect and, at the same time, minimize the likelihood of detection and arrest;
- because of the illegal status of drugs, many users are afraid to use health and social services, increasing their marginalization;
- for fear of being seen as condoning drug use, service providers may shy away from providing essential education on safer drug use;
- the illegal status of drugs fosters emotion-laden anti-drug attitudes toward users, adding to their marginalization and directing action toward punishment of the "offender," rather than fostering understanding and assistance.[6]

## What Is Required?

According to the Plan, Canada requires policies that

- encourage IDUs to access services;
- ensure services are relevant to client needs;
- allow society to move toward destigmatization of drug use and drug users;
- encourage multi-sectoral participation and community partnerships; and
- are ethical and involve consumers in their development.

### Specific Recommendations

Specifically, the Plan recommends:[7]

1. enhancing leadership and commitment to action by, among other things,
    - continuing or renewing national strategies to address HIV/AIDS and substance use with appropriate levels of funding, directed primarily at community-based initiatives;
    - ensuring that funding exists for alternative programs in prevention, drug treatment, and diversional sentencing to community programs; and
    - allocating existing funds to alternative programs and increasing funds through innovative options such as devoting to such programs (1) 50 percent of the revenues produced through Anti-Drug Profiteering/ Proceeds of Crime cases; and (2) revenue from a 25 percent surcharge placed on all fines to drug traffickers.
2. change the *Criminal Code* by, among other things,
    - providing specific exemptions under the legislation to ensure that physicians may prescribe narcotics to drug users in an effort to medicalize drug use and reduce harms associated with obtaining drugs on the street; and
    - decriminalizing the possession of small amounts of currently illegal drugs for personal use;
3. improve conditions in correctional settings;[8]
4. recognize, utilize and enhance research activities by, among other things,
    - involving IDUs in all aspects of research;
    - investigating local transmission patterns of HIV in IDUs;
    - including quantitative, qualitative and ethnographic methodologies in research designs.

### Prevention and Intervention

With respect to prevention and intervention issues, the Plan recommends that:

1. discriminatory attitudes toward drug users living with HIV or AIDS be combatted by, among other

things,

- actively involving drug users in policy development, program planning and implementation, and evaluation;
- creating community-based peer-support and advocacy groups for drug users, and integrating drug users into existing organizations;
- promoting awareness, recognition and acceptance in the justice system and in law enforcement that addiction is better dealt with as a health and social issue than a criminal one;
- providing training and information to the judiciary and others in the criminal justice system on the link between HIV/AIDS and injection drug use;
- promoting harm reduction as a "necessary component of a range of strategies" when developing programs and policies; and
- examining, and changing where necessary, policies and procedures of professional bodies (eg, physicians, pharmacists) to make sure they facilitate harm reduction and encourage the involvement of members in caring for IDUs;

2. services involving the exchange of needles be improved;

3. access to methadone treatment be improved by, among other things,

- revoking the need for physicians to have authorization from the federal Minister of Health to prescribe methadone;
- dramatically increasing the availability of methadone treatment;
- reducing and eliminating other barriers to being on methadone;
- making appropriate training available to physicians to encourage their involvement in providing methadone treatment to IDUs;
- investigating other alternative drug therapies such as buprenorphine, naltrexone and LAAM (Levo-Alpha- Acetylmethadol); and
- setting up a low-threshold maintenance program as a pilot project with the explicit goal of reducing injection frequency in heroin users;

4. needle disposal services be improved.

## Treatment

According to the Plan, it

> must be recognized that injection drug users living with HIV are individuals, suffering in a myriad of ways, and in need of the best possible interventions, tailored to their unique situations. They retain all the rights of every other citizen, and must therefore be given equal access to a continuum of services, as well as the dignity of making their own decisions. If lack of compliance with a drug treatment is feared, then the patient must be supported to ensure adherence to the treatment regime, just as any other individual is, whether diagnosed with diabetes, epilepsy or another condition. Bias against treating IDUs is unjustified and unacceptable [reference omitted].[9]

The Plan recommends that:

1. the continuum of available services and information be enhanced and expanded by, among other things,

    - providing treatment options that do not require total abstinence from all drugs;

    - ensuring each person seeking treatment is evaluated and offered anti-retroviral drug therapies meeting current standards of care;

    - developing cocaine-specific treatment options;

    - investigating the potential health risks of individuals using combinations of pharmaceutical/therapeutic and recreational drugs;

    - conducting clinical trials of prescription morphine, heroin and cocaine, such as in the United Kingdom and Switzerland;

    - developing alternative delivery systems for drug treatment in comprehensive care clinics, designed with community participation and licensed by the provinces (for instance, methadone programs could be provided at community health clinics rather than only through fee-for-service physicians); and

    - ensuring that a full spectrum of treatment options, including anti-retroviral drugs, are available to those in prisons;

2. the quality of professional training be improved.

### Aboriginal Peoples

The Plan points out that available data indicate dramatically increasing rates of HIV among the drug-using population of Canada's Aboriginal peoples. It continues by emphasizing that the injustices suffered by Aboriginal peoples in Canada have led to

> the loss of culture and identity of individuals and whole communities. This, and other factors, have led to the present situation in which Aboriginal people are over-represented among urban injection drug users, in correctional institutions and in data on sexually-transmitted diseases, and under-represented in treatment and HIV data. ... Additionally, issues of jurisdiction, governance, culture, racism and homophobia combine to further complicate this situation of overlapping risk-factors.[10]

The Plan concludes that, more than any other group, "Aboriginal peoples must play a strong role in addressing their health needs with regard to HIV, AIDS and IDU-quickly, comprehensively and effectively." It recommends that

1. data about HIV/AIDS and injection drug use be routinely gathered, and quality of that data improved by, among other things,

    - providing training opportunities to Aboriginal people to ensure that Aboriginal communities can design and undertake research initiatives for themselves; and

    - conducting research to address the unique concerns of Aboriginal peoples, such as the younger-than-average age at which they become infected, the higher incidence of injection drug use as a mode of transmission, steadily increasing HIV rates, and over-representation in correctional settings;

2. unique cultural factors be acknowledged and addressed; and

3. efforts to address the complex issues be coordinated by, among other things,

    - providing support, financial and otherwise, for the Canadian Aboriginal AIDS Network (CAAN);

    - addressing jurisdictional issues regarding who is entitled to services delivered by different levels of government, as well as the "on versus off reserve" issue; and

    - linking native HIV, AIDS and IDU programs with provincial services to lessen the overreliance on reserves.

## Women

The Plan points out that the number of women affected by HIV/AIDS in Canada is increasing at an alarming rate, "providing an urgent rationale for being proactive in addressing the unique issues women face without delay." It stresses that many factors –

biological, economic and cultural – make women more vulnerable to HIV infection than men, and that emotional and financial dependence on men and threats of domestic violence often prevent women from protecting themselves in needle-sharing and sexual relations. The Plan recommends that

1. key players be educated concerning the unique problems facing women, and how to address them, by, among other things,

    - training health-care professionals regarding diagnosis, treatment and prevention of HIV in women IDUs;

    - providing self-esteem training and skill development for IDU women and non-IDU women who are sexual partners of IDU men;

    - providing resources to assist women IDUs in the care of their children and families while dealing with HIV/AIDS; and

    - facilitating the development of accessible peer support groups for street-involved women so they can share practical strategies for protecting themselves;

2. research be enhanced to fully understand the nature and extent of HIV and AIDS in women, and to develop appropriate responses, by, among other things,

    - including IDU women in the development of policy, programs and research;

    - conducting research into the relationship between sexual abuse and HIV, and into the intersection of physical abuse, substance use and HIV; and

    - developing and making available women-controlled methods of HIV prevention.

## Conclusion

Embracing a framework of community and user involvement as its underpinnings, the Task Force has developed a Plan to initiate "urgently needed changes."[11] According to the Task Force, "immediate action is required."[12] It calls upon individuals, communities, non-governmental groups and governments to take responsibility for transforming the Plan from words into action. In particular, the Task Force "strongly reconfirms the responsibility of the federal Minister of Health to show leadership on this issue, in partnership with key ministries (Justice, Solicitor General, Corrections) through initiating action, monitoring implementation, and evaluating outcomes."[13] As stated in the Plan: "The roadmap is provided. The journey must be started."[14]

Copies of the National Action Plan can be retrieved at the website of the Canadian Centre on Substance Abuse at www.ccsa.ca or ordered through the National AIDS Clearinghouse. Tel: (613) 725-3434; fax: (613) 725-9826; email: aids/sida@cpha.ca

The National Action Plan was developed by a volunteer Task Force chaired by Dr Catherine Hankins. The Task Force responded directly to recommendations made by the Organizing Committee of the Second National Workshop on HIV, Alcohol and Other Drug Use.[15] It was funded by Health Canada and coordinated by the Canadian Public Health Association and the Canadian Centre on Substance Abuse. Development of the Plan involved consultation with some 80 stakeholders.

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Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTES

[1] *HIV, AIDS and Injection Drug Use: A National Action Plan*. Ottawa: Canadian Centre on Substance Abuse and Canadian Public Health Association, 1997.

[2] Ibid at 5. According to a study undertaken by Strathdee et al, 19 of 100 injection drug users in Vancouver who were uninfected on 1 January 1997 and who continue injecting will have become infected with HIV by the end of 1997 (SA Strathdee et al. Needle Exchange Is Not Enough: Lessons from the Vancouver Injection Drug Use Study. *AIDS* 1997 (forthcoming)).

[3] National Action Plan, supra, note 1, at 10.

[4] Ibid.

[5] Ibid.

[6] Ibid at 13.

[7] All recommendations are taken from the National Action Plan, supra, note 1 at 37 ff.

[8] For more details, see the article "Task Force Calls for Methadone Maintenance and Needle Exchange in Prisons" in this issue of the *Newsletter*.

[9] NAP, supra, note 1 at 22.

[10] Ibid at 25.

[11] Ibid at 30.

[12] Ibid at 5.

[13] Ibid.

[14] Ibid at 30.

[15] Second National Workshop on HIV, Alcohol and Other Drug Use, 1994.

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Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

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# Children: The Changing Face of AIDS

**Increasingly, the face of AIDS is a child's face. UNAIDS and WHO estimate that since the beginning of the HIV/AIDS epidemic, close to three million children under the age of 15 have been infected with HIV. In 1996, around a thousand children died daily of AIDS and even more became infected every day. At the end of 1996, it was estimated that 830,000 children under the age of 15 were living with HIV, a number that UNAIDS expects to rise to one million by the end of 1997. Well over 90 percent of these children live in developing countries.**[1]

Children are not only *infected* by HIV, they are also *affected*: the epidemic is having a direct and devastating effect on millions of children who are not themselves infected, but whose lives have been permanently altered by the intrusion of HIV/AIDS into their households or communities.

There are also strong indications that Canadian children are increasingly infected and affected by HIV and AIDS. The actual number of families in Canada where children and/or their parents are living with HIV or AIDS is unknown, but recent statistics confirm an increasing incidence of HIV in heterosexual and in intravenous drug using populations and a dramatic decline in the average age at which people contract HIV. In particular, an increasing number of young women are becoming infected. As HIV infection increases in women of childbearing age, the number of children with HIV or those who grow up "in the shadow of HIV" will inevitably rise.[2]

AIDS is changing the world for children everywhere. AIDS programs for children have been ad hoc and fragmented and have lagged behind those for adults. In both developing countries and in Canada, this situation is worsened by poverty.

In the past year, however, there have been several initiatives that could potentially help promote a more effective response to the needs and concerns of HIV/AIDS infected and affected children and their families, worldwide and in Canada. Some of the major initiatives are described below.

## 1997 World AIDS Campaign: Children Living in a World with AIDS

In 1997, the Joint United Nations Programme on HIV/AIDS (UNAIDS) has developed a "World AIDS Campaign," rather than World AIDS Day initiatives as in the past. According to UNAIDS, this will help "achieve more tangible results both in the advocacy and the programmatic areas, maximize use of available resources, ensure cost-effectiveness, and increase the reach and impact of mobilisation efforts around the world."

The theme of the 1997 World AIDS Campaign is "Children Living in a World with AIDS." The campaign focuses on every human being under the age of 18, in line with the definition of children set out in the United Nations Convention on the Rights of the Child. The 1997 campaign theme will overlap with that of the 1998 campaign, which will focus on the concerns of young people (15-24 years of age).

The 1997 campaign aims to achieve:

- better understanding of the magnitude and diversity of the impact of HIV/AIDS on children, their families and their communities;
- stronger commitment, improved policies and increased action for preventing HIV infection and minimizing the epidemic's impact on children, their families and their communities;
- increased and improved access to quality education and relevant information on the prevention and care of HIV/AIDS for children, their families, and their communities; and
- greater understanding of the interaction between children's rights, human rights, and HIV/AIDS.

In support of the 1997 World AIDS Campaign, UNAIDS has produced two documents: *Children Living in a World with AIDS: World AIDS Campaign Media Briefing*; and *1997 World AIDS Campaign: Statement of Objectives*. To obtain copies, write to Dominique De Santis, UNAIDS, 20 avenue Appia, CH-1211 Geneva 27. Email: desantis@unaids.org, or consult the UNAIDS website: www.unaids.org.

### Children and AIDS International NGO Network

As reported in a previous issue of the *Newsletter*,[3] the Children and AIDS International NGO Network (CAINN) held its first planning meeting in November 1996. CAINN is an international network of NGOs that aims to promote the voices, rights and needs of children and young people infected and affected by and vulnerable to HIV/AIDS. It promotes the principle of participation by affected children, families and communities in decision-making about policy and program development. Its objectives are to:

- promote the implementation of the Convention of the Rights of the Child and other relevant international declarations and agreements;

- ensure that children have the opportunity to express their views and wishes and are involved in decisions about their lives related to HIV/AIDS;

- promote increased awareness, solidarity, understanding, knowledge and action on matters of common interest among those concerned with issues concerning children and young people and HIV/AIDS, through the sharing of information and resources;

- identify the gaps in HIV/AIDS research in relation to children and young people, and advocate for ethical child-centred research;

- ensure that children and young people's HIV/AIDS issues are included on the agendas, policies and programs of decision-makers at international, national and local levels;

- advocate for the mobilization and adequate distribution of resources for children and young people infected or affected by HIV/AIDS; and

- promote the key role of families and communities in identifying solutions and support their participation in planning and decision-making.

To obtain copies of the Executive Summary of the CAINN Planning Meeting report, write to: CAINN Secretariat, c/o ICAD, 180 Argyle Avenue, Ottawa, Ontario K2P 1B7. Email: icad@web.net.

## Canadian Working Group on AIDS Affected Children Formed

A Working Group on AIDS Affected Children was formed in July 1997 at the Annual General Meeting (AGM) of the Canadian AIDS Society. Participants at a workshop on AIDS-affected children held during the AGM identified a need to work collaboratively to help ensure that more effective action is taken to readdress significant gaps in the provision of prevention, treatment, care and support services to AIDS-infected and -affected children, their families and their communities.

The Working Group identified three objectives to guide its work in the months following its establishment:

- to ensure that organizations representing AIDS-affected children and their families are included in consultations to develop the third phase of the National AIDS Strategy;

- to inform other organizations and individuals concerned about the needs of AIDS-affected children and their families about the existence of the Working Group and to encourage their participation in the activities of the Working Group;

- to secure funding to cover the costs of: (1) the Working Group; and (2) a stakeholder meeting to form a Canada-wide association that will focus on ensuring a more effective response to the needs and concerns of children and families infected and affected by AIDS in Canada.

For more information on the Group, contact: Richard Thomson or Bob Watkins, Teresa Group, 790 Bay St, Toronto, Ontario Phone: (416) 596-7703; or Bruce Waring, Interagency Coalition on AIDS and Development (ICAD), 180 Argyle Avenue, Ottawa, Ontario, K2P 1B7, Phone: (613) 788-5107, email: icad@web.net.

### Canadian Study on Psychosocial Issues for Families Living With HIV/AIDS

A major study on current and future needs of Canadian children and their families living with HIV/AIDS has been released. The study, *Children Born to Mothers with HIV: Psychosocial Issues for Families Living in Canada Living With HIV/AIDS*,[4] was based on in-depth interviews with caregivers of children in families living with HIV/AIDS. Interviews were conducted by social workers at 13 pediatric hospitals and AIDS service organizations across Canada between January 1994 and April 1996.

Among other things, the investigators concluded that there is a need to:

- work toward the elimination of stigma and discrimination through education, advocacy and protection of human rights and to support families in their decisions about disclosure;

- promote and support family health and well-being and ensure that parents with HIV/AIDS and their children can remain together as long as possible;

- provide transitional support to parents, children and caregivers if parents are unable to care for their children because of illness or death;

- ensure that families have the resources they need to care for themselves and their children, and pay for HIV-related needs;

- ensure that the special needs and issues of Aboriginal, minority and immigrant families are addressed; and

- increase support for families living with HIV/AIDS and address their needs through advocacy, education, planning and future research.

Investigators made several recommendations on how the above mentioned needs could be met by governmental and non-governmental actors.

The full report (200 pages) of the Study is available in English only at a cost of $10. A summary of the report (50 pages) is available in English and French at no cost. A study overview (5 pages) is available in English only at no charge. To obtain copies, contact: Dale DeMatteo, Research Coordinator, HIV/AIDS Program, The Hospital for Sick Children, 555 University Avenue, Toronto, Ontario, M5G 1X8.

- *Bruce Waring*

Publication of this article was made possible by a donation from the Rotary Club of Old Montréal.

Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTES

[1]Children Living in a World with AIDS: World AIDS Campaign Media Briefing, UNAIDS, 1997.

[2]Children Born to Mothers with HIV: Psychosocial Issues for Families Living in Canada Living with HIV/AIDS. Toronto: The Hospital for Sick Children, 1997.

[3]A Costigan. The Children and AIDS International NGO Network. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 3(1): 19-20.

[4]Supra, note 2.

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

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## DISCRIMINATION

# Your Health Is Back. Now You May Lose Your Protection against Discrimination

### While recent medical advances have brought cause for optimism for many persons with HIV or AIDS, developments in the law create cause for alarm.

Discrimination continues, but persons with asymptomatic HIV can no longer be confident that they are protected from discrimination on the job, in public accommodations and by governments. Instead of clearly asserting that all individuals who are HIV-positive are protected from discrimination, an increasing number of courts in the United States are taking the view that HIV infection per se is not a disability and insist that an individualized assessment of the HIV-positive plaintiff must be made to determine whether s/he is disabled. The assessment often focuses heavily on factors unrelated to whether or not the individual *requires* protection from discrimination.[1]

On 26 November 1997, the US Supreme Court announced that it will hear the case of *Bragdon v Abbott*,[2] the first case directly involving a discrimination claim by a person with HIV before the Supreme Court. The case will provide the Court with its first opportunity to elucidate the application of the Americans with Disabilities Act[3] (ADA) to people with HIV.

### The Case Before the US Supreme Court

*Bragdon v Abbott* directly poses the question whether persons with asymptomatic HIV are entitled to protection from discrimination under the ADA. *Abbott* was a case challenging a dentist's refusal to treat an HIV-positive woman. The Court of Appeals for the First Circuit engaged in a lengthy and detailed discussion of whether an individual who was asymptomatic could be found to have a disability within the meaning of the ADA.[4] The Court had little difficulty in finding that the plaintiff had a *physical impairment*. The far more troubling issue for the Court was whether that physical impairment *substantially limited a major life activity*. Under the ADA, an individual with a disability is any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment. During the legislative process leading to the adoption of the ADA, relevant committees in both the House and the Senate included in their formal written reports their understanding that HIV infection was an "impairment" under the ADA and that its impact on reproductive and sexual activity would qualify as substantially limiting major life activities. Then President George Bush specifically called for protection of people with HIV and AIDS from discrimination by urging passage of the ADA. Congressional proponents of the legislation made statements during floor debate asserting that people with HIV infection, regardless of whether symptomatic or asymptomatic, would be protected by the ADA.

In *Abbott*, the Court analyzed whether reproduction constituted a major life activity within the meaning of the ADA. The legislative history notwithstanding, the Court saw this as a difficult question whose answer was "not free from doubt," because the ADA did not answer the question explicitly, and other courts were split on it. The Court finally found that the plaintiff had shown that HIV in general substantially limits reproduction because "[n]o reasonable juror could conclude that an eight percent risk of passing an incurable, debilitating, and inevitably fatal disease to one's child is not a substantial restriction on reproductive activity." But also critical to the court's analysis was the finding that Ms Abbott herself was a "fecund" woman who had testified in her deposition that she had "made the decision after [she] tested positive not to have children because of the risk of infecting the child and the risk of impairing [her] own immune system." Thus, the Court's conclusion that Ms Abbott was disabled was based in large part on the fortuity of her own fertility. As pointed out by Parmet and Jackson, "[s]hould other courts adopt this analysis requiring an individualized demonstration of how HIV status affects an individual's own reproductive intentions, the fate of many individuals who cannot show that their HIV status had caused them to alter their childbearing plans will be uncertain."[5] In particular,

> many gay men might find it difficult to explain how they have altered their reproductive plans because of their infection. Thus, the protection for asymptomatic HIV-positive individuals might be quite haphazard at best and depends on a circumstance – the plaintiff's fertility and reproductive intentions – that really has nothing to do with the discrimination at issue.[6]

Further eroding the certainty of ADA protection was the Court's observation that the changing medical landscape could call into question the determination of disability. After finding that Abbott had a disability, the Court stated that, "presented with other facts and circumstances in a future case, perhaps reflecting dramatic improvements in medical science that substantially reduce the likelihood of transmitting HIV through reproduction, we might well reach a different conclusion than the one that we reach today."

### *Runnebaum v Nationsbank of Maryland*[7]

In the case of *Runnebaum*, the US Court of Appeals for the 4th Circuit went even further than the Court of Appeals for the 1st Circuit in undermining protection against discrimination for HIV-positive but asymptomatic persons. The case involved an HIV-positive gay man, Runnebaum, who had been hired by

Nationsbank in May 1991. Runnebaum was discharged in January 1993, only four months after he had told a bank official that he was HIV-positive. The bank claimed that the discharge was due not to Runnebaum's HIV status but to his poor performance at work. Runnebaum, however, presented evidence that he was doing as well or better than another of his coworkers and that he had received affirmative notes and comments from the bank about his work.

In an opinion for six members of the court, Judge Karen Williams held, contrary to the 1st Circuit Court, that asymptomatic HIV infection is not an "impairment," saying that "without symptoms, there are no diminishing effects on the individual." In addition, Williams rejected the contention that the impact of HIV infection on reproductive or sexual activity constitutes a substantial limitation on a major life activity. Williams argued that HIV-positive people can engage in reproductive and other sexual activity, drawing a distinction between impairments that prevent one from engaging in an activity as opposed to impairments that make the activity dangerous. And, in a personal dig against the gay plaintiff in this case, Williams noted there was nothing in the record indicating any interest by Runnebaum in "fathering a child."

Having concluded that an asymptomatic HIV-positive person is not disabled, Williams then moved to an analysis of whether Runnebaum was protected under the ADA because he was "perceived" as having "such an impairment." To Williams, this language means that a person is protected if s/he can credibly allege that the employer discriminated against him/her because of the employer's perception that s/he had a disabling impairment. Williams accepted as true Runnebaum's employer's statement that he had been discharged because of his alleged poor work performance and not because of his HIV status, and dismissed Runnebaum's appeal.

Judge Michael, for himself and four other members of the Court, wrote a detailed and outspoken dissent. Michael noted that the Court's definition of disability suggests that asymptomatic HIV infection will never qualify as a disability and argued that the decision

> moves this circuit even further from the mainstream of ADA interpretation. More importantly, it moves us completely away from the interpretation that Congress clearly intended.[8]

### Comment

According to Prof Leonard of New York University Law School, *Runnebaum* illustrates a trend among "the more conservative federal courts in narrowing access to ADA protection on several related grounds, but all based on a formalistic, literalistic interpretation of statutory language while eschewing legislative history."[9] Leonard suggests that "the result in this and other cases may suggest need to seek more directly explicit protection for people with HIV/AIDS under federal law, rather than continuing to rely on the generic protection of disability discrimination law."[10]

Commenting on *Abbott* and other recent decisions limiting protection against discrimination for persons with asymptomatic HIV, Parmet and Jackson point out that the decisions appear to rely on almost extraneous questions (such as whether the individual had the intention of having children or whether the employer thought that the plaintiff was incapable of performing a wide variety of jobs), instead of relying on the more relevant inquiry as to whether the presence of HIV has invoked an irrational and invidious response. They say: "In a world where discrimination remains prevalent, the courts' failure to consider the social context in which discrimination occurs has a profound effect."[11] In addition, courts have failed to consider the numerous other ways in which HIV affects an individual's life and have focused only on the impact of HIV infection on reproductive or sexual activity – sometimes holding, as in *Runnebaum*, that the impact of HIV infection on these activities does not constitute a substantial limitation on a major life activity. In particular, courts have failed to consider that, by requiring increased medical care and a drug regimen that may include up to 30 pills, twice daily, HIV infection has a major impact on an individual's life. Further, as stated by Parmet and Jackson, only a narrow and reductionist interpretation of the term "major life activity" would fail to recognize the impact that the prospect of premature death can have on an individual's day-to-day existence. Finally, the courts neglect the fact that it is often the social reaction to a disability, rather than the physical impairment alone, that causes a substantial limitation of a major life activity. As Parmet and Jackson conclude:

> Perhaps HIV will eventually lose its power both to kill and to arouse social discrimination. At that time, when both the physical and social conditions that have made HIV a disability are gone, neither individuals nor the public health will require the protection of disability law. Until that time, however, a doctrine that views HIV as no longer a disability is dangerous.[12]

## The Canadian Situation

Thus far, no Canadian court has followed the new US trend. There have been no decisions in recent years on whether HIV infection constitutes a disability or handicap under Canadian human rights acts. The last and most comprehensive Canadian decision on HIV/AIDS as a disability, handed down on 11 April 1995 by the Québec Human Rights Tribunal, stated that the fact of being an asymptomatic HIV carrier constituted a "handicap" within the meaning of the Québec *Charter of Human Rights and Freedoms*.[13] However, for Canadians living with HIV and for those providing services to them, it will be important to closely watch US developments.

## Additional Readings

For an excellent overview of US cases and, more generally, the legal impact of the new social construction of HIV, the reader is referred to the above-cited article by Parmet and Jackson.[14] Regular updates on how US courts interpret the ADA are provided by *Lesbian/Gay Law Notes* (contact Daniel R Schaffer at (212) 353-9118 or le-gal@interport.net for circulation information). The *Newsletter* will report on the decision by the Supreme Court, which is expected by the summer of 1998, and continue to report on other important cases in the area, in Canada and internationally.

- *Ralf Jürgens*

> "The legal protections which have helped individuals with HIV to continue to work and access medical services may be undone. Ironically, the result may be that once we no longer think of HIV as invariably terminal, the actual ability of individuals infected to continue to work, go to school and afford the very medical treatments that have led to the altering social images may diminish."
>
> - Parmet and Jackson, 1997

> "The courts seem to struggle with what they perceive to be a paradox: the plaintiff claims disability while actually looking and acting quite well. Thus, individuals with HIV, like those with acrophobia or obesity, are seen as plaintiffs whose rights to protection against social disapproval is questionable."
>
> - Parmet and Jackson, 1997

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Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTES

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[2]No 97-156, 1997 WL 434576.

[3]Pub L No 101-336, 104 Stat 328 (1990) (codified at 42 USC §§12101-13 (1994)).

[4] *Abbott v Bragdon*, 107 F 3d 934.

[5] Supra, note 1 at 35.

[6] Ibid.

[7] 1997 WL 465301.

[8] Reported in AS Leonard. 4th Circuit Guts Statutory Protection for "Asymptomatic" People with HIV. *Lesbian/ Gay Law Notes* September 1997, 113-114 at 114.

[9] Ibid.

[10] Ibid.

[11] Supra, note 1 at 40.

[12] Ibid at 43.

[13] Québec Human Rights Commission v Dr G G, QHRT, Québec, no 200-53-000002-944, 11 April 1995, Michèle Rivet J. See B Guillot-Hurtubise. Dentist Found Guilty of Discrimination. *Canadian HIV/AIDS Policy & Law Newsletter* 1995; 1(4): 1, 14-15.

[14] Supra, note 1.

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

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# Gay and Lesbian Legal Issues and HIV/AIDS: A Discussion Paper

**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 *Discussion Paper* on gay and lesbian legal issues and HIV/AIDS in August 1997.**[1]

The following provides a brief summary of the Paper and its conclusions.

## Why a Discussion Paper on Gay and Lesbian Legal Issues and HIV/AIDS?

In Phase I of the Joint Network/CAS Project on Legal and Ethical Issues Raised by HIV/AIDS, over sixty individuals and organizations identified gay and lesbian legal issues as one of eight "top priority" legal and ethical issues raised by HIV/AIDS in Canada. They and the participants at a National Workshop on Gay and Lesbian Legal Issues held in March 1996 agreed that discrimination against gay men and lesbians in Canada continues and affects every aspect of their lives; and that discrimination and homophobia have a negative impact on their ability to protect themselves from contracting HIV, HIV prevention programs in general, and on the care, support, and treatment provided to people living with HIV/AIDS.

## What Is the Link between Homophobia and Discrimination against Gays and Lesbians and HIV/AIDS?

Respecting the rights and dignity of gay and lesbian Canadians is a moral and legal imperative. In addition,

> [i]n the context of AIDS, respect for human rights and dignity is not only a moral and legal imperative, but the basis for effective policies. There can no longer be any doubt that respect for human rights saves lives. It is widely recognized that laws and practices that discriminate against people with HIV or AIDS or those considered likely to be at risk of infection [such as gay men], or that in other ways violate human rights, are both morally indefensible and impede effective public health efforts.[2]

As stated by Justice Michael Kirby,

> [t]he 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.[3]

Examples of how homophobia impacts on government and institutional responses to HIV/AIDS, on HIV prevention, and on care, support, and treatment of people living with HIV/AIDS include:

- because HIV/AIDS has primarily affected gay men and other marginalized populations, governments have been and continue to be less committed to fighting the disease;
- because many school systems remain reluctant to provide positive education about homosexuality, young gay men are more vulnerable to contracting HIV;
- because many provincial – and, until 1992, also the federal – prisons have refused to make condoms available to prisoners for fear of being seen as "condoning homosexual activity" (a clear example of homophobia), prisoners and their partners outside prison are more vulnerable to contracting HIV;
- because many still see HIV/AIDS as fundamentally a gay disease, the efforts of non-gay communities to generate their own effective responses to the epidemic have been hampered; and
- because of a fear of being identified as gay, some people may not seek (or may not seek early enough) testing for HIV and care, support and treatment for HIV-related diseases.

### What Does the *Discussion Paper* Contain?

The *Discussion Paper* is divided into two parts. The purpose of Part I is to show the various forms that marginalization, stigmatization, discrimination and other intolerant attitudes take in a number of social sectors: first, it gives an account of discrimination against people living with HIV/AIDS and of the views of society with regard to homosexuality. Second, it assesses the impact of discrimination and stigmatization on the social environment and living conditions of gay men and lesbians, in particular through a consideration of the coming-out process and of internalized homophobia. Third, it illustrates the impact of HIV infection on gay men. Fourth, it discusses the issue of hidden discrimination in specific areas relating to HIV infection, namely research and health services. Finally, using the concept of social vulnerability, it illustrates the adverse affects of discrimination on efforts to prevent HIV infection.

The second part of the Paper is devoted to an analysis of how **the law** treats gays and lesbians. It shows how pervasive discrimination against gays and lesbians is, in all of the following areas: criminal law; censorship; protection from discrimination; benefits; children and parenting; immigration; and incapacity, wills, and estate litigation.

## What Are the Goals of the *Discussion Paper*?

The goals are to document how pervasive discrimination against gay men and lesbians is in many sectors of life and in the law; to show how discrimination impacts on the lives of gay men and lesbians and, in the context of HIV/AIDS, on efforts to prevent the spread of HIV and to care for those living with HIV/AIDS; and to propose solutions that will enable Canada to decrease discrimination against gay men and lesbians and to increase and improve prevention and care efforts in the area of HIV/AIDS.

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. The conclusions in the *Discussion Paper* are preliminary conclusions that, it is hoped, will stimulate discussion on the many issues raised in the Paper.

## What Does the *Discussion Paper* Conclude?

### General Conclusions

The *Discussion Paper* provides clear evidence of how pervasive discrimination against gay men and lesbians is, and of the impact it has on their daily lives. This discrimination needs to be combatted, and the rights of gays and lesbians protected, first and foremost **because it is right to do so**:

> We accord every human being that person's human rights because it is our duty and their right.[4]

In addition, the rights and dignity of gay men and lesbians need to be respected in order to better prevent the spread of HIV, and to provide better care, support, and treatment to people living with HIV or AIDS.

The conclusions in the *Discussion Paper* are directed to these goals. They do not propose a "quick fix" or offer easy answers to the many problems raised by HIV/AIDS. Nor do they suggest that the impact on human rights is the only consideration in designing public health policy. But they do argue that the fight against discrimination and for respect of the dignity of all persons needs to be treated "as seriously as science, medicine, and public health,"[5] recognizing that HIV and AIDS have disproportionately affected vulnerable populations, including gay men, at least in part because of their vulnerability and the discrimination they have been subjected to. While prevention campaigns, public health measures and the other interventions that have been undertaken to reduce the spread of HIV have been and continue to be important, they often do not address the underlying problems that cause vulnerability to HIV. These conclusions do. Some require only minor changes in laws. Other require changes in attitudes that can only be achieved in the longer term. They all require a commitment to fight HIV/AIDS, rather than the people most affected by it and their behaviours, and to fight bigotry and prejudice in society. They are not directed at giving gay men and lesbians "special rights." Rather, they recognize that discrimination – although it has diminished and although certain rights have been extended to gay men and lesbians – remains endemic and that gay men and lesbians deserve to be treated with equal respect, as a matter of justice and, in the context of HIV/AIDS, because this would help reduce the spread of HIV and allow us to better care for those living with HIV/AIDS.

### Specific Conclusions

Among the specific conclusions reached in the *Discussion Paper* are:

- A study on homophobia and heterosexism in social policies and legislation and their impact on the social environment and well-being of gays and lesbians should be carried out. Social policies and legislation should be revised in light of the results obtained.

- Teachers and others involved in schools, centres and shelters should be educated about homosexuality in order to provide them with the skills needed to offer support to young gays and lesbians.

- Homosexuality should be included in the sex education programs given in schools.

- The establishment of support groups for young gays and lesbians in secondary and post-secondary educational institutions should be supported in order to help them through the coming-out process, among other things.

- A sexual orientation component should be integrated into research on the general population that deals with health and well-being.

- Multidisciplinary research should be undertaken on the social environment of gays, self-affirmation and empowerment, based on the participation of men who have sex with men, to evaluate the impact of discrimination on the spread of HIV.

- All curricula in medicine, nursing sciences and the social sciences should include a component on homosexuality.

- Funding for HIV prevention among gays should be increased.

- Multidisciplinary research should be carried out on less-known, less-reached groups, in particular youth, the socioeconomically disadvantaged, intravenous drug users, bisexual men, and those who do not identify themselves as either homosexual or bisexual.

- "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."[6]

- The government of Canada should acknowledge its responsibility for suppressing for many years safe-sex information that could have helped educate the gay community about safe-sex practices. This acknowledgment would help to redress the public prejudice that gay men are "to blame" for HIV.

- All provincial and territorial human rights acts need to include protection against discrimination on the ground of sexual orientation, to provide uniform protection from discrimination for lesbians and gays across Canada.

- Human rights protections in legislation must be accompanied by meaningful education programs and public awareness campaigns to ensure that discriminatory attitudes can be redressed over time.

- Programs, policies and legislation that confer rights and/or responsibilities on heterosexual spouses need to be examined in light of their purpose and redrafted to ensure that all those who fit within that purpose are covered, whether the relationship is same-sex or opposite-sex and, in some cases, whether or not a person is in a relationship.

- Judicial education programs on sexual orientation and homophobia are necessary in all areas of the law, but particularly in child custody and access cases, where there is considerable judicial discretion in determining the best interests of the child.

- The "family class" must be extended in the immigration regulations to permit lesbians and gays to sponsor same-sex partners to immigrate to Canada.

- All provinces and territories that do not currently have legislation providing for an effective means for the appointment of a representative for health-care decisions should adopt such legislation.

- All provinces and territories should provide that same-sex partners have the same rights (1) of inheritance in cases of intestacy; and (2) to apply for administration of an estate as heterosexual married spouses.

### Next Steps

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 March 1998, a final report will be published, 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.

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

Copies of the *Discussion Paper* can be retrieved at the website of the Canadian HIV/AIDS Legal Network at 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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Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTES

[1]A Vassal, J Fisher, R Jürgens, R Hughes. *Gay and Lesbian Legal Issues and HIV/AIDS: A Discussion Paper*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1997.

[2]J Hausermann. International Law, Advocacy, and Human Rights in the Context of AIDS. *Pediatric AIDS and HIV Infection: Fetus to Adolescent* 1992; 3(5): 248-250.

[3]M Kirby. Human Rights and the HIV Paradox. *Lancet* 1996; 348: 1217-1218. Reprinted in *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 50-52.

[4]Ibid.

[5]LO Gostin, Z Lazzarini. *Human Rights and Public Health in the AIDS Pandemic*. New York & Oxford: Oxford University Press, 1997, at xvii.

[6]*Guidelines on HIV/AIDS and Human Rights*. Geneva: UNAIDS and United Nations High Commissioner for Human Rights/ Centre for Human Rights, 1997. Reprinted in part in *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 1.

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

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## Publication Noted: *The Impact of Homophobia and Other Social Biases on AIDS*[1]

**As expressed by Jonathan Mann, Professor of Health and Human Rights at the Harvard School of Public Health, this report is a major step toward a broader and clearer understanding of the "inextricable links between health and societal stigma, discrimination, human rights, and dignity."**[2]

The report points out that the phenomenon of HIV/AIDS is unique in the US experience because "even as it has represented a clear and overwhelming threat to our public health and our national stability, it has simultaneously received less public attention and a more ambivalent government response than any public emergency of a comparable dimension in our century."[3]

In the United States,

- President Ronald Reagan made his first public mention of the word "AIDS" in a speech delivered on 31 May 1987, **nearly seven years** after the illness had first appeared. On that date, AIDS had been diagnosed in over 36,000 men, women, and children in the US, and had already claimed over 20,000 lives. In contrast, only two days after the outbreak of Legionnaire's Disease had been announced, the President of the United States had been photographed holding an emergency meeting in the Oval Office to deal with the outbreak.

- The House of Representatives began emergency hearings into possible causes of Legionnaire's Disease only three months after the initial outbreak of the illness. By contrast, the first House of Representatives hearings on AIDS began on 9 May 1983, nearly two years after the disease first appeared in the US.

- By the end of the first 12 months of the AIDS epidemic, the Centers for Disease Control had spent a total of US$1 million investigating and fighting the illness. By the end of the first 12 months following the appearance of Legionnaire's Disease, the CDC had spent a total of US$9 million fighting it.

> • Two years into the AIDS epidemic, and with 634 cases, *The New York Times* had printed only six articles on the epidemic, none of them on the front page. This is in contrast to the 33 articles – 11 of them on the front page – that *The New York Times* printed during the first 30 days of the Legionnaire's Disease outbreak, when the death toll from the illness had reached 24.

The report shows how the linkage of homophobia to HIV/AIDS, and the widespread identification of AIDS as a gay disease, continue to hamper efforts to address the many issues raised by HIV/AIDS. Just how important was the association of HIV/AIDS with gay men and other stigmatized "risk groups" and the lethargic public response to the epidemic? According to the report,

> [o]ne can get a partial answer by returning to our example of The New York Times' coverage of AIDS issues. In 1983, infected individuals finally began to be discovered outside of the previously identified "risk groups" of gay men, intravenous drug users, hemophiliacs, Haitians, and immigrants; around the same time, scientists realized that individuals could carry and transmit the virus without exhibiting any physical indications of HIV infection themselves. In other words, the disease could strike anyone. Coverage of the AIDS epidemic by the New York Times suddenly skyrocketed. From a total of only six news stories on AIDS throughout all of 1981 and 1982, Times coverage jumped to almost daily stories beginning in mid-1983. The year 1983 became the year that America discovered the AIDS epidemic – two years and literally hundreds of deaths after it had first appeared. *Life* magazine's famous "Now No One Is Safe From AIDS" cover appeared in 1985. Even now, the only comprehensive governmental initiative to address the AIDS-care needs of the American public is named after a child – Ryan White – who, although indisputably a true American hero, was also considered an "innocent victim" of the epidemic by virtue of his having received the virus through a contaminated blood transfusion.[4]

The Report contends that "just as AIDS-Related Stigma is the driving force behind our nation's lackluster response to HIV/AIDS, so the unaddressed issue of homophobia remains the unseen cause of the spread of AIDS-Related Stigma within U.S. society."[5] It concludes that until the issue of homophobia is properly and adequately addressed, the US [and other countries] are unlikely to generate an objective, focused response to the epidemic of HIV and AIDS.[6]

Copies of the Report can be obtained from Public Media Center, 466 Green Street, San Francisco, CA 94133.

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Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTES

[1] A Special Report by Public Media Center. San Francisco: The Center, 1995. All citations are taken from this report.

[2] At 3.

[3] At 5.

[4] At 17.

[5] At 5.

[6] Ibid.

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# Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

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## US – Life Insurer Discriminates

**A federal judge in California has ruled that Prudential Life Insurance Co breached the *Americans With Disabilities Act* by refusing to sell life insurance to anyone in a sexual relationship with a person with HIV.**[1]

In *Cloutier v Prudential Insurance Co* the plaintiff was refused a $500,000 life insurance policy after Prudential reviewed his medical records, which showed that he practises safe sex with his HIV-positive partner. Cloutier himself tested negative for HIV.

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Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTE

[1]Reported in [Australian] HIV/AIDS Legal Link 1997; 8(2): 20, with reference to *AIDS Policy and Law*, 16 May 1997.

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

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### HIV/AIDS LEGAL CLINICS

# Provision of Legal Services to Persons with HIV or AIDS: Barriers and Trends

**The following is the first of a series of articles about HIV/AIDS legal clinics in Canada, the issues and problems they confront, and the trends they are observing.**

## The HIV & AIDS Legal Clinic (Ontario) (HALCO)

HALCO is a poverty law clinic for people with HIV/AIDS living in the province of Ontario. Because our clients all have very limited means, the range of problems they bring to us is varied, and frequently their problems appear at first glance to be more about their poverty than their HIV status. However, it is not quite that simple.

### Profile of Legal Problems

The poverty law clinics in Ontario all keep track of the number of people who call them for help and of the kinds of problems they seek help with. The average legal clinic's statistics show that the vast majority of callers are experiencing difficulties in two primary areas:

- government income maintenance programs (Welfare, Family Benefits, Canada Pension Plan, Employment Insurance, and Workers' Compensation); and
- issues related to the rental housing market.

Inadequate or too-expensive housing and insufficient income for basic necessities are the primary problems encountered in legal clinics across the province.

HALCO experiences a wider variety of problems. In 1996, the profile of problems we were approached with was as follows:

| | |
|---|---|
| Government Income Maintenance | 10.56% |
| Housing | 11.73% |
| Insurance | 8.48% |
| Wills & Substitute Decision Making | 14.49% |
| Bankruptcy | 4.44% |
| Human Rights | 4.04% |
| Criminal / Prison Law | 8.49% |
| Health Issues (excluding malpractice) | 3.12% |
| Employment | 3.26% |
| Immigration | 5.22% |
| Family | 3.00% |
| Miscellaneous Other Civil | 23.17% |

It is clear that for HALCO to serve our population effectively, we must have expertise in the prime poverty law areas, in addition to expertise in a wide range of legal matters normally outside clinic practice. The "Miscellaneous Other Civil" category includes medical malpractice, other tort-based actions, non-profit incorporations, tax issues, the drawing up of affidavits and other documents required by law, and anything else that comes up.

### Funding and Activities

The wide range of demand creates a serious resource problem for HALCO, as we currently have funding for only one full-time lawyer. In order for the clinic to ensure that it has in-house expertise in all the areas of demand, additional resources would be needed in order to increase the number of legal staff. For the 1997-98 fiscal year, this problem was addressed, at least in part, by hiring an articling student who can handle many of the traditional poverty law matters and small claims court trials, freeing up the lawyer’s time for other, non-traditional cases. The funds to hire the articling student were obtained over a number of years through donations, and it is unlikely we will be able to hire an articling student again.

The Ontario government and the Ontario Legal Aid Plan (which funds the legal component of our services) are currently examining the legal aid system in Ontario with an eye to decreasing expenditures and restructuring the entire system. Since the election of the current government, Ontario has seen a significant curtailment of the Plan, particularly in the areas of civil law. As a result, there is a great deal of uncertainty as to whether or not HALCO, or any component of Ontario’s current legal aid system, will survive the current review and exist after the end of the current fiscal year on 31 March 1998.

HALCO currently has a total budget of $175,000 a year. Of that total, $75,000 is from the AIDS Bureau of the Ministry of Health and funds the education, outreach, and community development work we do. With the AIDS Bureau funds we hired a full-time community worker and produced a number of public legal education pamphlets available from HALCO free of charge. They include:

- *HIV and Testing in Ontario*;
- *What to do when someone dies and there is no will*;
- *What to do when someone dies and there is a will*;
- three pamphlets on Bill 142, the *Social Assistance Reform Act, 1997*; and
- a number of law reform briefs submitted to the Ontario government on topics such as proposed changes to tenant legislation, the legal aid review, and public health records.

In addition, we produce an occasional newsletter for our membership.

The remainder of our funding is from the Ministry of the Attorney General's office and is distributed to us through the Clinic Funding Committee of the Ontario Legal Aid Plan. Those funds support all the legal work we do. In early August 1997, we had seventy active case files; we receive about 100 requests for information and services every month. Our case work is as varied as the requests we receive. For example, in the summer of 1997 we completed a three-day Charter challenge hearing before the Health Services Appeal Board, challenging the regulation under Ontario's *Health Insurance Act* that denies access to most health services to immigrants who are HIV-positive. In September 1997 we obtained party status on behalf of the Prisoners with AIDS Support and Action Network (PASAN), at an inquest held in connection with the death of prisoner William Bell, who died from AIDS at Kingston Penitentiary. The inquest was important because Mr Bell died in prison when he was past his mandatory release date and despite the fact that the Correctional Service of Canada has publicly stated that prisoners with terminal illnesses should be released earlier rather than later in their sentences.[1]

## Trends in Litigation

### The HIV-Positive Employee

One of the trends that has appeared in our litigation work involves employers and how they treat HIV-positive employees. The courts are willing to accept that the standard of care that an employer has toward an HIV-positive employee, where the employee's status is known to the employer, includes freedom from unwarranted stress, or harassment of the employee.[2] The fact that the courts accept negligence claims in employment scenarios and recognize that the standard of care for HIV-positive employees may be higher, holds out great promise for the community in making the workplace more accommodating and less hostile for HIV-positive employees. Given the continuing difficulties with the Ontario Human Rights Commission (such as extraordinary time delays and the Commission's refusal to proceed to a hearing of the majority of complaints), this is a very positive development and an alternative for HIV-positive employees to complaints under the *Ontario Human Rights Code*. It also means that AIDS service organizations, which often employ HIV-positive people, have obligations to those employees that, when breached, can lead to damage awards in the courts.

### Insurance Issues

Another trend, overall a very disturbing one, is the way in which the availability of the new protease inhibitors and the treatment results that are being achieved have affected the insurance industry and how it treats HIV-positive people. It is now possible for a totally asymptomatic individual who is not planning treatment to get access to private health insurance, although we know of only one insurer who will issue such policies. On the other hand, individuals who receive private disability insurance benefits are under heavy scrutiny by insurers and are being reassessed constantly with an eye to discontinuing insurance benefits. This has created a number of problems.

First, people are being harassed for additional medical information. In some cases the demands for medical information are constant and the HIV-positive beneficiary is left feeling threatened and uncertain regarding his or her income. Doctors are becoming increasingly frustrated by these demands, which are an unreasonable burden on busy practitioners.

Second, there has been an increasing trend toward out-and-out denials for short- and long-term disability benefits. The industry does not seem to recognize the serious side effects that many people are experiencing from the treatment protocols, or the fact that many people cannot take protease inhibitors at all, or the fact that the treatment protocols do not necessary result in instantaneous well-being.

Cases involving the insurance industry are extremely difficult for a small legal clinic like HALCO to address. The remedy available in almost all cases is to sue for breach of contract, a process that is labour-intensive, expensive, and lengthy, and insurance companies are very sophisticated litigants. There are a small number of private practitioners we rely on to handle some of these cases, who are willing to defer a substantial portion of their fees until the conclusion of the case. Unfortunately, this informal network is insufficient to meet the demand. Despite these generous souls, a significant number of people with very serious and valid insurance claims cannot access legal services and are left without a remedy unless HALCO can find the resources to represent them ourselves. Given our staffing numbers we can only pursue a handful of these kinds of cases every year.

### Disability and Access to Benefits

The existence of the new protease inhibitors and the positive media spin that has been put on them has created a number of other difficulties for people. It is becoming increasingly difficult to convince government income maintenance programs such as the Canada Pension Plan or the Ministry of Community and Social Services (Family Benefits) that our clients meet the definition of disabled person in the respective statutes. In addition, in Ontario the provincial government has just introduced Bill 142, the *Social Assistance Reform Act, 1997*, which drastically changes the definition of disabled person for the purposes of the provincial social assistance scheme for the disabled. The new definition requires that one demonstrate a substantial functional restriction in the workplace, in the home, and in the community. The definition is a shift away from a focus on one's ability to work towards a "too sick to get out of bed and function" type of analysis. As a result, people who stop working because working is contraindicated for their health and who are functional as a result of not working may find themselves ineligible for disability benefits and may have to participate in mandatory municipal work programs (which may make them as sick as they were when they were working). Bill 142 has received second reading and the Ontario Disability Support Program Act is expected to come into force in March 1998.

## Medical Malpractice

The other major area of litigation where HIV-positive people face almost insurmountable barriers to justice is medical malpractice. Because our clientele has so much contact with health-care professionals, medical malpractice issues arise fairly frequently. Like insurance claims, these actions are expensive and lengthy and only limited resources are available in the legal aid system to support them. One of the types of medical malpractice that we see is the failure of doctors to inform their patients that the patient has tested HIV-positive, and a subsequent failure to treat the patient for HIV disease. This is not an isolated or even unusual phenomenon. If one cannot access legal assistance to pursue court action, the only remedy available for the client is a complaint to the College of Physicians and Surgeons, a remedy that at best results in a doctor being disciplined, and provides no compensation or further remedy for the complainant.

- *Ruth Carey*

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Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTES

[1] See the article by Rick Lines entitled "The Case against Segregation in ‘Specialized’ Care Units" in this issue of the *Newsletter*.

[2] *D.L.* v *CATIE*, Toronto Small Claims Court #23739/96, 7 March 1997, per Cengarie DJ.

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

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## RETURN TO WORK

# Return to Work for Persons with HIV/AIDS: Back to the Future?

**Since protease inhibitors became available in 1996, combination antiretroviral therapy has led to significant improvements in the health of many people living with HIV/AIDS (PHAs). Canadian AIDS Service Organizations (ASOs) are responding to an emerging need for programs and services designed to assist those who want to return to the workforce. In this issue of the *Newsletter*, we present some of the return-to-work initiatives recently undertaken by various groups throughout the country. The next issue will present more initiatives and include a discussion of some of the legal, ethical and human rights issues raised.**

### The ACT Feasibility Study

**In 1997, the AIDS Committee of Toronto (ACT) commissioned a feasibility study on return-to-work programming for PHAs.**[1] **Although the study primarily addresses issues for PHAs in Toronto, it contains information that may assist return-to-work planning by ASOs in other Canadian cities.**

### Objectives

The objective of the study was to assess

- the return-to-work issues being experienced by PHAs;
- the vocational rehabilitation services available at non-HIV/AIDS agencies;
- the suitability of these programs in responding to the needs of PHAs and the potential for alliances/partnerships between ASOs and these agencies;

- what return-to-work programming has been established at ASOs elsewhere in Canada and in one or two major centres in the United States;

- what documentation exists on return-to-work programs and issues for PHAs; and

- what government programs are available in this area and whether they are a potential source of partnership of funding.

## Methodology

Between September and November 1997, ASOs were consulted in Toronto, elsewhere in Canada, and in the United States. Existing information about PHA needs and return-to-work programming was gathered and documented. Consultations were also held with the Canadian insurance industry, federal and provincial government welfare, rehabilitation and benefits agencies, health-care workers and community-based vocational rehabilitation services in Metro Toronto.

A PHA needs assessment was conducted using a self-administered questionnaire and facilitated focus group discussions at an action research forum in Toronto attended by 21 PHAs.

## Findings

The study identified numerous barriers to effective reintegration of PHAs into the workforce, particularly in relation to current income support programs, long-term disability plans and psychosocial issues. However, it concluded that significant opportunities exist for programs and partnerships aimed at overcoming these barriers.

## Recommendations

The study recommends a range of potential return-to-work strategies for ACT, including:

- possible short-term programs and activities;

- the development of a pilot study in vocational rehabilitation for PHAs in partnership with government and industry;

- the expansion of current benefits advice services offered by ASOs and the development of relevant information and education programs; and

- other education and information strategies for PHAs, vocational rehabilitation agencies and the insurance industry.

## MIELS-Québec's Study/Action Project

**MIELS-Québec is organizing a series of 15 bi-weekly meetings for PHAs who are considering returning to work.**

The first meeting was held on 7 January 1998. The series aims at informing PHAs interested in return-to-work issues about questions such as: is it really possible to begin an active life again? What do you do and have to say about pre-hiring tests? How do you explain the gap(s) in your curriculum vitae? Should you disclose your seropositivity in the workplace or not?

For more information about this project, contact Lina E Racine at MIELS-Québec, tel: (418) 649-1720; fax: (418) 649-1256.

## Labour Force Participation for People Living With HIV: A New CAS Research Project

The Canadian AIDS Society is coordinating a seven-month research project to provide information on the labour force participation needs of people living with HIV and to assess whether or not existing programs and policies facilitate labour force integration. The project is guided by a National Advisory Committee, with membership from each CAS region, representing expertise in income support programs, private insurance and other fields relevant to labour force issues. A consultant has been hired to coordinate the project and prepare the final report.

Five regional consultations will be held to solicit input from people living with HIV in each CAS region. A comprehensive national survey is in preparation and will be widely distributed through local community organizations. In addition, project staff will conduct a review of public and private sector vocational rehabilitation and income support programs to assess existing barriers, opportunities and possible models for innovation. A final report will be prepared, presenting the findings and providing a series of recommendations for future action on this issue.

Information gathered from this project can be used to inform education and advocacy initiatives with federal and provincial policymakers, rehabilitation service providers, private insurers, and business and labour groups. As stated by CAS: "As the epidemic continues to grow in Canada, it will become increasingly important to ensure that workforce participation remains a viable option for people living with HIV."

For more information on the CAS Labour Force Participation Project, contact Jim Zamprelli at (613) 834-9463 or Rodney Kort at (613) 230-3580, ext 113.

---

Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTE

[1]The following text is taken, for the most part, from the executive summary of the study. See I Grubb, C McClure. *Back to the Future: A Feasibility Study on Return-to-Work Programming for People Living with HIV/AIDS*. Toronto: AIDS Committee of Toronto, November 1997, at iii-iv.

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

---

# Triple-Drug Therapy and Return to Work: Results of a Québec Survey

## Background

For the last two years new treatments have given people living with HIV/AIDS new hope. Although these new treatments are not effective for all such people, some experience improvement in health and a reduction in some factors that were affecting their ability to work. The most recent Québec and Canadian statistics show that the death rate among people living with HIV/AIDS has decreased over the past year. Residents of hospices are noticing improvement in their health and waiting lists have become shorter.

What we are now observing among people with HIV/AIDS who are on triple-drug therapy is an increase in life expectancy, a decrease in the death rate and a radical change in their needs. Indeed, those working for community AIDS service organizations (ASOs) in Québec are now noticing this new need of people living with HIV/AIDS: the need to return to work.

According to a US study of 55 Chicago people living with HIV/AIDS, 82 percent of respondents said that they had discussed the possibility of returning to work with their case manager, and 58 percent discussed the matter with their physician.[1] Of these respondents, 66 percent seemed to want to return to work and some had even taken action to do so, 77 percent thought they could work for an indeterminate period, 72 percent wanted a gradual return to work, 93 percent thought they could work effectively with others, and 82 percent thought they couldn’t return to their former employment. Of the latter, 51 percent said the reason was the need to disclose personal information and 60 percent didn’t know how to explain the gap in their employment histories.

According to another US study of 389 gay or bisexual seropositive workers, more than half (52 percent) of respondents disclosed their sexual orientation to their employer.[2] Of course, it’s easier to disclose one’s sexual orientation when the employer is also gay and disclosure of one’s seropositivity is made when the employee is no longer in the workplace. Of the respondents (35 percent) who disclosed their seropositivity to their employer, four were dismissed and eight had to change their type of work.

Faced with these changes in the effects of HIV/AIDS, a survey was prepared and distributed throughout the ASO network and in two gay publications (*B@B Magazine* and *Fugues*) in September 1997. A second distribution will be made in January 1998 in the health and social services network through the Immunodeficiency Treatment Information newsletter and to subscribers to the newsletter in order to collect information from people with HIV/AIDS who do not go to ASOs or frequent gay places. The self-administered questionnaire is anonymous and confidential and doesn't contain any questions that could identify the respondent, his/her type of work or his/her workplace. The questionnaire contains 16 questions in all. Respondents could deliver their questionnaire in four ways: by mail, by fax, through the community organization, or over the Internet. In all, 418 questionnaires from 361 men and 57 women were collected. The results that follow come from the first mailing and were filled in by people living with HIV/AIDS who frequent ASOs or gay places.

## Results

In our sample, 86 percent of respondents were men, 82 percent were under 45, 69 percent lived on the Island of Montréal, 35 percent had been seropositive for five to ten years, 70 percent were receiving triple-drug therapy (half of them for more than a year) and 5 percent had stopped triple-drug therapy, 14 percent were working, 65 percent were on income security, 34 percent wanted to return to work, 71 percent were covered by the Québec government drug insurance program, 56 percent weren't having any difficulty paying for their drugs, 87 percent said that employers should provide their employees with training on AIDS in the workplace, and 82 percent were unaware of the AIDS in the Workplace program.

In general, respondents under 45 tended more to want to return to work. On the other hand, those over 45 didn't want to or were uncertain about returning to work. The longer a respondent is seropositive, the less inclined s/he is to return to work. The obstacles listed by the respondents with regard to a possible return to work can be divided into seven main categories: social, family-related, training, health, workplace, economic, and individual. Nevertheless, the main obstacle remains state of health.

In our sample, the women were younger than the men, live in Montréal, had been seropositive for around one to three years, were not working (only five were in the work force), didn't have group insurance, wanted to return to work more than the men and had a harder time paying for their drugs. The factors most often mentioned are: being a single parent, having young children, and having a seropositive child. These results confirm the lack of job security and the poverty of these women.

Of the respondents who were employed (n=59), 54 percent lived in Montréal, 85 percent were under 45 (51 percent fall into the 36-45 age group), 73 percent had been seropositive for less than 10 years (39 percent had been seropositive for between 5 and 10 years), 75 percent were receiving triple-drug therapy (41 percent for more than a year and none had stopped treatment), 54 percent had group insurance and 37 percent were covered by the Québec government drug insurance program, 34 percent were having difficulty paying for their drugs, 66 percent were going to an ASO, 73 percent were not unionized, 22 percent said that their employer has an AIDS in the workplace policy, 78 percent were in favour of AIDS training for employees, and 49 percent had disclosed their seropositivity to their employer. Of those who disclosed their seropositivity, one in five had problems with their employer. Whether or not the workplace is unionized does not appear to be a factor associated with the disclosure of one's seropositivity.

The respondents who do not take drugs (11 percent) refrain from doing so for the following reasons: the fear of being identified in one's workplace, fear concerning insurance (primarily because of the possible breach of confidentiality), fear of losing one's job, fear of triple-drug therapy, and a preference for waiting to learn the effectiveness of triple-drug therapy.

The respondents who have the most difficulty paying for their drugs are those who are on employment insurance, studying, or looking for work. In addition, the amount that has to be paid out before reimbursement by the insurance company, the drug insurance premium, and the purchase of such products as vitamins, dietary supplements and over-the-counter remedies increase the difficulty of paying for drugs.

## Conclusion and Prospects

The results of this study enable us to formulate the following problems that affect people living with HIV/AIDS in the workplace.

- There are three types of "silence" in the workplace: silence about one's sexual orientation, silence about one's seropositivity, and silence about taking medication. These silences create stress, fear, and the choice whether or not to receive treatment.

- The study reveals that people living with HIV/AIDS are not necessarily secure in their jobs, and disclosure of seropositivity to one's employer can still lead to dismissal for some.

- State of health is the major concern of people living with HIV/AIDS. Triple-drug therapy increases life expectancy without thereby automatically improving quality of life. The amount of drugs that must be taken, the strict schedule required by the drug regimen, compliance with treatment, and side effects are the obstacles that people living with HIV/AIDS have to take into account if and when they return to work.

- Most people living with HIV/AIDS don't want to return to their former jobs because of stress, discrimination or the employer's attitude. Such people prefer to seek out workplaces where there is more openness about sexual orientation, seropositivity and triple-drug therapy. Community work is the sector of choice. According to some respondents, community organizations encourage return to work because of their flexibility and respect for people living with HIV/AIDS – except that volunteer work is not income-producing.

- The obligation for employers to reasonably accommodate their employees is the most difficult aspect to have accepted. How can a person living with HIV/AIDS who wants to return to work have access to: a flexible schedule because of his/her state of health, drug regimen, medical appointments, testing and treatment; a number of working hours that respects one's state of health; a level of productivity that respects one's state of health; tasks that are compatible with one's state of health; a work environment that minimizes exposure to microbes, etc?

· How can a person with HIV/AIDS explain being absent from the labour force for more than a year on his/her curriculum vitae?

· The positive effects of the Québec drug insurance program for people living with HIV/AIDS should be pointed out. However, the government should revise its policy concerning mandatory coverage under a group-insurance plan in order to enable people living with HIV/AIDS to benefit from drug insurance without being obliged to disclose their seropositivity, thereby enabling them to be hired without worry.

· Employee training and the adoption of an AIDS in the workplace policy should, in our view, be part of the agenda of all Québec businesses.

- *Yves Jalbert*

The AIDS in the Workplace program is a consultation service about problems relating to AIDS for businesses and private, public and parapublic organizations in Québec. Its mission is: to provide tools for evaluating and analyzing the needs of the business or organization; to help businesses and organizations develop an AIDS in the workplace policy; to set up training sessions for managers and employees on the transmission and prevention of AIDS within a context of personal and professional activities; to provide information about the rights of people living with HIV/AIDS, of employees and of employers, and to identify the responsibilities of each; to provide information kiosks on AIDS-related problems; to ensure follow-up on training sessions; to intervene in crisis situations; to provide resource persons; to assess the impact of the workplace training sessions; and to ensure that the information dealing with AIDS is up-to-date.

For information concerning the program or to obtain a copy of the study, contact Yves Jalbert at (514) 282-1015 or write to 4205 St-Denis, Suite 320, Montréal, Québec H2J 2K9.

---

Top of this page

Return to Table of Contents

Return to Home Page

---

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[1] Howard Brown Health Center. Employment Options Survey Results – Summary. Chicago, 1997, 3 pp.

[2] JM Simoni, HRC Mason, G Marks. Disclosing HIV Status and Sexual Orientation to Employers. *AIDS Care* 1997; 9(5): 589-599.

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

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# Workers' Compensation Claims and Disclosure

**We disclose information every day. To our friends, family, colleagues, and partners we tell many things. Often we have a variety of reasons for choosing to disclose information – to gossip, inform, educate, or elicit information from others. At other times we are compelled to disclose by the law, courts or administrative bodies. In some situations we are able to decide on the degree and amount of information we will provide. However, in other situations other people have control over the content of the disclosure or can be compelled to provide disclosure of information pertaining to us.**

## Confidentiality and Exceptions

Many professionals, doctors, lawyers, reporters, and priests have certain levels of privileged confidentiality between themselves and their clients. However, only with lawyers is the privilege absolute. In contrast, doctors are often required to provide information. For example, the Ontario *Health Protection and Promotion Act*[1] and similar public health legislation in other provinces and territories require physicians to notify public health authorities if a patient has a communicable disease listed in the Act. In all provinces and territories, cases of AIDS and sometimes HIV seropositivity have been made notifiable.[2]

## Workers' Compensation Claims

In addition, in a variety of different situations, physicians are required to provide information to panels, boards, or tribunals. The case that will be discussed in more detail in this article concerns workers' compensation claims, where physicians are often required to submit a medical report.[3]

In such claims, the question that should concern physicians and any potential claimant is: should a medical report contain information concerning an individual's HIV status? There are no guidelines outlining when a physician should disclose HIV/AIDS-related (or other medical) information. Many statutes do not set limits on the degree to which such information can be requested. Some statutes provide that "any reasonable and necessary information" should be disclosed. The question remains: is a patient's HIV status reasonable and necessary information with regard to a workers’ compensation claim?

Certainly, if a claim is related to a claimant being exposed to, and becoming infected with, HIV (eg, a medical worker being stuck with a contaminated needle), it would be reasonable to include information regarding the claimant's HIV status. However, it is less clear whether such information should be included if the claimant’s status is peripheral to the injury for which compensation is being claimed. Is a doctor required to reveal a claimant's HIV status to a workers' compensation claim for a head injury? There may be situations where a physician feels that a claimant's HIV status is relevant information that has an impact on the condition at hand and should be reported. In such circumstances, however, the physician should be aware of the potential prejudices that may arise once a person's HIV status is revealed.

## A Recent Case

A recent case in Nova Scotia is indicative of the problems that may occur if an individual's status is unnecessarily included in a medical report. The claimant had injured his spine while performing his duties at his workplace. In the report to the Workers’ Compensation Board, the attending physician included the statement that the claimant was HIV-positive but asymptomatic. The claimant was refused long-term benefits because the Board found that the problems with the claimant's spine were not the result of the injury, but more likely the result of an existing congenital problem.

The claimant later moved to Ontario, where he underwent further examinations, showing that there was no congenital problem and that the injury itself had caused the damage to the spine. By that time, however, the claimant was barred from appealing the Board's decision because the limitation period had expired.

Throughout the process the claimant felt that the handling and outcome of his case would have been different had the physician not disclosed his HIV status. In particular, the claimant felt that the Board had been prejudiced against him because of his HIV status. While it is difficult to address and challenge such prejudice unless it is overt and readily apparent to all, and while it is difficult to prove that prejudice indeed played a role in this particular case, it is important to recognize the consequences that unnecessary disclosure of a claimant's HIV status may have.

## Solutions

When requested to provide medical information regarding an HIV-positive worker’s compensation claim, physicians should undertake the following steps:

- determine if a claimant's HIV status has any relevance to the claim;

- determine the claimant's opinion regarding the inclusion of their status in a medical report to the board;

- if a decision is taken to include the claimant's status in the report to the board, the physician should notify the claimant prior to doing so; and

- if a physician is uncertain as to whether to disclose such information in a medical report, he or she should consult a lawyer or the provincial governing body for advice.

Individuals living with HIV or AIDS who submit a workers' compensation claim should be aware that such information may be included in a medical report. They should discuss any concerns with their physician and ask to see a copy of the medical report prior to its being released.

Generally, unless HIV status is an issue in a particular claim (such as in the case of a medical worker exposed to HIV), a board will unlikely specifically request information concerning a claimant's HIV status. For many reasons, physicians should therefore never feel compelled to provide such information unless it is requested by the board:

- it is more difficult to correct any damage to an individual's claim due to bias or prejudice resulting from disclosure, than to wait and disclose the information at a later stage, when it may become apparent that it is relevant;

- if disclosure of a claimant's HIV status was not relevant – regardless of whether or not it resulted in being detrimental to the claim – physicians may be opening themselves to potential litigation or professional review;[4] and, finally,

- aside from the possibility that a claim may be negatively affected by the disclosure of HIV status, the possibility exists that the claimant's HIV status could become public as a result of disclosure to the board.

Given the potential for social stigma associated with HIV/AIDS, physicians and other providers should always exert great caution and be reluctant to disclose information regarding a patient's HIV status.

- *David Smagata*

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Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTES

[1]Health Protection and Promotion Act, RSO 1990, c H7.

[2]HIV is not reportable in Québec, Alberta, British Columbia, and Yukon. For more information, see R Jürgens, M Palles. *HIV Testing and Confidentiality: A Discussion Paper*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1997, at 251-254.

[3]Many provincial statutes grant workers' compensation boards the power to requisition reports from any medical personnel who have ever attended the claimant. See, eg, the *Workers' Compensation Act*, RSO 1990, c W11, s 51; *Workers' Compensation Act*, RSNS 1989, c 508, s 67; *Workers' Compensation Act*, SA, c W-16, s 29 (1).

[4]Some statutes contain provisions protecting authors of medical reports from the report being admitted into court as evidence against the author, unless it was written maliciously. See *Workers' Compensation Act*, SA, c W-16, s 29(3).

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# Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

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## US – Confidentiality Breach Punished

**William Calvert, a former Florida public health worker, has been sentenced to one year of probation on his no-contest plea for breaching the confidentiality of AIDS patients.**

As reported in the October 1996 issue of the *Newsletter*,[1] Calvert had taken a list of 4000 persons with AIDS home on a computer, where his former partner obtained access to the list, printed it out, and used it in unauthorized ways. Calvert's former partner, Gregory Wentz, had previously been convicted of a second-degree misdemeanour and sentenced to 60 days in jail for his part in the affair. That sentence is under appeal.[2]

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Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTES

[1]The Editor. US – List of 4000 Persons with AIDS Leaked. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 3(1): 41.

[2]Reported in *Lesbian/Gay Law Notes* October 1997, at 154.

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

---

## CANADIAN NEWS

# Legal Issues New "Strategic" Area Under NAS III

**Recognizing the ever-increasing importance of legal, ethical, and human rights issues in the response to HIV/AIDS, Minister of Health Alan Rock announced on 1 December 1997 that, for the first time since the beginning of the National AIDS Strategy (NAS), these issues will represent a "strategic" area in Phase III of the Strategy.**

Minister Rock thus accepted the advice of a group of national stakeholders, including the Canadian AIDS Society (CAS), the Canadian Public Health Association, the Community AIDS Treatment Information Exchange, the Canadian Treatment Advocate Council, the Canadian Aboriginal AIDS Network, the Canadian HIV/AIDS Trials Network, the Canadian Association for HIV Research, the Interagency Coalition on AIDS and Development, the Canadian Hemophilia Society, and others. Based on the results of extensive, though rushed, Canada-wide consultations that showed that discrimination continues to be a primary concern for Canadians living with or affected by HIV/AIDS, and that it negatively impacts on efforts to reduce the spread of HIV and to provide care, support and treatment to those living with HIV or AIDS, the group had recommended that legal, ethical and human rights issues become a "strategic" area in NAS III. The group also recommended that work on these issues be funded at a level of $1 million yearly over the next five years. However, at the time of going to print no final decision had been reached over funding allocations.

According to the stakeholders’ recommendations, funding in the area of legal, ethical and human rights issues should be used, among other things, to

- allow follow-up work in areas in which work has started in Phase II of the NAS (such as legal and ethical issues raised by HIV/AIDS in prisons; criminal law and HIV/AIDS; testing and confidentiality; gay and lesbian legal issues and HIV/AIDS; discrimination against persons living with HIV/AIDS or affected populations);
- undertake work on "top priority" legal and ethical issues identified during a vast

consultation process undertaken in 1995 by the Joint Project on Legal and Ethical Issues Raised by HIV/AIDS of the Canadian HIV/AIDS Legal Network and CAS (ie, access to care and treatment for people living with HIV/AIDS; drug laws and HIV/AIDS; laws and policies regulating prostitution and their impact on the spread of HIV); and

- undertake consultations to establish and continuously reassess a list of new and emerging legal, ethical, and human rights issues, and to work on those issues.

On 15 October, the Legal Network submitted a brief to the HIV/AIDS Consultation Secretariat, entitled The Legal, Ethical, and Human Rights Dimensions of HIV and AIDS: Where Should We Go From Here? Copies of the document can be obtained by contacting the Network at info@aidslaw.ca (tel: (450) 451-5457; fax: (450) 451-5134).

---

Top of this page

Return to Table of Contents

Return to Home Page

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

---

# HIV/AIDS and Aboriginal People: Legal Issues

**The Canadian HIV/AIDS Legal Network is undertaking a project on legal issues raised by HIV/AIDS in Aboriginal communities in Canada.**

Funded by Health Canada under the National AIDS Strategy, Phase II, the project involves extensive consultations with individuals and organizations working in the area of Aboriginal people and HIV/AIDS, including Aboriginal AIDS organizations, provincial and federal health ministry representatives, community health representatives, and others. In February 1998, discussion papers on three key issues will be released:

- Aboriginal people, HIV/AIDS and discrimination;
- problems of jurisdiction and funding; and
- issues relating to testing and confidentiality for Aboriginal people.[1]

Work undertaken thus far confirms that the development and implementation of an effective response to HIV/AIDS by Aboriginal AIDS organizations and health-care workers is complicated by a number of issues, including a lack of awareness about the disease in some communities, a failure – by Aboriginal and non-Aboriginal leadership – to recognize the potential impact of AIDS on Aboriginal communities, the poor overall health of many Aboriginal people in Canada, the racism they encounter, and the frustration of living under and being defined by an externally imposed legislative regime.

Those consulted were alarmed about the rapidly increasing HIV infection rates among Aboriginals and pointed out that risk factors for HIV and other infectious diseases such as hepatitis are prevalent among Aboriginals. Many concluded that the impact of HIV/AIDS on Aboriginal communities could be devastating and emphasized the continuing need for education and the increased need for culturally appropriate care, treatment and support initiatives.

Generally, it was stressed that Aboriginal AIDS organizations, people living with HIV/AIDS, women, two-spirited people and others most affected by the disease have been leaders in the response to HIV/AIDS. According to those consulted, it is from the ranks of these individuals and organizations that effective models for overcoming problems that hamper efforts to control the spread of HIV must come. Finally, everyone consulted agreed that it is high time for governments at all levels to implement coordinated strategies designed by and focused on Aboriginal people infected or affected by HIV/AIDS.

- *Stefan Matiation*

For more information about this Project, contact Ralf Jürgens at (450) 451-5457 or ralfj@aidslaw.ca

Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTE

[1] The papers build upon work undertaken by Stefan Matiation as human rights intern with 2-Spirited Peoples of the 1st Nations in the summer of 1994. See HIV/AIDS and Aboriginal Communities: Problems of Jurisdiction and Discrimination: A Review, *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 3(1): 1, 47-48).

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Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

---

## INTERNATIONAL NEWS

# End-of-Life Summit in Madrid

**Representatives from 10 countries participated in the International Summit on End of Life Care for Persons with HIV and AIDS held in Madrid, Spain, from 13 to 15 June 1997. The Summit resulted in the development of a position statement and eight resolutions designed to promote standards of care for persons with HIV disease.**

The summit was originally conceived by John Campbell of the UK Coalition of Persons Living with HIV & AIDS and was supported by the Royal Free Hospital School of Medicine and Glaxo Wellcome's Positive Action program. In addition to the position statement, an "Invitation to Initiate Change Around End of Life Issues" was developed to assist community groups in promoting better care for the dying. The four-point document identifies fundamental issues that members of the Summit felt should be addressed: information and education; care for the dying; respect for choices; and aid in dying.

Representatives from the International Summit have presented the documents at regional and national AIDS conferences in 1997 and will present them to the International Conference on AIDS in Geneva in June 1998. The following is the text of the position statement.

**Preamble:**

The International Summit on Promoting Standards of Care for People Living with HIV and AIDS Around End-of-Life Decisions is a consortium of persons with HIV, care providers, activists, and academics with a diversity of experiences with HIV disease.

We have given careful reflection to our experiences and have identified fundamental common grounds concerning the many issues that arise at the end of life for persons with HIV disease.

The dying experiences for persons with AIDS vary significantly both within and across cultures. In some cultural settings, the dying person may be surrounded by high levels of professional and technical care; others will be distinguished by the provision of human, non-professional and non-technical care. Furthermore, there are some settings, irrespective of cultural norms and economic resources, where a person with AIDS will experience a dying process that is divorced from any human, professional or technological care.

We do not take a position on whether one manner of dying is intrinsically better than another. We do, however, strongly oppose the taking of a person’s life against her or his consent. We also agree that when a person dies in a manner that might be acceptable to others, but is inconsistent with the dying person’s values, it is an affront to human dignity.

Regardless of one’s socio-cultural setting and economic circumstance, we believe that the dying process for all persons with HIV can be improved.

**Resolved:**

Therefore we resolve to encourage, promote, and improve standards of care at the end of life. Areas of attention will include:

1. Promotion of the notion that decisions regarding the dying process are as important as decisions concerning living. After all, dying is an integral part of living;

2. Promotion of the development and dissemination of information concerning end of life options for those infected and affected by HIV and AIDS;

3. Promotion of the early consideration regarding end of life care and treatment decisions;

4. Promotion of the psycho-social well-being of the dying person;

5. Promotion of improved management of symptoms both physical and mental that are associated with HIV and dying;

6. Promotion of the right to make deeply personal decisions concerning our bodies, including decisions regarding the manner and timing of death;

7. Promotion of the involvement of persons with HIV and AIDS in the discussion and debate concerning end of life decisions; and

8. Promotion of legislative reform and policy development to protect the rights of persons with HIV and AIDS.

- *Russel Ogden*

Parties wishing to comment on or sign the position statement may write to: UK Coalition of People Living with HIV & AIDS, 250 Kennington Lane, London, England SE11 5RD. Email: editor@positivenation.co.uk

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Top of this page

Return to Table of Contents

Return to Home Page

---

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

---

### DRUG POLICY

## HIV/AIDS and Injection Drug Use: A National (and Rational) Plan

**Eugene Oscapella, an Ottawa-based barrister and solicitor and founding member of the Canadian Foundation for Drug Policy, reacts to the National Action Plan on HIV/AIDS and Injection Drug Use.**

> Injection drug users do not live in a vacuum. They are members of our community.[1]

If only parliamentarians and the bureaucrats who influence them could learn accept the simple and humane proposition above! Yet only days before the release of the Task Force report, Parliament’s latest sacrifice to the god of prohibition, the *Controlled Drugs and Substances Act* came into force. As the Task Force was enumerating the harms caused to injection drug users by Canada’s drug laws and urging Parliament to change those laws, Cabinet was proclaiming in force even more repressive prohibitionist legislation. The *Controlled Drugs and Substances Act* will do nothing to address the spread of HIV and other blood borne infections among drug users and their contacts. Instead, it will continue to foster the conditions that lead to these infections.[2]

Even before the advent of HIV/AIDS, Canada's drug laws were fatally flawed, causing far more harm than they prevented. Now, with epidemics of HIV/AIDS and hepatitis among injection drug users – epidemics that are strongly linked to drug prohibition – policy makers and politicians should be driving the last few nails into the coffin of prohibition. Unfortunately, too many seem skittish about funerals – unless, of course, they are the funerals of those with AIDS and hepatitis.

The Task Force report pulls few punches. It assembles many of the analyses that have been used to show that our present social and legal systems are worsening the problem of HIV/AIDS and injection drug use. Among its boldest positions, the Task Force calls for an end to the criminalization of possession of small amounts of currently illegal drugs for personal use. (This recommendation parallels one made by the Canadian Foundation for Drug Policy during Senate and House of Commons hearings on the bill that became the *Controlled Drugs and Substances Act*).

Other important recommendations include changing legislation to ensure that physicians can prescribe currently illegal substances – for example, heroin and cocaine – to drug users to reduce the harm associated with obtaining drugs on the street; and a recommendation that half the revenues produced through anti–drug profiteering / proceeds of crime cases be allocated to programs in prevention, drug treatment and diversional sentencing. This latter recommendation is almost certain to displease law enforcement agencies that may be looking forward to using seized assets as a potential milk cow to bolster their funding, as some US police forces have done.

One problem – disease and death through injection drug use – but two fundamentally different policy and legislative responses: Parliament’s response, through the newly proclaimed *Controlled Drugs and Substances Act*, will ensure a steady flow of new HIV and hepatitis infections among injection drug users and, through them, to others in the non-injecting community. The other response – that proposed by the Task Force – offers Canadians a chance to save lives and at the same time lift themselves out of the quagmire created by our current drug laws and policies.

The greatest service offered by the Task Force report may be to deny bureaucrats and elected representatives the excuse that they just did not know how bad the problem of HIV infection was among drug users and how to work toward a solution. Until the release of the Task Force report, many bureaucrats and politicians could plead (or feign) ignorance at the suggestion that their laws and policies might be responsible for the needless deaths of many Canadians. Such pleas of ignorance will now appear rather disingenuous. What used to be called (in US politics) "plausible deniability" ("I had no idea that this carnage was happening") will no longer be an avenue of escape.

Perhaps soon, as with the tainted-blood scandal in France (where public officials knowingly allowed the distribution of infected blood), Canada's recalcitrant bureaucrats and politicians may find themselves on the wrong side of the law. HIV/AIDS activists and drug policy reformers are increasingly mentioning the possibility of civil actions against government officials who fail to act, or who act negligently. Perhaps more compelling, and more likely to light a fire under those who wish to ignore the issue of HIV infection among drug users, is the prospect of being prosecuted by private *criminal* prosecution for criminal negligence.

The Task Force report puts forth some sound ideas for change. Like the work of so many other advisory bodies, the report risks consignment to oblivion by unyielding bureaucrats and timid politicians. Yet in its favour, the report is now in the hands of a government that can risk innovation because it does not face another election for several years. Strike while the iron is hot and the government new.

- *Eugene Oscapella*

> "Harm reduction is not just about allowing some drug use in the short term until abstinence can be achieved, as is implied in the report. Many users never achieve

> abstinence and nevertheless, or perhaps as a result, lead healthy, happy and even ‘productive’ lives."
>
> - D Riley, D McKenzie, 1997
>
> "We must include the drug using community and its advocates in our work and acknowledge what harm reduction is really about: not a softening of the language of prohibition to fit the needs of our political masters and funders, but an acceptance of drug use and drug users as valuable human beings who may not want or need treatment and who may never ‘achieve’ abstinence – ever. Perhaps that excludes them from the Kingdom of Ottawa, but it does not exclude them from being human."
>
> - D Riley, D McKenzie, 1997

---

Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTES

[1] *HIV, AIDS and Injection Drug Use: A National Action Plan*. Ottawa: Canadian Centre on Substance Abuse and Canadian Public Health Association, 1997, at 10.

[2] See, for more details (all references are to articles in the *Canadian HIV/AIDS Policy & Law Newsletter*), D Riley, E Oscapella. Bill C-7: Implications for HIV/AIDS Prevention. 1995; 1(2): 1, 11-13; R Jürgens. Drug Laws and HIV/AIDS. 1996; 2(3): 1, 26-28; D Riley, E Oscapella. Bill C-7: An Update. 1996; 2(3): 5; J Conroy. Canadian Bar Association Joins Protest Against Bill C-8. 1996; 2(4): 18-20; Editor. Taskforce on HIV/AIDS and Drug Use Created. 1996; 3(1): 11; E Oscapella, D Riley. Senate Urges Review of Canada's Drug Laws, Policies and Programs. 1996; 3(1): 12-13.

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Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

---

# The Terry Parker Case: Marijuana for Epilepsy – And Soon for HIV/AIDS?

**Terry Parker, a 42-year-old resident of Toronto, has been using marijuana to treat his epilepsy since he was a teenager. Following an Ontario Court ruling on 10 December 1997,[1] he can now use marijuana and grow his own plants legally.**

Terrance Parker was four when he first showed symptoms of epilepsy. Seizures became a daily event for him, even with heavy doses of prescription drugs. At the age of 14, Parker underwent a right temporal lobotomy on the advice of his neurosurgeons. The seizures intensified and he experienced his first grand mal seizure in the recovery room. A second temporal lobe cortical resection was carried out three years later, but the seizures continued. It was during this time that an orderly in one of the hospitals gave him some marijuana. Parker noticed that the more he smoked, the less frequent and intense his seizures were. On his physician's advice he began to keep a diary and noted the direct relationship between having seizures and not smoking marijuana. The physician provided Parker with a letter specifying that he needed marijuana for medicinal purposes.

"When I feel a seizure coming on, I smoke a couple of joints ... and everything is under control," says Parker. Marijuana is also free of the side-effects of depression and loss of appetite that come with the prescription drugs. When he does not smoke, Parker experiences from three to five grand mal and a dozen petit mal seizures per week. He has been hospitalized more than a hundred times due to accidents during seizures. In court Parker stated that

> When I'm treated only with prescription medicine, my life is very difficult to live and at times truly miserable. When I can consume marijuana every day I'm able to enjoy my life, free from seizures, and carry on in a relatively normal way.

Parker was first arrested for cultivation and trafficking in July of 1996, when 71 plants were confiscated. He was again arrested in September of 1997 and charged with possession. Three plants were confiscated. Because Parker admitted to giving marijuana to others for medicinal purposes, Judge Sheppard convicted him of trafficking and sentenced him to one year on probation. Judge Sheppard acquitted Parker on the other two charges on the grounds that both the old drug law, the *Narcotic Control Act*, and the new drug law, the *Controlled Drugs and Substances Act*, are over-broad and unconstitutional and violate section 7 of the *Canadian Charter of Rights and*

*Freedoms*. In his decision, Judge Sheppard drew heavily on another case (the Chris Clay case) that had challenged Canadian drug laws with respect to the recreational use of marijuana,[2] stating that "Marijuana causes no physical or psychological harm for the vast majority of users." He ruled that to deny Parker marijuana amounts to an infringement of his Charter right to life, liberty and security. He ordered that the three marijuana plants that had been confiscated on the second raid be returned to Parker on the grounds that they are necessary medicine, saying that Parker, being on disability allowance, could not afford, nor should have to, purchase the marijuana on the street.

The lawyer for the Crown requested that the ruling be stayed for six months to give Parliament an opportunity to deal with the decision, and argued that allowing marijuana for medicinal use would cause chaos. Judge Sheppard rejected these arguments and requests, emphasizing the fact that it will be doctors who will be deciding who uses marijuana for medical purposes.

The Crown has appealed the decision. In the meantime, Parker is free to cultivate and possess marijuana, but other medical marijuana users will have to take their cases to court until a decision is made by a higher court or the federal Parliament moves to change the law. Parker’s comments after the decision were very apt: "When the Supreme Court of Canada decides pot should be approved for medical purposes, then we'll have the victory we truly need to help people who require it." Meanwhile in Ontario and throughout Canada, numerous other challenges to the laws regarding medicinal marijuana are in the works, and on 18 December Ottawa physician Don Kilby applied to obtain access to marijuana for medical use for one of his patients with AIDS.

_ *Diane Riley & Eugene Oscapella*

For further information and research materials about medicinal marijuana, visit the Canadian Foundation for Drug Policy Internet site at http://fox.nstn.ca/~eoscapel/cfdp/cfdp.html

Top of this page

Return to Table of Contents

Return to Home Page

ENDNOTES

[1] *R v Parker* (Ont Ct Prov Div), 10 Dec 1997, Sheppard J.

[2] *R v Clay* (Ont Ct Gen Div), 14 Aug 1997, McCart J.

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

---

# Swiss Government Report: Heroin Prescription Works

**On 10 July 1997, the Swiss Federal Office of Public Health issued a report containing the results of an experimental heroin prescription program. The report found that crime dropped by 60 percent, unemployment among participants fell by half, and the general and nutritional health of participants improved rapidly during the prescription program.**

The program, which began in January 1994 and continued through

December 1996, eventually prescribed heroin to over 800 heroin addicts in 15 cities.

According to Dr Ethan Nadelmann, Director of the Lindesmith Center, a drug policy research think tank in New York City,

> [t]his report proves that heroin maintenance is a feasible option for cities trying to reduce the harm associated with heroin addiction. As the US and other countries consider alternatives to treating heroin addiction, it is critical that all options, including the prescription of heroin and other drugs, are considered as viable means to reducing crime and improving public health.[1]

Specific results set out in the report include:

- Both the number of offenders and the number of criminal offences decreased by about 60 percent during the first six months of treatment.
- Most illicit drug use, including that of cocaine, rapidly and markedly declined, whereas benzodiazepine use decreased only slowly and alcohol and cannabis consumption hardly declined at all.
- The number of participants unemployed fell by more than half (from 44 percent to 20 percent).

- Participants' housing situation rapidly improved (in particular, there were no longer any homeless).

- Physical health improved during treatment (in physical terms, this relates especially to general and nutritional status and injection-related skin diseases).

- More than half of the program dropouts switched to another form of treatment or became abstinent.

- Court convictions decreased significantly (according to the central criminal register).

- One-third of patients who, on admission, were dependent on welfare required no further support. On the other hand, others who were dependent on illicit income turned to welfare support.

- Retention rate in the study, 89 percent over a period of six months and 69 percent over a period of 18 months, proved to be above average when compared with other treatment programs for heroin dependents.

- No disturbance of note was caused to the local neighbourhoods, or if so only temporarily.

A summary and the full text of the report are available on the Lindesmith Center's website at: www.lindesmith.org/presumm.html.

## Heroin Provision Makes Its Debut in the Netherlands

### In 1998, an experiment to dispense heroin to "untreatable addicts" will be launched in several Dutch cities.

The Dutch parliament has approved the Minister of Health’s proposal to start an experiment in which 750 users will receive heroin. The study is to investigate the effects of heroin provision on the psychosocial and medical condition of the clients.

The research protocol describes a controlled, randomized study.[2] All subjects will first undergo a two-month qualification period to make sure that they satisfy the eligibility criteria. They will then be randomized into three groups. The first group will receive heroin three times daily for twelve months, with a maximum dosage of 1000 mg a day. The second will receive only methadone for the first six months and then heroin for six more months. The third, the control group, will receive methadone alone for twelve months, and at the end of the study can receive six months of heroin. Methadone will be available for the entire period of the study. Half the subjects will be injectors and half will be users who inhale their heroin. The effects of the heroin medication on the subjects' physical, psychological and social condition will be measured every two months. The heroin dispensed in the study will be marked with heavy water during the production process, by replacing a hydrogen atom in the molecule with a deuterium atom. Any side use of illegal heroin can be detected in urine tests.

Top of this page

Return to Table of Contents

Return to Home Page

ENDNOTES

[1]See: Swiss Government Report: Heroin Prescription Works: Crime Dropped, Illicit Drug Use Fell and Patient Health Improved. Press release of 10 July 1997 by the Lindesmith Center, New York, NY.

[2]The description of the protocol is taken from I Hurkmans. Medical treatment, not a stoned paradise – Heroin provision makes its debut in the Netherlands. *Jellinek Quarterly* 1997; 4(3): 1, 12 at 12.

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**Canadian HIV/AIDS Policy & Law Newsletter**

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

---

# Australia – Parliamentarians Recommend Drug Law Reform

**The Australian Parliamentary Group for Drug Law Reform has released a report supporting the controlled availability of illicit drugs and calling for the decriminalization of personal drug use.**[1]

Controlled availability involves the supply of drugs on prescription, dispensed at clinics under strict control based on the methadone treatment model.

The report is entitled *Drug Lore: The Questioning of Our Current Drug Law*. It points out that the illicit drug trade is "the second largest industry in the world after arms" and estimates its annual profits at around Cdn$450 to 500 billion. "At the heart of the problem is the definition of drug use as a law enforcement matter rather than a health concern," the report says. "Criminal sanctions reduce opportunities for future employment [and] stability in life and do not appear to reduce dangerous drug use."

The report refers to a range of adverse consequences that flow from criminal laws against drug use. These include police corruption, the diversion of law enforcement resources, and contribution to the spread of HIV/AIDS and hepatitis B and C in prisons.

---

Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTE

[1] Reported in the [Australian] *HIV/AIDS Legal Link* 1997; 8(2): 3.

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Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

---

# Harm Reduction in the US: A Movement for Change

**By simplifying the problems of drug use, polarizing debate and stigmatizing behaviour, the "War on Drugs" has made it difficult to recognize, let alone organize around, a broader social and political agenda to address the harms of drug use. This article argues that harm-reduction activists and drug-user groups need to establish common ground for action with other progressive movements to overcome the divisions maintained by the "War on Drugs."**

## The Harm-Reduction Approach

Policies and programs based on a harm-reduction approach to drug use seek "to reduce the adverse consequences of mood altering substances without necessarily reducing their consumption."[1] While the origins of harm-reduction practice and philosophy may be traced to user self-help initiatives, harm reduction became a phrase and a legitimate policy option in many countries in response to the severity of one of the adverse consequences of injecting drugs, namely the transmission of HIV through the sharing of injection equipment. For this reason needle exchange programs (NEPs), which distribute clean injection equipment and retrieve used needles and syringes, have come to be both the site and symbol of the harm-reduction approach, which accepts the reality of licit and illicit drug use and seeks to minimize its harmful effects.

## Needle Exchange Programs in the US

A hundred NEPs exist in the US, largely due to the courage and energy of the activists who started them. However, the picture is a varied one:

- Some states, such as New York, Connecticut, Washington, and Hawaii, now publicly fund and support NEPs.
- In some states, such as California, the state does not support NEPs, but public monies support local programs through city and county funding.

- New Jersey and New Hampshire, on the other hand, not only will not support NEPs but have actively sought out the underground programs for prosecution.

The backdrop to this varied picture at state level is the continuing ban on federal funding for NEPs. Congress has banned the use of federal funds for needle exchange until researchers prove that NEPs both reduce the transmission of HIV and do not lead to an increase in drug use. This has been proved, but the ban remains. All federally commissioned expert panels have supported the lifting of the ban. In February 1997, a report by a committee convened by the National Institutes of Health concluded that NEPs are "very effective means to prevent the spread of HIV infection" and do not lead to increased drug use.[2] The panel urges that "significant policy and legal barriers must be removed in order for these interventions to protect the population,"[3] for example by amending the Prescription and Drug Paraphernalia laws as some states have already done.[4]

## The "War on Drugs"

But the policy and legal barriers to NEPs and the harm-reduction approach will remain as long as America's "drug problem" is portrayed and perceived as a greater threat than the acknowledged public health emergency of AIDS. The fact that the "War on Drugs" takes precedence over the fight against AIDS (a fact that distinguishes US policy from that of industrialized nations in Europe, Australasia, and – to a certain extent – from that of Canada) in spite of the scientific research should come as no surprise given the political, economic and social imperatives served by the War. The basic question is no longer "Do needle exchanges work?" or even "How can programs be improved?" but rather "What political, economic and social conditions would need to prevail for NEPs, and the harm-reduction approach more generally, to flourish in the US?"

Answering this question is urgent, given the many lives that are being lost in this drugs war. About two-thirds of new HIV infections in the US stem from injection drug use – 50 percent through sharing infected syringes and an additional portion through fetal transmission or sexual contact involving an injecting drug user. It is estimated that 50 percent of all injecting drug users in New York City are HIV-positive, and AIDS is now the leading cause of death among Americans aged 25 to 44. As Chris Lanier of the National Coalition to Save Lives Now points out, "the Clinton administration has the power to stop tens of thousands of new cases of AIDS within the next several years, simply by ending the ban on needle exchange funding."[5]

The "War on Drugs" throws away other lives. One-third of the increase in prison and jail populations since 1980 is due to the increase in the number of drug-law violators behind bars. The number of drug-law violators in federal prisons increased by 850 percent between 1980 and 1994. Service providers working to reduce the impact of the drugs war are punished. NEPs in some states face criminal proceedings, and the NEP in Santa Clara, California, was pressured to close in 1996 by state intervention. Recently passed immigration and welfare legislation singles out drug users for sanction. In fact, the rhetoric and misinformation about drug use within American culture is so extreme that any acknowledgment of the legitimate needs or rights of a drug-using individual leaves one open to sanction and ridicule.

## The Functions of the "War on Drugs"

Some see the harmfulness of American drugs war policy as evidence of its failure. Others point to increasing drug consumption and trafficking as unequivocal signs that the war is being lost, while the libertarian right emphasizes the fiscal benefits of abandoning costly interdiction efforts and legalizing and taxing drugs instead. But far from being a failure, the American "War on Drugs" is a functional success, if we properly understand those functions.

Reeves and Campbell have described Reagan's drugs war as "a political spectacle that depicted social problems grounded on economic transformations as individual moral or behavioural problems that could be remedied by simply embracing family values, modifying bad habits, policing mean streets, and incarcerating the fiendish 'enemies within.'"[6] Drug policy and policymaking thus serve as a false, individualized representation of a painful and fearful social reality. Economic and social transformations create anxiety, fear and, potentially, dissent and protest. The "drugs problem" – and its solutions – contains this dissent by projecting anxiety and fear onto the "Other" and away from the real problem – social injustice.

## Drug Problems

This is not an argument about whether drug problems exist. As the national voice of the harm-reduction movement in the US, the Harm Reduction Coalition is unequivocal in saying that it "does not attempt to minimize or ignore the many real and tragic harms and dangers associated with licit and illicit drug use."[7] Many people use drugs for many different reasons. Clearly, for some people drug use is problematic. But the "drugs problem" as it is defined in many societies constitutes a purposive distortion of the complex relationships between drug use, harmful drug use, socioeconomic circumstances and individual psychologies. This complexity is finessed when drugs become THE problem and the drug user an object of blame.

## Objects of Blame

Systems in transition or under strain require "objects of blame" in order to mask their own weakness or the damage they are doing. Dr Sam Friedman of the National Development and Research Institutes argued at the US' First National Harm Reduction conference, held in Oakland in September 1996, that transformations in global capitalism, while influencing patterns of drug production and consumption, have also *necessarily* fueled the demonization of drugs that passes for current debate in the US and, increasingly, elsewhere. *Necessarily*, Friedman argues, because the globalization and deregulation of capital and labour markets has created extreme poverty in communities in the developed and the developing world amidst the affluence of a few, and thus created the need for scapegoats to divide and distract potential opposition.

Gaps between the rich and the poor, instead of diminishing, have increased substantially over the last decades. For example,

- the United Nations Development Programme 1996 Human Development Report notes that between 1975 and 1990 the richest one percent of Americans increased their share of total assets from 20 to 36 percent;[8] and
- in 1980 the ratio of chief executive officer pay to factory worker pay was, on average, 41 to one. By 1992, the ratio was 157 to one.[9]

Public protest at the injustices these figures represent has been muted by the ideological celebration of the "free market." Its "who dares wins" philosophy rationalizes these widening inequalities in terms of individual achievement and failure, and drugs are bound up in explanations of this failure. The linking of drug dependency and welfare dependency found legal expression in the recently enacted welfare bill and its provision for drug testing of welfare recipients. Cuts in programs of public assistance, themselves the cause of serious harm to some drug users, are backed by not only economic but also moral arguments that invoke the notion of the "undeserving poor" so beloved in Victorian England. Drugs bear the stigma of immorality and drug use has become a marker to be used to separate the deserving from the undeserving claimant.

## Moral Conservatism

The moral conservatism that has rolled back welfare provision, attacked affirmative action and challenged feminism, deploys drugs in its depiction of evil. When illicit drug use is equated with addiction, drug users are placed outside a moral framework that has long celebrated independence, individual achievement and "hard work." In the family values "crisis" within which the backlash of the Right has thrived, drugs play a potent role, threatening the innocence of youth (just say "no," kids) and decent motherhood. As Dr Denise Paone, of the Chemical Dependency Unit of Beth Israel Medical Center points out,[10] at the height of the moral panic around crack in the mid-80s, "crack babies" became the symbol of the abrogation of motherhood and evidence of crack use was treated by welfare authorities in New York as a prima facie case of neglect, rendering the mother liable to prosecution. The symbolism of race and class was clear. The pathologized crack mothers were invariably black, poor and single. But Paone notes that drugs were also being used to tell a story about the danger of women's, particularly black women's, sexuality and their precarious self-control, the instant highs of crack turning mothers into whores. In this sense, the drug war has been enlisted in patriarchy's project to challenge feminist ambiguity and restore its control over the identity of "good" and "bad" women.

## Class, Race and Gender

The drugs war provides us with signs at the intersections of class, race and gender, identifying those who lie outside and threaten the moral and economic order. One result of such scapegoating is the very real oppression of many people. "The history of drugs and drug policy in the United States has always been racialized and that racialization [is] used to support repressive policies and measures,"[11] argues Lisa Moore, Assistant Professor in the Department of Health Education at San Francisco State University. For example,

- it takes 5 grams of crack to get 5 years in federal prison, versus 500 grams of powder cocaine;
- 94 percent of crack defendants in federal courts in 1994 were black;
- black males make up 12 percent of the US population, an estimated 13 percent of drug users, but 55 percent of convictions for drug possession; and
- one in 15 black males is incarcerated.

A significant implication of racist drug sentencing, and the criminalization of black people, is political disenfranchisement. A study by the Sentencing Project, released on 30 January 1997,[12] found that 14 percent of black men are currently or permanently barred from voting because they are in prison or have been convicted of a felony.

An insidious effect of the drugs war and its scapegoating of the "Other", is the way it helps to erode class as a useful concept for analyzing inequities in America's social order. In an era of identity politics, drugs confer an individual identity on inequality and provide a set of individualized explanations of social and economic injustice.

### A Sustained Panic

Indeed, America's drugs war is a sustained moral panic, both serving and being served by many complex interests and interested complexes. The majority of federal prison inmates are incarcerated for drug-law violations. Drug sentencing has fueled an enormous prison building program, bringing much-needed jobs, construction contracts, and an illusory sense of security and achievement. Drugs are also used to justify an expanding surveillance complex. Domestic drug testing kits have brought intergenerational surveillance into the home. The New York Police Department's recent proposals to place cameras in high-crime locations looked to drug dealers as one of the necessary objects of scrutiny.

### Simplification as a Key Function

These complexes about drugs thrive on simplification and this simplification is a key function of drug wars. It has at least two strands – polarization and dehumanization. US public debate on drug issues is currently polarized between supporters and opponents of prohibition. Given the devastating harms inflicted on sections of the US population (predominantly black/Hispanic, urban and poor) by the criminal justice system in the cause of drug prohibition, some opponents of prohibition make a convincing case for harm reduction through a modification of prohibition, if not its outright abolition.

But it is not the only case, nor are the harms of prohibition the only harms associated with drug use or experienced by drug users. Focusing on the issue of legalization, in whatever form, blurs the reality that race and class are critical determinants of drug-related harm, whether the drug use is licit or illicit, and that ending or modifying drug prohibition would not create decent housing, jobs, rights or respect for the many drug users currently denied them.

Associated with polarization is a dehumanization of the debate, wherein people are reduced to labels ("junkie," "addict") and the complexity of lives is simplified to insulting stereotypes. Of course, it is easier to scapegoat people if they are regarded as less than people. The basic lack of humanity and attention to issues of human rights that characterizes current drug debates and drug policy is striking, given that researchers have found that "the power of syringe exchanges to alter behavior is not just in the provision of injection equipment but also in the mutually respectful interactions between the participants and the staff."[13] Consequently, "regulations and procedures that undermine such mutual respect may be the biggest potential hindrance to the effectiveness of syringe exchanges in the United States."[14]

## Prospects for Change

How should the harm-reduction movement address the dehumanizing, polarizing and scapegoating imperatives of the drugs war? A necessary first step is to continue to place respect for human rights and human dignity at the heart of harm-reduction practice. By emphasizing that any program or intervention must begin "where the user is at," harm-reduction practitioners are shifting the client–service provider power imbalance that continues to be a feature of many drug services. In this way, not only is the individual users’ right to determine their own process of change recognized, but also their power to influence services and assert control over other aspects of their lives is supported. Yet this shift in power, taking place at the level of individual users and specific drug-related programs, does not often translate into a changed relationship with policymaking processes and centres of power.

For some, the prospects of such a change appear bleak. Writing in *The Nation* (6 Jan 1997), Bertram and Sharpe fear that "drug war defectors, treatment reformers and harm reduction advocates ... may share a critique of the failures and contradictions of the drug war, but they do not share an agenda for change, and alliances between them are few and fragile." This is itself, however, an indication of the success of the "War on Drugs" in framing the public debate. An agenda for change, and the alliances that could coalesce around such an agenda, are more likely to emerge if the successes and functions of the drug war are recognized. From such recognition it follows that changes in drug policy, an end to the drugs war, will only occur in the context of broader political, economic and social changes. This suggests that the harm-reduction movement’s efforts to counter the scapegoating and dehumanization of current drug policy should make common cause with the efforts of other movements seeking to effect social change.

## Impediments

But there are impediments to making this common cause. Ironically, the public health thinking that has done so much to help legitimize harm reduction elsewhere in the world, and to a lesser extent in this country, is a potential obstacle to a broader political alliance. This is not the thinking of public health pioneers of the late 19th and early 20th centuries, who located health within social and economic conditions and not merely individual pathology, and whose outlook was celebrated in Virchow’s famous dictum: "Health is politics, and politics is health on a large scale." Far from seeing harm reduction in political terms, current public health bureaucracies depoliticize and rationalize the harm-reduction approach in terms of a set of technical interventions directed at drug users (Them) for the sake of the public (Us). Given this, it is unsurprising that harm reduction in the US is usually equated with needle exchange and HIV prevention and that, for many, there remains "something distasteful about helping addicts to their fixes; but, in public health terms, this may be an acceptable trade-off to slow the spread of AIDS."[15]

### Drug User Organizing

The public health approach to harm reduction carries its implicit message that the behaviour of injection drug users is a threat to the public (of whom they are not a part) and thus subtly reinforces the dehumanization and marginalization connected with the drug war. One way this has been challenged, and from which the harm-reduction movement must draw strength, is user organizing. "Every time users get together to talk and tell their experiences is another blow against the silent death of stigma, discrimination and abuse of human rights," says Dave Burrows, IDU Policy Officer at the Australian Federation of AIDS Service Organizations.

But user groups face enormous obstacles in organizing to challenge US drug policy. In contrast to European and Australian experience, user groups in the US have often been initiated by states’ requirements that needle exchange services be advised by a group of service users. Thus, the groups that have arisen are constricted by their mandate to advise on services rather than criticize policy, and this officially mandated position unsurprisingly arouses the suspicion of many members of their constituency – ie, other users.

It could be argued that user organizing needs to identify a broader political agenda for its work if it is to challenge users’ marginalization, because such marginalization is a product not only of substance use per se but also of the role that the story of "drug dependency" plays in legitimating growing inequalities in wealth and power in society and in the exercise of control over those who may pose a threat to the social order. A broader constituency with whom user groups can make common cause may be all those who experience and challenge the inequities of current social and economic policy.

### Alliances with Other Movements

Establishing a common ground for action is a priority for the emerging coalitions of harm-reduction activists, user groups and other movements. Inevitably, much of this work is local by nature. But it is possible to identify certain issues around which different groups could coalesce. The links between drugs and violence are often drawn, but they must be properly understood in the context of gun control (or, more accurately, its absence in the US). Commenting on the US efforts to pressure his country into allowing American ships to operate in national waters on grounds of drug interdiction, the Jamaican Minister of National Security, Mr KD Knight, emphasized that "the gun issue is integrally connected with the drug issue" and called for greater American gun control.[16] In the US, the gun-control lobby and harm-reduction advocates can make common cause in naming the problem as being that of gun availability and a firearms culture rather than that of pathological individuals, often linked to drugs through either use or dealing, who abuse their constitutional right to bear arms.

It is possible to identify other organizing issues like drug testing and its infringement of civil liberties, sentencing reform (especially with regard to mandatory minimums as they are applied to drug-law violations), and the use of harm-reduction programs as sites for voter registration and welfare reform agitation. However straightforward it may be to name these issues, the far greater challenge lies in the work needed to forge and maintain the coalitions around them. The work can be taken forward by a continuing dialogue about the analysis of the functions and successes of the drugs war and the contribution harm reduction can make to a broader movement for social, economic and political change.

- *Alan Greig*

The author gratefully thanks Allan Clear, Executive Director of the Harm Reduction Coalition, for his assistance in the preparation of this article.

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Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTES

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[2]Interventions to Prevent HIV Risk Behaviors. National Institutes of Health Consensus Statement. 11-13 February 1997. In press, at 14.

[3]Ibid.

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[16]L Rohter. US–Jamaica Spat Undermines Region's Anti-Drug Efforts. *The New York Times* 9 February 1997.

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

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## PRISONERS AND HIV/AIDS

# Methadone, But No Needle Exchange Pilot in Federal Prisons

**On 1 December 1997, the Correctional Service of Canada (CSC) announced "new" measures to combat the spread of HIV and other infectious diseases in federal penitentiaries.[1] According to representatives of the Canadian HIV/AIDS Legal Network and the Prisoners with HIV/AIDS Support Action Network, the measures are "woefully inadequate"[2] and fall "far short of the recommendations made by CSC's own Expert Committee on AIDS in Prisons in 1994."**[3]

The "new" measures, which are part of CSC's National HIV/AIDS Program, include the introduction of methadone maintenance treatment and "greater efforts to promote widespread HIV/AIDS testing as well as the introduction of an anonymous testing project to be piloted in one designated federal correctional institution."[4]

However, methadone maintenance treatment will be offered initially only to offenders who are already on a methadone treatment program in the community prior to being sentenced, although it has been widely recommended that, where such treatment is a treatment option available to opioid-dependent persons outside prisons, these persons should also be allowed to start the treatment in prison.[5]

In addition, CSC first announced support for an anonymous testing pilot project in a federal prison in March 1994, in its response to the *Final Report* of the Expert Committee on AIDS and Prisons.[6] Its re-announcement of a commitment made over three-and-a-half years ago is therefore hardly a "new" measure to combat the spread of HIV; it is the long-overdue fulfilment of an old promise and yet another sign of how slow change is within the Correctional Service of Canada.

Once again, CSC has failed to be proactive and has remained paralyzed by concerns that, if it introduced real change – such as pilot projects for distribution of sterile injection equipment and safe tattooing – it could be seen as condoning drug use and tattooing. In the meantime, the number of prisoners living with HIV or AIDS behind bars increases steadily and risk behaviours, particularly the sharing of injection equipment, continue. Most recently, they have led to concerns regarding a potential outbreak of HIV infection in two federal prisons. As representatives of the Legal Network have said:

> The government could be held morally and legally responsible. It is clearly negligent. Do we need a commission of inquiry such as the Krever Commission before the prison system will finally do what should have been done years ago? The government could have saved many lives and a lot of money by following the experts' recommendations."[7]

- *Ralf Jürgens*

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Top of this page

Return to Table of Contents

Return to Home Page

---

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[1]Correctional Service Canada. News Release: Correctional Service of Canada to Introduce Methadone Maintenance Treatment. Ottawa: The Service, 1 December 1997.

[2]Canadian HIV/AIDS Legal Network. Press Release: Correctional Service Failing to Respond to HIV Crisis in Prisons – World AIDS Day Brings Little Good News for Prisoners. Montréal: The Network, 1 December 1997.

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Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

---

# Task Force Calls for Methadone Maintenance and Needle Exchange in Prisons

**In its National Action Plan,[1] the Task Force on HIV/AIDS and Injection Drug Use renews calls for methadone maintenance and needle exchange programs in prisons.**

According to the Task Force, "[i]ncarceration is a risk factor for acquiring HIV, with few innovations being implemented which would improve the situation."[2] The Task Force emphasizes that the

> legal aspects of drug use, and their intersection with HIV/AIDS, have created an emergency situation in our prisons. Many injection drug users spend time in prison settings, either directly, because of drug convictions, or due to other criminal convictions related to that use.[3]

It points out that between April 1994 and August 1995, the number of known cases of HIV/AIDS in federal correctional institutions rose by 40 percent, and that rates of hepatitis C range from 28 to 40 percent. It continues by saying:

> It is a fact of life that inmates will continue to engage in high-risk behaviours. Unfortunately, administrative responses within federal and provincial correctional services aimed at preventing the spread of HIV have thus far been limited (Jürgens, 1996). With the majority of prisoners moving back to the community once their jail terms have been completed, the seriousness of this issue for all Canadians cannot be ignored.[4]

The Task Force concludes that "conditions in correctional settings must be improved"[5] by

- allowing prisoners who have been in a methadone maintenance program prior to incarceration to continue to receive such treatment in prison;

- ensuring that methadone treatment is available to opiate-dependent prisoners who were not receiving it prior to incarceration;

- instituting programs to evaluate the need for methadone maintenance therapy prior to prison release, and ensuring priority transfer to community programming on the outside upon release; and

- conducting needle exchange pilot programs in federal and provincial correctional settings.

Top of this page

Return to Table of Contents

Return to Home Page

ENDNOTES

[1]*HIV, AIDS and Injection Drug Use: A National Action Plan*. Ottawa: Canadian Centre on Substance Abuse and Canadian Public Health Association, 1997. A summary of the Plan can be found in this issue of the *Newsletter* (The National Action Plan on HIV/AIDS and Injection Drug Use: A Call for Action).

[2]Ibid at 8.

[3]Ibid.

[4]Ibid, with reference to R Jürgens. *HIV/AIDS in Prisons: Final Report*. Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1996.

[5]National Action Plan, supra, note 1 at 15.

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

---

# Methadone in Provincial Prisons in British Columbia

**In September 1996, the BC Corrections Branch officially adopted a policy of continuing methadone for incarcerated adults who were already on a prescribed methadone maintenance program in the community prior to incarceration.[1]**

Continuing methadone treatment of pregnant female inmates had been the standard for years, ever since it was recognized that methadone withdrawal causes an increased risk of miscarriage. But this was the first time in any correctional jurisdiction in Canada that methadone maintenance therapy was made available to inmates in a uniform way.

Previously, inmates admitted to a correctional centre on an approved methadone program would be withdrawn according to a medical protocol, under close supervision. However, it was felt that the withdrawal of methadone, though medically safe, might expose the inmate/patient to an increased risk of using injection drugs while in prison and also make it less likely or more difficult for him/her to resume participation in the methadone program after release.

The Corrections Branch adopted a very progressive, largely harm-reduction approach to the provision of methadone in prison. This came after a two-year period of consultation with experts in the field of addiction and communicable-disease transmission, and fourteen months of work by a multidisciplinary team, the BC Corrections Harm Reduction Committee. This committee of ten individuals was comprised of medical and nursing practitioners, correctional administrators, an alcohol and drug counsellor, correctional officers and a provincial occupational health and safety representative, and was chaired by the undersigned. The Harm Reduction Committee undertook the daunting task of performing a thorough review of the world harm reduction and addiction literature. It also embarked on an international, national and local consultation process with experts from both correctional and public health arenas, and received input and presentations from inmate committees, persons with AIDS societies, the BC Civil Liberties Association, the College of Physicians and Surgeons of BC, the Office of the Ombudsman, several medical and legal federal and provincial experts, the Provincial Advisory Committee on Methadone, and local medical practitioners, to name a few. Individuals involved with methadone and needle exchange programs in Swiss prisons were extensively consulted.

Committee members reviewed various written submissions and relevant documents and met monthly to listen to a wide range of speakers and guests. Anyone who wished to address the committee to express their views or ask questions was welcome. Following this, the committee considered all materials and discussed all aspects of the issue.

In the beginning, committee members' opinions were widely divergent and debate was often heated. But as the weight of medical, social, psychological and legal evidence grew, a truly amazing process of coming together occurred within the group. In the end, the committee was able to formulate a cohesive and unanimous set of recommendations that endorsed a spectrum of harm-reduction strategies. These included methadone, bleach, condoms, advice on safe needle use, addiction treatment and counselling, security measures, and comprehensive substance-withdrawal management. Needle exchange received the unanimous support of the committee as a medically valid harm-reduction measure. However, it was suggested that implementation be delayed in the correctional context because of serious labour relations issues and potential liability risks. Research into the best way to apply this strategy continues.

All recommendations of the committee were accepted by the Corrections Branch Senior Management, which proceeded with immediate implementation. A status report will be produced by the committee after one year's time. Bleach and condoms had already been available in BC correctional centres for several years and these measures were reinforced.

The committee proposed that methadone be made available in two phases. The first phase involves, as discussed above, the continuation of methadone treatment. The second phase, proposed for sometime after the successful completion of the first year of phase one, involves the initiation of methadone maintenance during incarceration or prior to release, for heroin addicts wishing this form of treatment. In both phases, extensive addiction therapy and counselling is strongly encouraged.

At the beginning of phase one, health-care staff had to go through thorough orientation on the prescribing and distribution of methadone. Physicians had to follow extensive training from the College of Physicians and Surgeons of BC in order to obtain their methadone authorization. This was not popular with everyone at first. Eventually, all physicians obtained their methadone authorizations and they now see methadone treatment as a necessary tool in the application of a comprehensive harm-reduction program and as a possible strategy on the road to abstinence.

The second phase of the methadone recommendation has yet to be implemented. A review and status report by the harm reduction committee is planned for late 1997, and the feasibility and value of initiating methadone treatment in prison will be ascertained. Methadone initiation requires highly skilled, well-trained practitioners, and frequent dosage reviews and adjustments in the first few months of therapy. Doctors have expressed concerns about the practical aspects of trying to stabilize short-term inmates and the difficulties with adequate follow-up in a high-movement, high-turnover population.

An interim solution that has worked well involves escorting inmates to their first and second appointments with experienced methadone practitioners in the community to begin planning their methadone therapy. Then, upon release, the patient is escorted to his/her next appointment, at which time s/he receives his/her first methadone prescription. Preliminary results show high initial compliance with this approach.

So far, methadone availability in BC Corrections has gone very well, though it has significantly increased the workload of health-care staff in communicating with local pharmacies, practitioners, and the College of Physicians and Surgeons, which manages the methadone program in BC. This is necessary in order to verify patients' histories and methadone dosages. As of early September 1997, 200 patients (58 female and 142 male) had been continued on methadone after incarceration.

According to BC Corrections methadone guidelines, urine drug screens are done on all methadone patients at the time of admission. In the overwhelming majority of cases, drug screens have shown the presence of a wide variety of substances other than methadone. Almost without exception cocaine and benzodiazepines (tranquilizers) are present. Most of our patients on methadone are still actively using injection drugs at the time of their incarceration. Though this is not necessarily a reason to discontinue their participation in the methadone program, it is a worrisome finding and certainly raises some questions about the effectiveness of current harm-reduction strategies in the offender population.

Encouragingly, during incarceration, urine drug screens on methadone patients are mostly negative for illicit drugs, despite the clear presence of such drugs in the prison context. This suggests that this group of patients can do well under certain circumstances. However, because of the very short duration of incarceration in a provincial correction system, long-term follow-up of these patients remains to be assessed.

- *Diane A Rothon, MD*

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Top of this page

Return to Table of Contents

Return to Home Page

---

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[1]See also C McLeod. Is There a Right to Methadone Maintenance Treatment in Prison? *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 2(4): 22-23.

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

---

# Death Exposes Treatment of Prisoners Living with HIV/AIDS

**A coroner's inquest into the death of a prisoner with AIDS revealed that he had died alone, "like a dog in a back kennel."[1] The coroner's jury issued a series of recommendations aimed at preventing a recurrence of the "unfortunate and regrettable circumstances" surrounding the prisoner's death.**

## The Circumstances surrounding the Prisoner's Death

On 15 May 1996, Billy Bell died from AIDS. He was 32 and a prisoner at Millhaven Institution in Kingston, where he had been chairman of the Inmate Committee. When he died, Billy was alone in his cell in the Regional Hospital Unit of Kingston Penitentiary. Billy, who was serving a five-and-a-half-year sentence, had been diagnosed with full-blown AIDS in early 1995, and soon thereafter with AIDS-related cryptococcal meningitis.

In September 1997, a coroner's inquest into Billy's death was held. At the urging of the Bell family, the Toronto-based Prisoners' HIV/AIDS Support Action Network (PASAN) sought and received public interest standing at the inquest. Billy had been a client of PASAN since 1995, and the organization had maintained contact with his family after his death. PASAN was represented by the HIV & AIDS Legal Clinic Ontario (HALCO).

At the inquest, a specialist from the HIV clinic at the Kingston General Hospital, Dr Sally Ford, testified about how the prison failed to provide Billy the quality care that her patients outside prison receive. The prison pharmacy would run out of doses of AZT and Billy would miss his dose days at a time. Billy experienced difficulty accessing proper pain management medication, lack of compassion from staff, and dangerous delays in the diagnosis of AIDS-related illnesses. It was a chaplain, not the prison health staff, who suggested that his chronic migraine headaches might be caused by the deadly meningitis.

In December 1995, six months before his death, Billy was sent to a halfway house in Toronto with no arrangements made to meet his medical needs. The halfway house had no medical staff and had never worked with someone as ill as Billy. Other prisoners placed plastic over chairs that Billy had sat on. By January 1996, Billy's parole was revoked because he was unlawfully at large – away from the halfway house. He had received permission to seek care in a hospital, but, when he could not get admitted, failed to return to the halfway house on time.

Billy was returned to Millhaven Institution, and was eventually sent to the hospital unit at Kingston Penitentiary, which houses all chronically ill prisoners in the region. Billy was terrified at the prospect of dying in prison. Despite his expressed wish that he not be left to die alone, and assurances to his family that the prison would contact them so they could be by his side, Billy died alone in his cell. The circumstances so outraged one of the prison chaplains that he left a note on a colleague's door, stating "Billy Bell died tonight, like a dog in a back kennel." Another prison chaplain resigned over the treatment Billy received.

## Problems

Billy's death highlighted many problems with how CSC deals with HIV/AIDS and with HIV-positive prisoners. At the inquest, PASAN chose to focus on two issues: palliative care and compassionate release.

## Palliative Care

The treatment Billy received during the later stages of his disease did not come close to meeting the recognized standards of palliative care in Canada, although CSC's own mandate states that the Service will provide health care to a standard "comparable to that in the community."

## Compassionate Release

Billy was denied parole only 19 days before his death. In its response to the Final Report of the Expert Committee on AIDS in Prisons, CSC stated that it would "recommend ... the release of inmates with progressive life-threatening diseases, including AIDS, earlier in the course of their disease, before they become terminally ill." However, this is seldom the case. It could be said that compassionate release does not really exist because CSC has no criteria, and no application process, for accessing it. What CSC calls "compassionate release" – the release of terminally ill prisoners a few days before they die – should more accurately be called "strategic release" – releasing prisoners so that they do not die on CSC property, thereby prompting a coroner’s inquest. In her summation to the jury, PASAN's attorney, Ruth Carey, suggested that

- CSC implement a real compassionate release process, including criteria and application and appeal processes; and

- compassionate release decisions be taken out of the hands of the National Parole Board (NPB), and that, instead, compassionate release applications be heard by tribunals combining representation from medical experts, community members, and the NPB.

### The Jury's Recommendations

At the end of the inquest, the coroner's jury issued a series of recommendations aimed at preventing a recurrence of the circumstances surrounding Billy Bell's death. The recommendations include the following:

- that CSC "review and upgrade their palliative care approach" to meet "the principles and practices developed by the Canadian Palliative Care Association";
- that pain management be available to prisoners;
- that proper pre-release planning be done;
- that "CSC revise its Compassionate Release Program ... to increase the influence of the palliative care team in the Parole Board's decision-making process";
- that all forms of testing, including anonymous testing, be easily and readily available to all inmates and staff; and
- that "CSC investigate needle exchange programs in other penal systems and consider a CSC pilot program."

The jury's findings are significant not only for their content, but because they were made by a group of randomly selected members of the Kingston community. Five members of the community, after hearing testimony on the AIDS crisis in the Canadian prison system, developed recommendations that mirror many of the recommendations previously made by experts and advocates. CSC has used fears of negative public reaction as an excuse to delay or deny necessary AIDS prevention and care programs (such as the introduction of needle exchange programs), but the results of this inquest clearly show that, when provided with the facts, "average" Canadians – and not just the experts and advocates – support and demand comprehensive AIDS programs for prisoners.

*- Rick Lines*

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Top of this page

Return to Table of Contents

Return to Home Page

---

## ENDNOTE

[1] A note written by Rev Arnold Main, prison chaplain, on 15 May 1996, after Billy Bell died from AIDS-related causes in prison.

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

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# The Case against Segregation in "Specialized" Care Units

Since the beginning of the HIV/AIDS epidemic, some people within governments and some public health officials have demanded the segregation of HIV-positive people. While such demands have become rare with regard to HIV-positive people in the general community, they continue to occur with regard to HIV-positive people living in prisons.

## Traditional Segregation

In some prison systems in the United States, mandatory HIV-antibody testing and forced segregation of HIV-positive prisoners is standard practice. In Canada, such measures have been consistently opposed and, instead, it has been recommended that a comprehensive strategy be adopted to respond to the needs of HIV-negative and the ever-increasing number of HIV-positive prisoners. Nevertheless, some within and outside the prison systems continue to discuss segregation as a solution to the HIV/AIDS crisis in Canadian prisons. In November 1996, the Commissioner of the Correctional Service of Canada (CSC), Mr Ole Ingstrup, told the Parliamentary Sub-Committee on HIV/AIDS that CSC does not consider mandatory testing or forced segregation as a useful part of their HIV/AIDS strategy.[1] Still, recent moves by provincial and the federal prison systems toward adopting elements of the US model - and a political climate that continues to scapegoat prisoners for societal woes - have raised concerns among AIDS and prisoners' rights activists about recent rumours within correctional systems concerning HIV and segregation. It seems as if a combination of elements - high rates of HIV prevalence among prisoners, the rising costs of treatment, and government cutbacks - has created a situation in Canadian prison systems where discussions about segregation are again coming to the fore. However, rather than being expressed in terms of a mandatory, forced segregation of HIV-positive prisoners - which would be seen as quarantine and subject to Charter challenge - today's discussions of segregation are framed in a more "benign" fashion.

## Segregation in "Specialized" Care Units

Within CSC, the concept discussed most often is the creation of "specialized" care units in one or several of the existing federal prisons. Such units would be specially staffed and equipped to address the health-care needs of people living with HIV or AIDS. HIV-positive prisoners could choose to be "voluntarily" transferred to such units, and thereby access "state-of-the-art" medical care. It is argued that creation of such units would save the prison system money, while at the same time providing prisoners with HIV or AIDS with access to specialized medical, social, and dietary supports.

While superficially this may seem like a good idea, a closer analysis reveals that, however well-intentioned, it has no place in an effective HIV/AIDS strategy. There are at least seven reasons for this.

### "Voluntary" Segregation Is Not Voluntary

"Voluntary" segregation at a prison providing specialized care is never voluntary. The very existence of a prison or prisons whose health-care unit(s) provide "specialized" care for prisoners with HIV or AIDS is an admission that other prisons provide less than optimal care. Therefore, prisoners with HIV or AIDS would have to chose between staying at a prison that may be closer to their friends and family, but where they receive less than optimal care, and being transferred to a prison that may be farther away, but where they may obtain "specialized"care. This is not a voluntary choice.

### Responsibility to Provide Health Care

CSC has the responsibility to provide consistent and adequate standards of health care in all its facilities. Their responsibility toward prisoners with HIV or AIDS cannot be fulfilled by opening one or a few specialized health units, but rather by ensuring that all health-care staff are trained and equipped to deal with the needs of prisoners with HIV or AIDS, and that prisoners in all institutions have access to care, support and treatment equivalent to that available outside.

It is feared that the existence of "specialized" units would result in the deterioration of the already inconsistent levels of care available to prisoners with HIV or AIDS in other penitentiaries, and would limit avenues for legal redress by HIV- positive prisoners and their advocates. For example, if a prisoner with HIV or AIDS refused the "voluntary" transfer and subsequently received substandard care or died in custody of AIDS-related illnesses, could the prisoner be seen to be at fault for not having "chosen" to access the "best" medical care offered by CSC (rather than the system being seen at fault for failing to provide a consistent and adequate level of medical care across the board)?

### Segregation Deters Testing

Fears about loss of confidentiality, stigmatization, and discrimination continue to be significant barriers that deter people from choosing to be tested for HIV antibodies. If prisoners know or fear that they would have to be transferred to another institution in order to receive optimal care if they tested HIV-positive, some prisoners will likely choose not to test rather than "choose" transfer and segregation.

In response to this concern, some people have argued that, in any case, prisoners should be mandatorily tested for HIV antibodies. However, in addition to raising serious Charter and human rights issues, mandatory testing would not allow prison systems to identify all prisoners with HIV: it can take up to one year after transmission of HIV before the antibodies that trigger a positive test result are produced. This means that in any testing program some people would test negative although they carry HIV and are infectious. Therefore, even if we leave Charter issues aside, mandatory testing is not justified because it cannot work in the manner its proponents claim.

### Stigmatization

Anyone who would serve time in a prison with a specialized unit would necessarily be "suspected" of being HIV-positive by all staff and prisoners in that prison and in other institutions. This would stigmatize all prisoners in that prison, regardless of their HIV status.

### False and Counterproductive HIV-Prevention Messages

The existence of such prisons would create the unrealistic and dangerous assumption among prisoners and staff at other prisons that all prisoners with HIV or AIDS are held in those special facilities. This could easily lead to the further assumption that (1) prisoners held in other prisons need not practise safer sex or safer needle use, and that (2) staff in other prisons do not need to use universal precautions because "there's no HIV"in their institution. Mandatory HIV testing of prisoners would only reinforce this dangerous assumption. Generally, the messages that would be given run counter to effective HIV-prevention education, and could lead to an increase in unsafe behaviours and HIV transmission.

### Problems in Security Classification

Federal prisoners in Canada are classified and housed in maximum, medium, or minimum security penitentiaries based upon their criminal records and incarceration history. However, HIV infection does not discriminate between security ratings. If there was only one institution, or few institutions Canada-wide, providing an adequate standard of care for people living with HIV/AIDS, how would they house a population with a variety of security ratings? Experience demonstrates that the institutions with "specialized"health-care units would most likely be classified maximum security, because prison systems are far more likely to hold minimum-security prisoners in a maximum security setting than vice versa (indeed, this is how it is done today in detention centres across Canada).

Housing lower-security prisoners (who are most often incarcerated for non-violent offences) with maximum-security prisoners (who are often incarcerated for violent offences) creates high-stress and potentially dangerous conditions, particularly for the lower-•security prisoners. Therefore, medium/minimum-security prisoners with HIV or AIDS could be placed in a position of not only having to "volunteer"to be segregated, but also to "volunteer"to be segregated in a higher-security institution.

### What Happened to Compassionate Release?

Segregation in a state-of-the-art medical prison is no substitute for compassionate release.

In March 1994, CSC stated that it agreed with the recommendation contained in *HIV/AIDS in Prisons: Final Report* that inmates with AIDS and other progressive life-threatening diseases "regularly be released earlier in the course of their disease, before they are terminally ill, and whenever they do not constitute a threat to public safety." [2] Prisoners living with AIDS have yet to see the concrete benefits of those fine words.

## Conclusion

The dangers and pitfalls of segregating people with HIV or AIDS from the general population are great, whether inside prison or not. Segregation for so-called "humanitarian" reasons and for the purpose of providing "specialized" care in one or a few institutions also carries many negative consequences. It does not serve the interests of prisoners living with HIV or AIDS. It will not reduce the rates of HIV transmission. It is bad policy.

- *Rick Lines*

Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTES

[1]See also J Dussault. Methadone and Sterile Needles Soon in Canadian Federal Prisons? Parliamentary Sub-Committee Hears Witnesses. *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 26-29 at 27.

[2] Correctional Service Canada. *HIV/AIDS in Prisons: Final Report of the Expert Committee on AIDS in Prisons*. Ottawa: Minister of Supply and Services Canada, 1994, at 107.

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

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# Evidence About HIV Transmission in Prisons

**Few studies of HIV transmission in prisons have been undertaken. Some have shown relatively low rates of transmission, while others have shown how frighteningly quickly HIV can spread behind bars.**

Studies of risk behaviour in prisons show that injection drug users (IDUs) account for one-quarter to one-half of prisoners. Approximately one-third to one-half of IDUs continue injecting drugs when imprisoned and virtually all injecting involves syringe sharing. Many inmates also use tattooing equipment and five to ten percent of male prisoners engage in sex while in prison. HIV prevalence is universally higher in prisons than in the surrounding communities. HIV prevention programs in prisons are limited. Yet some studies of HIV transmission in prison show low incidence rates. Some reasons for this are outlined in the following text, which was presented at the 3rd European Conference on Drugs and HIV/AIDS Services in Prison in Amsterdam in February 1997. The text then suggests ways to study HIV transmission in prisons.

## Evidence of Transmission

In at least three countries, HIV infection among IDUs has been associated with a history of imprisonment: in France (Richardson et al, 1993), Spain (Granados et al, 1990) and Thailand (Choopanya, 1996). In Bangkok, Thailand, HIV infection among IDUs rose from two percent to 43 percent between 1987 and 1988. The increase closely followed, and is believed to be due to, the release of hundreds of prisoners (including many IDUs) in an amnesty on the King's birthday (Choopanya, 1989; Wright et al, 1994; Choopanya et al, 1996).

A total of ten studies of HIV transmission in prison have been undertaken: two retrospective studies, four prospective studies, two mathematical models and two outbreak investigations (see Table 1).

### Table 1 Evidence of HIV Transmission in Prison

| Location | Study type | Reference |
|---|---|---|
| USA | 2 retrospective studies | CDC, 1986; Mutter, 1994 |

| | | |
|---|---|---|
| USA | 4 retrospective studies | Kelly, 1986; Horsburgh, 1990; Brewer, 1988; Castro, 1991 |
| UK, NSW | 2 mathematical models | Medley, 1992; Dolan, 1994 |
| Scotland | outbreak investigation | Taylor, 1995 |
| Australia | outbreak investigation | Dolan, 1996 |

### Retrospective Studies

In the first retrospective study, HIV testing was offered in 1985 to inmates who had been imprisoned in Maryland for at least seven years (Centers for Disease Control, 1986). Approximately one-third of inmates accepted testing. Of these, two (one percent) tested HIV-positive. Both had been incarcerated for nine years.

The second retrospective study was conducted in Florida in 1991. Medical files of 556 prisoners who had been continuously incarcerated for the past 14 years were examined. HIV test results were recorded in the files of 87 inmates. Of these, 18 were HIV-positive. Eight of the inmates were still asymptomatic at the end of 1991, after 14 years in prison, and it was assumed that they were probably infected in prison. However, some individuals are known to have been infected with HIV and be asymptomatic for more than 15 years (Deacon et al, 1995). Therefore, in both retrospective studies the evidence of infection occurring in prison can be said to be strong but not conclusive.

### Prospective Studies

In four prospective studies, HIV incidence in prison ranged from zero to four percent.

In the first study, one percent of 913 inmates in a US maximum- security prison was HIV-positive in 1983 (Kelley et al, 1986). Repeated testing of 542 inmates who remained incarcerated found no cases of HIV seroconversion. However, the sample was atypical of prison populations, with an underrepresentation of drug offenders (15 percent) and an overrepresentation (38 percent) of sex offenders. In addition, inmates in maximum security often have limited opportunities to associate with other inmates and to engage in risk behaviours.

In the second study, repeated testing of 1069 inmates in Nevada in 1985 found that three inmates had seroconverted in prison (Horsburgh et al, 1990). The 3 seroconverters had spent a relatively short time in prison when they last tested negative for HIV infection, and some of them may have been infected prior to imprisonment. The authors of the study concluded that HIV transmission among inmates was rare in Nevada (Horsbugh et al, 1990).

In the third study, Brewer (1988) tested 393 prisoners twice in Maryland in 1985 and detected two prisoners who had seroconverted in prison. The seroconverters had spent 60 and 146 days in prison when they had last tested negative for HIV infection. As in the previous study, it was not possible to determine with certainty that they had contracted HIV behind bars, although this was probable. In the study, inmates who refused to participate or were missed at follow-up were significantly more likely to have committed a drug offence, to be black, or to have received sentences of less than five years. As these characteristics were associated with HIV infection at entry, it is likely that those most at risk of HIV infection were underrepresented in the study. Using the results of this study, Hammett calculated that up to 60 new cases of HIV infection were occurring annually in the Maryland prison population (Hammett et al, 1993).

In the fourth study, HIV prevalence among prison entrants in Illinois was 3.9 percent (n=2390) in 1989 (Castro et al, 1991). After one year in prison, eight inmates had seroconverted. The evidence of transmission in prison was strong, but again acquisition of infection prior to incarceration could not be excluded. The study relied on mass screening of prisoners serving sentences of at least one year, meaning that short-term prisoners were excluded.

## Mathematical Models

Two mathematical models have calculated the level of transmission in prison in England and New South Wales, Australia (Medley, Dolan and Stimson, 1992; Dolan, Wodak, Hall and Kaplan, 1994). Both studies estimated the number of prisoners with a history of IDU, the number who continued injecting in prison, and the proportion of the latter who shared syringes. The prevalence of HIV and the number of syringes in circulation were taken into account. Both studies estimated that two percent of sharers would become infected each year.

## Outbreak Investigations

### Glenochil Prison

Taylor (et al, 1995) investigated an outbreak of HIV in Glenochil prison, Glasgow in 1993 (see Table 2). Before the investigation began, 263 of the inmates who had been at Glenochil at the time of the outbreak had either been released or transferred to another prison. Of the remaining 378 inmates, 227 were recruited into the study. Recruitment ranged from 26 to 51 percent across 11 subunits at Glenochil. Anecdotal reports suggest that many inmates who were not recruited were injectors from one particular subunit where injection was prevalent (Scottish Affairs Committee, 1994). Of the 227 inmates recruited, 76 reported a history of injection and 33 reported injecting in Glenochil prison. Twenty-nine of the latter were tested for HIV, with 14 testing positive. Thirteen had a common strain of HIV and it is therefore proven that they became infected in prison (McMenamin et al, 1996). All IDUs infected in prison reported extensive periods of syringe sharing (see Taylor and Goldberg, 1996).

## Table 2 HIV Outbreak in Glenochil Prison

| | **Inmates** | **Percent** |
|---|---|---|
| Inmates when outbreak occurred | 645 | 100 |

| | | |
|---|---|---|
| In Glenochil at study outset | 378 | 59 |
| Recruited | 224 | 35 |
| History of injecting | 76 | 12 |
| Injected in Glenochil | 33 | 5 |
| Tested for HIV | 29 | 4.5 |
| Tested HIV-positive | 14 | 2.2 |
| Same strain of HIV | 13 | 2.0 |

The Scottish Affairs Committee speculated on the extent of the outbreak in Glenochil prison after discussions with prison medical officers. The Committee assumed that, if inmates who declined testing were as likely to be injectors and to have become infected as inmates who were tested, the total number of inmates infected during the outbreak could be between 22 and 43 inmates.

**Australia**

Epidemiological and genetic evidence was used to confirm an outbreak of HIV in an Australian prison (see Table 3). Criteria for establishing that HIV infection had indeed occurred in prison included: HIV-antibody test results, documented primary HIV infection (Kinloch, 1993) assessed by a panel of HIV experts, time and location in prison, risk behaviour in prison, and genetic relatedness of HIV sequences obtained from respondents. Attempts to trace 31 IDUs resulted in 25 being located. Of these, two were HIV-negative, seven were deceased, two declined to participate and 14 were enrolled. It could be proven that eight of the 14 were infected with HIV while in prison. All of them reported sharing syringes, two also reported tattooing and one reported engaging in anal sex.

**Table 3 HIV Outbreak in an Australian Prison**

| | |
|---|---|
| Attempted to trace | 31 |
| Found | 25 |
| HIV-negative | 2 |
| Deceased | 7 |

| | |
|---|---|
| Declined | 2 |
| Enrolled | 14 |
| Infected in prison | 8 |
| Same HIV strain | 5 |

### Discussion

The retrospective and prospective studies found relatively low levels of HIV transmission in prisons, while the mathematical models and the outbreak investigations found much higher levels. There are several reasons for this: (1) Four of the retrospective and prospective studies were conducted before 1986, early in the HIV epidemic, when rates of HIV among IDUs were still relatively low; it is therefore not surprising that they found lower rates of transmission. (2) Retrospective and prospective studies probably result in a biased sample: they sample long-term prisoners, who are less likely to be IDUs. In fact, studies have shown that IDUs experience shorter but more frequent prison sentences than non-IDUs (Dolan et al, 1996; Gore, 1995). In addition, long-term inmates are usually held in higher-security prisons than short-term prisoners and will have less opportunity to associate (and become infected).

### Ways to Study HIV Transmission in Prison

In many countries conclusive evidence of HIV transmission among inmates is needed before adequate prevention measures will be implemented. If the cooperation of prison authorities can be secured, then examination of medical files may reveal cases of HIV transmission having occurred in prison. New cases of blood-borne viral infection can be followed up, as in the outbreak study undertaken by Taylor. Alternatively, a short-term cohort study could be undertaken among IDU inmates who would be tested regularly for HIV infection.

If co-operation from prison authorities cannot be secured, ex-prisoners – in particular, HIV-positive ex-prisoners – can be studied. It may be possible to gain access to their prison medical files if subjects are willing to provide consent.

### Conclusions

HIV transmission does occur in prison, but it is difficult to gather conclusive evidence. On occasion the lack of evidence has been interpreted as transmission being rare (Brewer, 1992; Braithwaite et al, 1996; Horsburgh, 1990). However, most of the studies that have reported relatively low levels of HIV transmission in prison were conducted early in the HIV epidemic and sampled long-term prisoners who would have been at less risk of infection than short-term prisoners.

Efforts to reduce transmission in prison need to focus on reducing the prevalence or frequency of injecting (eg, through low-threshold methadone maintenance programs); the risk of infection (eg, through syringe exchange and/or bleach programs); and the number of inmates at risk of infection (eg, through diversion programs).

– *Kate Dolan*

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Fax: (61-2) 9398 9333; email: ndarc8@unsw.edu.au. For a summary of the above text (in English, French and German), see the *Report of the 3rd European Conference on Drug and HIV/AIDS Services in Prison, February 1997, Amsterdam, The Netherlands*. London, UK: Cranstoun Drug Services, 1997, at 19-21.

---

Top of this page

Return to Table of Contents

Return to Home Page

---

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Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

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# Prison Privatization and HIV Prevention in Australia

Prison privatization is increasingly being discussed in Canada, particularly in Ontario. Are the goals of privatization - saving costs, in particular - compatible with the state's moral and ethical responsibility for determining and allocating punishment? And what could the consequences of privatization be for provision of care to HIV-positive prisoners and for HIV prevention in prison? The following article summarizes the results of a recent Australian conference on prison privatization. It warns that HIV-prevention strategies may not be adequately addressed in the process of contracting out health services to private contractors.

The Australian Institute of Criminology hosted a conference entitled Privatisation and Public Policy: A Correctional Case Study in Melbourne, Victoria on 16 and 17 June 1997.[1] The conference was prompted by public concerns about crime and by policy responses to those concerns, including trends in sentencing legislation that have resulted in offenders spending longer periods of time incarcerated and a marked increase in the prison population. This increase has been accompanied by moves toward privatization or contracting out of correctional services in all Australian jurisdictions.

The conference was attended by academics and policymakers from relevant state departments and agencies, and by correctional and management personnel from both the public and private sectors. It was also attended by representatives of the People’s Justice Alliance, a local activist organization that coordinated protest actions outside the conference venues to call attention to problems in the administration of private prisons in Victoria.

## Prison Privatization in the Australian Context

In Australia most criminal law and the criminal justice system itself are the responsibility of the various states. With the exception of a remand facility in the Australian Capital Territory, there is no separate federal system of corrections, and the terms prison and jail are interchangeable. Offenders convicted of federal crimes such as customs violations, or who offend within the geographic boundaries of the Australian Capital Territory, are incarcerated in New South Wales facilities under a contractual arrangement between the Commonwealth and State governments. The costs of their imprisonment are borne by the Commonwealth, and the terms of their sentences and parole conditions may differ in some respects from those of New South Wales prisoners housed in the same institutions.

Private-sector involvement in corrections has a long history in the Australian context. The first European residents to arrive in the late eighteenth century - convicts and related custodial, medical and administrative personnel - were transported from England on privately owned and crewed ships that were contracted for the purpose by the Admiralty Office. Those contracts were monitored on the voyage by representatives of the Admiralty, usually the Surgeon Superintendents responsible for the health and welfare and, in the case of women convicts, also the discipline of the prisoners.

The division between medical authority, vested in the Surgeon Superintendents, and the custodial authority of the various police corps, represented in the convict transports a system of parallel, and often competing, philosophies of penalty that had begun to develop in England in the second half of the eighteenth century in response to reform movements. Legislation providing for systematic health services to prisoners was roughly contemporaneous with the beginning of transportation of convicts to New South Wales.[2] A form of this division survives in contemporary Australian corrections, where prisoners' health services are provided by the various State Departments responsible for health, operating within the institutions under the surveillance and scrutiny, and subject to the operational procedures, of the respective justice and/or correctional departments.

The operation of the criminal justice system, and in particular the administration of correctional facilities, has traditionally been the responsibility of the state. However, there has been an upsurge of private-sector activity during this decade, employing models of privatization ranging from contracting out of specific services such as training of custodial staff or inmate industries and program delivery, to fully operational prisons built, owned and operated by private companies and consortiums.

At present, prisons in Australian states are owned and managed on the corporate model by private and two state-owned corporations: CCA, ACM, Group 4,[3] and CORE (state owned) in Victoria; ACM in New South Wales; CCA, ACM, and QCORR (state owned) in Queensland; and Group 4 in South Australia.

The balance of private- and public-sector activity in correctional services is determined by the political ideology of the respective state governments. For example, New South Wales, which currently has the only Labour government in Australia, maintains one private prison that was built by the former Conservative government, and contracts out limited local services for prisons and some aspects of community corrections. By contrast, the present Victorian government, with a conservative and aggressively market-based ideology, is not only engaged in contracting out construction and operation of institutions, but was also the first state to restructure its department of corrections on a corporate model, and now requires it to compete for custodial and program delivery contracts along with private companies.

## Conference Themes

The major themes running through all the conference sessions were "access", "accountability" and "confidentiality", terms that clearly carried divergent meanings across sessions and speakers. Parties directly involved in the processes of contracting out correctional centres and services construed them in terms of financial competition: access to information about tenders, administrative procedures and operational practices where that information might allow a competitor to calculate running costs, etc; accountability of service providers to the state for fulfilling the terms of their contracts, and penalty provisions for non-performance; confidentiality of any and all information that might be useful to a market competitor.

Others, such as visitor and prisoner representatives, were concerned about community access to prison facilities, prisoners themselves, and custodial and health records. Accountability, in this framework, referred to prison managements' responsibility toward prisoners and the community for providing humane conditions and adequate health services. Concerns about confidentiality related to the practice of some private prison managements of refusing to disclose a wide range of non-fiduciary information about their institutions and inmates under "commercial in confidence" claims that transparency of operations would compromise them in relation to their market competitors.

Justice Frank Vincent of the Victorian High Court,[4] and a number of academics, expressed their concern that commercial construction of the issues may pose a challenge to the nature of the democratic state itself, by obscuring the ethical and moral responsibilities of the state for determining and allocating punishment and discharging the resultant duty of care owed toward those it incarcerates, and also by clouding the fact that all parties - public and private correctional services, state departments, health-service providers and judicial systems - must be accountable in the final analysis to society.

## Privatizing Health Services

The conference session on Health and Special Services: Models for Managing Health and Special Services in a Multiprovider System, included papers on a violent-offenders program outsourced by the Western Australian government[5] and two models for contracting out total prison health services. South Australia, which already contracts out the management and operation of one men's prison as well as Prisoner Movement and In Court Management services, is in the process of developing its preferred model for private-sector management of health services. It is currently engaged in defining stakeholders and clients, and identifying issues and needs. Bloodborne communicable diseases (BBCDs) such as HIV/AIDS and hepatitis B and C are among the issues being examined. However, no details were given about the scope of BBCD-related treatment, prevention, education, etc, that are likely to be included in contractual agreements for privatized health care.[6]

The Victorian Government is currently in the process of implementing full private-sector health services for all prisons in the state.[7] The state-owned corporation (CORE) runs ten prisons, and an additional four institutions are run by three private-sector prison operators. Primary (clinic-style) health services in state-managed prisons have traditionally been provided by the state department responsible for health, but are now to be outsourced to individual accredited health-care providers (AHCPs). Primary health services in private-sector prisons are outsourced by the company, thus setting up an extra level of contracting and administration between the state and the prisoners who use the clinic services. Secondary health services for all prisoners in the state are to be provided in hospital facilities managed by contracted providers through their associated AHCPs, and located within privately managed prisons - one male and one female institution. Tertiary health-care (specialist and emergency) services are to be provided within major hospitals through AHCPs contracted to prison-management providers.

Health-care specifications for contracting out prison health services in Victoria are based on the requirement that "health care facilities and services [be] provided for prisoners to a community standard, while also taking into account the special health needs of prisoners [eg, drug abuse and mental health issues]." Explicit requirements relevant to bloodborne diseases include: provision of (unspecified) HIV/AIDS services at secondary-care level; provision of infection-control programs (to accepted hospital standards), including education of staff and prisoners in infection control; ensuring that infected or potentially infectious prisoners and staff are managed, counselled, referred and tested as required; provision of methadone to prisoners, but only if they are already on an established program and on remand, serving less than six months’ total sentence, pregnant, or on a methadone reduction program (ie, new prescriptions and methadone maintenance are prohibited).

While the specifications, including contract monitoring and policy advice provisions, are reasonably explicit in relation to treatment services, their implications for public health and behaviour-focused preventive programs are less clear. From the beginning of the HIV/AIDS epidemic in Australia, the political response has been characterized by a public health perspective and strong commitment to harm minimization, including promotion of safe sex and safe injecting practices, easy availability of condoms, dams and injecting equipment through pharmacies and needle and syringe exchanges, education and legislation covering infection-control measures related to tattooing and body piercing, together with a wide range of targeted and general public education campaigns. It is arguable then that, in the Australian context, HIV-appropriate health services "to a community standard" must include availability of condoms, access to needles and syringes and other injecting and/or cleaning equipment, either for purchase or on an exchange basis, and tattooing equipment sterilized to hospital standards - none of which are available to prisoners in Victoria or in the majority of Australian prisons.

### Health-Service Models and HIV

In terms of care and prevention programs for HIV/AIDS and other communicable diseases in prisons, the New South Wales model is the most comprehensive and successful in Australia. In 1987, at the first indication that HIV/AIDS might present a problem in prisons, the New South Wales Department of Corrective Services established the Prison AIDS Project (now the HIV and Health Promotion Unit, HHPU), a dedicated unit set up to address all aspects of the impact of the epidemic in the state’s prisons. The unit has strong formal links with the Corrections Health Service, which provides prison health services, including methadone maintenance as an HIV-prevention strategy. The HHPU provides information and education programs for staff and inmates, peer education for prisoners, and occupational health and safety training and resources for custodial officers. It manages a "time out" program for positive prisoners, bleach distribution for cleaning injecting equipment, and it has completed a successful condom distribution trial that is to be expanded to all NSW prisons.

These programs have taken a long time and a lot of lobbying and negotiation to achieve and, while the NSW prison program is far in advance of other states, it still lags behind community standards. Prison programs based on harm-minimization principles have evoked strong negative responses in custodial staff and inertia in politicians, despite Australia's national commitment to the model.[8] The HHPU's success so far can be attributed to a number of factors that are unlikely to be achievable under a contract model of health-service provision.

The HHPU has formal ties to both the Department of Corrective Services and Corrections Health, meaning that it is within the security cordon of both bodies, and notionally has access to internal information and practices of both departments. Staff of the unit have access to prisons and prisoners on an internal staff basis, and the HHPU is not screened from the processes of policy and decision-making by security or "commercial in confidence" barriers, as would be the case for any similar service that might be outsourced to the private sector. In a dual system of custodial and health services, where each state agency may separately contract services out to private-sector providers, it seems inevitable that lines of communication and responsibility become attenuated, and that providing programs such as HIV education and prevention will fall outside the jurisdiction of any of the parties.

The working brief of the HHPU is not limited by commercial contractual requirements. The unit has demonstrated that it has flexibility to engage in negotiations and other activities as the need arises. It is not appropriate or possible to impose the same type of specification and performance monitoring on public and preventive health services that can be applied to custodial management contracts. The very process of defining contract specifications in terms that are quantifiable and able to be monitored and evaluated is contrary to the characteristics and scope required for effective public health programs. Therefore, it seems more likely than not that HIV-prevention strategies will not be adequately addressed in the process of contracting out health services.

HIV/AIDS has already emerged as a problem for privatized custodial services, with the management contract of at least one private prison (Borallon in Queensland) exempting the provider from having to accept HIV-positive inmates.[9] There are obvious problems in guaranteeing such a provision: it requires coerced HIV testing of inmates before transfer (notwithstanding limitations related to the window period and post-test risk activity), and it promotes the impossible notion that this (or any) prison can be infection-free.

The Australian Institute of Criminology listed the link between rising prison populations and increasing privatization foremost among its reasons for convening the conference. It is stating the obvious to note that private corporations expect to make profits from running prisons, although one speaker representing a private-sector operator claimed that the profits to be gained per "bed" are not large. The logical inference to be drawn is that corporations rely for their profitability on economies of scale. What, then, are the implications for public health and HIV programs in private-sector prisons, when the whole purpose of the programs is to reduce the need for services by preventing transmission?

*- Jan Cregan*

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Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTES

[1]See: Australian Institute of Criminology. Conference Proceedings, *Privatisation and Public Policy: A Correctional Case Study*. Melbourne, 16-17 June 1997.

[2]J Sim. *Medical power in prisons: The prison medical service in England 1774-1989*.. Open University Press: Milton Keynes; 1990.

[3]ACM: Australasian Correctional Management (through Wackenhut Corrections Corporation), subsidiary of Wackenhut Corporation, USA; CCA: Corrections Corporation of Australia (Corrections Corporation of America); Group 4 Corrections Services: Netherlands-Antilles based multinational corporation.

[4]Justice Frank Vincent, Supreme Court of Victoria, conference paper: Contracting out Community Corrections: The Judicial Perspective.

[5]G Hall, conference paper: The Delivery of Specialist Services: A Western Australian case study.

[6]M Boswell, conference paper: Managing Health and Special Services in a Multiprovider Environment.

[7]M Burt, conference paper: Models for Managing Health and Special Services in a Multiprovider System.

[8]For a discussion of this resistance, see J Cregan, S Kippax, J Crawford. Sex, Contagion, Control: Prison Officers vs Condoms in New South Wales Gaols. *Australian and New Zealand Journal of Criminology* 1996; 29(3): 227-246.

[9]RW Harding. Trends and Issues in crime and criminal justice - No 36. *Private Prisons in Australia*, May 1992. Canberra: Australian Institute of Criminology, 1992.

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

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# Prescribing Narcotics to Drug-Dependent People in Prison: Some Preliminary Results

**Based on a series of federal measures dated 20 February 1991 and designed to reduce problems relating to drug use, since January 1994 Switzerland has been testing the prescription of narcotics under medical control to drug-dependent people. The *Project for the prescription of narcotics under medical control in prisons* (PSTEP) is a distinct component of a broader research plan involving these scientific trials (see "Swiss Government Report: Heroin Prescription Works" in this issue). How it rates on evaluation will determine whether the prescription of narcotics under medical control is feasible in prisons.**

## The Project

The Oberschöngrün penitentiary at Soleure has 75 prisoners. To be eligible to serve one's sentence at Oberschöngrün, a prisoner may not constitute a danger to society or be an escape risk. PSTEP allows the establishment to play an active role in the social reintegration of prisoners. It also makes it possible for drug-dependent inmates to feel better, to have the possibility of becoming stable in prison without the physical and psychological stress of maintaining a supply of drugs, and to escape from the vicious circle of scoring/using that is closely linked with crime.

## Implementation and Operation of PSTEP

Drug-dependent prisoners whose criminal behaviour is related to drug addiction are eligible for PSTEP. Because their conduct remained "deviant," they could not be housed in an "ordinary" prison and thereby take advantage of the possibilities it provided for social integration. Participation in the trials was a voluntary decision: prisoners were not formally invited or encouraged to participate in them, but were simply informed of their existence.

To be eligible to participate, one had to be at least 20 years of age (exceptionally, 18); to have been drug-dependent for at least two years; to have unsuccessfully undergone therapeutic treatment and/or have good reason to believe that treatment according to existing therapies would fail; and to present with medical, psychological and/or social deficits due to dependence. Candidates had to give consent in writing after being informed of the analyses and studies that were going to be carried out. An additional selection criterion was illegal consumption of heroin while incarcerated. In order for the scientific research to be meaningful, candidates had to be incarcerated for at least nine months. They could not have been sentenced to expulsion from the country, and the legal authorities had to have given their consent to participation in the trials and to reintegration of the prisoner in the event of exclusion from the project. Furthermore, participants had to be able and willing to work with animals on a farm.

During the course of the project, the eight participants lived and worked in an annex partially isolated from the other prisoners, three kilometers from the Oberschöngrün prison. The building was not fenced in and, seen from the outside, didn't look like a prison. Each prisoner received heroin three times a day for self-injection in a hand-over area specially designed for cleanliness and safety. The nurse and a staff person were present when the heroin was handed over. A few nurses were hired to handle the heroin, but the other project-related tasks were handled by prison staff.

The participants did farm work and were trained and supervised by professional instructors. The prisoners' working hours were based on the requirements of running a farm, which meant that they worked seven days a week. Work began at 5:30 am, two hours before the first dose of heroin.

## First Results

The results presented below derive from qualitative analyses[1] and are grouped into themes that, in our view, clearly highlight the major implications of such trials for a prison establishment. The results are based - where not otherwise indicated - on data gathered during interviews, reworked and systematically classified. The categories are based on the statements of all the people connected with the prison and thus reflect to some extent their perception of their own reality.

The project began on 8 September 1995, and there was a three-•month (September-November) pilot phase with four participants. Following an adaptation period that enabled the people involved to become used to the new situation, the project continued until March 1996 without any serious incident other than a medical problem with one participant who, after the first shot of heroin, had to be resuscitated.

### Capacity for Work

At the beginning, the expectations concerning the amount of work participants would do were barely met; some participants were not able to meet the requirements at all. This was due partly to the sedative effects of the heroin and partly to the fact that several of the participants had never really worked, not having completed their vocational training or engaged in paid work for any length of time. After a few weeks, their performance improved considerably, meeting expectations. Before the trials began, there were doubts about the capacity for work of the prisoners who were going to receive heroin. It was feared that they would be passive, too affected by the heroin, with less motivation to work than the others. But

the results were positive and the capacity for work under the controlled use of heroin is no longer in doubt at Oberschöngrün prison: the prisoners using heroin can work in a way indistinguishable from the other prisoners as long
as the dose doesn't have overly sedative effects or create a withdrawal attack.

## Intra-group Conflicts

According to the participants, the greatest difficulties came from "intra-group conflicts," but the problem became less serious. Various kinds of frustration fueled the conflicts between the participants: teasing when the heroin was being handed out, certain participants dominating others during daily activities, being forced to do others' work, verbal abuse, denunciations or threats of denunciation, dishonest behaviour, and threats of violence. The inability of the participants to find constructive solutions to their conflicts was striking and almost always led to confrontation or escape from confrontation.

The prison tried to alleviate the climate of conflict within the group by holding "weekly group discussions." These discussions were perceived as clear and comforting by the staff people; participants considered them in various ways, sometimes conciliatory and sometimes without any really concrete effects. The prison reacted to these situations by "keeping rivals apart" during heroin distribution and by "transferring the agitators" who, at the outset of the project, lived in the annex without participating in the project. In addition, the introduction of television sets into the cells allowed participants to avoid others by going to their own cells.

Both the participants and the staff people attributed these conflicts to the general context of the project, including the following facts relating to the intra-group conflicts:

- the "suppression of stress connected with the supply of the drug "changed the relationships between the participants, given that they were no longer dependent on each other to obtain or distribute heroin in the prison. Because the situation among the participants was no longer based on social dependence, conflicts increased;
- these drug addicts had been dependent for a long time and were thus part of "a group of individuals with serious social deficits."For this reason, living together was necessarily very difficult; and
- the participants lived in a "forced community" with few possibilities of avoiding others.

The conflicts that arose in the context of PSTEP are typical of prison settings, but aggravated in this case by the fact that the participants were incarcerated together and could only avoid each other by withdrawing to their own cells. In cases of highly dysfunctional adaptation, it is assumed that the participants could also have serious problems adequately managing pressures and conflicts after release. This runs counter to the reintegration efforts that are part of the project. From a therapeutic point of view, it seems necessary to provide the participants with socio-pedagogical support so that they can learn certain social rules. From another point of view, it is difficult for a prison to treat a group of prisoners "differently" from the others, because this can undermine its credibility and create conflict with organizational objectives.

## Implementation of the Project

In interviews, how the staff people expressed how they perceived and judged the organization and carrying out of PSTEP was based on their job functions. From the theme "functioning of the organization," we have selected a few "problematic" topics that, in our view, are particularly interesting.

### Unilateral Decision by the Prison to Adopt the Project

In order to carry out the project, the institution had to make a considerable extra effort. The staff people responsible for the project were overworked and had to neglect other tasks. The priority given to the project created opposition among staff and prisoners who were not involved in the project.

### Flexibility Instead of Regularity

Thanks to a real organizational effort at the start of the trials, it was possible for the organization to adapt quickly and with flexibility. The flexible use made of the original idea was well-accepted and encouraged by those responsible for the project. Other staff people, however, criticized it as a "lack of regularity."

### Conflicts of Roles and Objectives

This type of conflict became more pronounced. For some of the staff people, the objective and the path followed with heroin prescription was in contradiction to the idea of the reintegration of drug-dependent prisoners. This was also evident in the standardized survey of "the objectives of a prison" given to staff people, who agreed that it was necessary to reintegrate prisoners through work, occupation, order, readiness to discuss things, motivation, and prevention. At Oberschöngrün, everybody agreed in saying that maintaining order and security, as well as a consistent attitude toward prisoners, were important goals. On the other hand, opinions varied on the punitive aspects of prison sentences and on the special attention and treatment given drug-dependent prisoners. Similarly, the question of whether Oberschöngrün prison should be a pioneer in the field was a matter of heated discussion.

## Preliminary Conclusions

Based on the results of the interim report, we can say that despite initial doubts, prescribing heroin under medical control in prisons is feasible. All the medical and social problems could be resolved in a satisfactory way. In spite of the above-mentioned social problems, the participants experienced an improvement in their quality of life. After a few start-up problems, adapting to the requirements of the prison sentence was considered to be satisfactory by the prison staff. For the prison itself, this pilot project was a major challenge that, thanks to the extra efforts of motivated and available staff, could be carried out successfully.

In the face of such a challenge, the fact that problems were encountered is not surprising: a prison, by its very structure, is a totalitarian and authoritarian environment that aspires to stability more than to flexibility, an environment where a hierarchical system of functioning confronts a prisoner subculture. The interactive space in such a system is limited, and the forms of interaction are rather stereotyped. In the view of staff people, order, the regular and consistent treatment of prisoners, and stability and the predictable operation of the system are the priority and, from this point of view, PSTEP could have appeared to constitute a threat to the objectives of a traditional institution and to the normal operating of the system. In terms of the traditional objectives and functioning of a prison establishment, the prescription of heroin is a remarkable and rather daring act: the project radically changed the relationship between the prison and the participants. The prison made an official pact with this prisoner group in the "subcultural" realm of narcotics use, which it had until then pursued repressively. Oberschöngrün prison did this and understood this to be a step toward the "reintegration" of drug-dependent prisoners. In this respect, it must have recognized that the traditional, punitive approach to resolving drug problems in prison had run counter to its reintegration policy and had failed with respect to drug-dependent prisoners. The initiative of prescribing heroin is a courageous act for a prison establishment. Consequently, it is not surprising that there were heated discussions on the subject. With the prescribing of heroin and the removal of the stress connected with maintaining a habit, basic progress was made with the participants with a view to reducing harms. The participants were able to escape from the vicious circle of scoring and using drugs. In this way an important condition for the reintegration of drug-dependent criminals was met. It remains an open question whether the participants can learn a way of behaving socially that will enable them to take charge of their lives after release if they are not offered a more active social support framework.

For the prison, the question arises as to the degree to which it wishes to and must have a therapeutic function. This touches on the old and insoluble conflict between punishment, limitation of freedom and paying one's debt to society on the one hand, and reintegration on the other. These differences of opinion exist not only with respect to prison sentences but, more generally, to society: what should be done about drug-related problems? Prisons must necessarily deal with this dilemma, because both goals - that of punishment and that of reintegration - exist and cannot be denied. There are always some prison staff who identify, depending on what they do, with one or the other of these goals. But each prison, and each society, must find its own solution to this paradox. For Oberschöngrün prison, it seems that it is important to join these two objectives that might appear opposed, so that its ability to function is not put in doubt, as could have been the case in simply maintaining longstanding conflicts of roles and objectives.

- *Beat Kaufmann, Réjane Drelfuss, Anja Dobler-Mikola*

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Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTE

[1] The results presented here are based on the research period that began in September 1995 and ended in March 1996. They are part of the intermediate report by B Kaufmann, A Dobler-Mikola. Die kontrollierte Opiatabgabe in der Strafanstalt Oberschöngrün: Forschungsplan und erste Ergebnisse. Ein Sonderbericht im Rahmen des zweiten Zwischenberichtes der Foschungsbeauftragen Uchtenhagen A, Gutzwiller F, Dobler-Mikola A (Hrsg). Institut für Suchtforschung in Verbindung mit der Universität.

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

---

# US – Prisoner Contracts HIV in Prison

**A federal district court in St Louis acquitted several prison officials of violating the civil rights of a former prisoner who apparently contracted HIV in prison.**

The 29 August 1997 verdict in the lawsuit by the former prisoner is not the final word in the case, since the jury failed to reach a decision with respect to two of the co-defendants, and a new trial will be set for them.

The former prisoner tested HIV-negative when first incarcerated in Menard Correctional Center after conviction for car theft and burglary. He claims that he was made a sex slave by fellow prisoners and repeatedly raped. He first tested HIV-positive a year after his admission. After testing positive, he was transferred to another prison, where he had surgery on his rectum for what he claimed were injuries due to rape.

In order to win damages in his US$1.5 million federal torts suit, the former prisoner had to persuade the jury that prison officials showed deliberate indifference to his well-being. Prison witnesses testified that the former prisoner never complained about being sexually abused while at the Correctional Center, and that he had actually declined an offer of protective custody.[1]

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Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTE

[1]Reported in *Lesbian/Gay Law Notes* October 1997, at 155, with reference to *St Louis Post-Dispatch*, 30 August 1997.

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

---

# Australia – Reform Urged in South Australian Prisons

**The South Australia (SA) Parliament's Social Development Committee has recommended that condoms, bleach, a methadone maintenance program, and safe tattooing procedures be introduced to SA prisons.[1]**

SA Health Minister Dr Armitage has promised "due and serious consideration" of the recommendations, contained in the Committee's report *HIV/AIDS, Hepatitis B and C: The Rights of Infected and Non-Infected Persons.*

The report found that prisoners in SA do not have access to measures (such as condoms and needle and syringe exchange) that have successfully reduced the spread of HIV and hepatitis C outside of prisons. It states that "the rights of prison inmates to remain uninfected was severely compromised under existing conditions."

---

Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTES

[1]Reported in the [Australian] *HIV/AIDS Legal Link* 1997; 8(2): 4.

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

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# HIV Prevention in South Australian Prisons

**The South Australian Parliament's Social Development Committee has recommended that condoms, bleach for cleaning needles, a methadone maintenance program, and safe tattooing procedures be introduced to South Australian prisons.**[1]

South Australian Health Minister Dr Armitage has promised "due and serious consideration" of the report *HIV/AIDS, Hepatitis B and C: The Rights of Infected and Non-Infected Persons*.

The report found that prisoners do not have access to measures (such as condoms and needle and syringe exchange) that have successfully reduced the spread of HIV and hepatitis C outside of prisons. The report states that "the rights of prison inmates to remain uninfected was severely compromised under existing conditions."

---

Top of this page

Return to Table of Contents

Return to Home Page

---

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Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

---

# New Publications on AIDS in Prisons

**The concern about the growing epidemic of HIV/AIDS behind prisons is reflected in an ever-increasing number of publications on HIV/AIDS and drug use in prisons, some of which are briefly reviewed in the following text.**

## UNAIDS Publishes Its Point of View on Prisons and AIDS[1]

In April 1997, the Joint United Nations Programme on HIV/AIDS (UNAIDS) published an extremely useful set of two documents on HIV/AIDS and drug use in prisons around the world, with basic information about the issues, challenges, responses, resources, and UNAIDS' point of view. This is probably the best summary available on HIV/AIDS and drug use in prisons. The *Point of View* and the *Technical Update* are available in English, French, Russian, or Spanish from a UNAIDS Information Centre. To find the closest one, visit UNAIDS on the Internet (www.unaids.org) or contact UNAIDS by email (unaids@unaids.org), telephone (41-22) 791-4651, or post (UNAIDS Information Centre, 20 Avenue Appia, 1211 Geneva 27, Switzerland).

## Québec Report on HIV Prevention in Provincial Prisons[2]

After a year of work, including consultations with numerous experts in the area of HIV/AIDS and drug use, a working group established by the Québec ministry of public security released a report in June 1997. Its recommendations include better education programs for inmates and staff in Québec provincial prisons, wider and more discreet access to condoms, increased access to bleach, continuation of methadone maintenance for prisoners who were on such treatment on the outside, and education about safe tattooing techniques.

The recommendations are consistent with those made by other Canadian and international agencies and groups of experts. They are nevertheless noteworthy because they were made by a group consisting entirely of persons from within the prison system and the Québec government, with the majority coming from various provincial prisons. Acknowledging that "it is doubtless not realistic to target the complete elimination of risk behaviours among inmates,"[3] the group recommended that the Québec prison system "take a harm-reduction approach to health issues, in accordance with the public health approach recommended by the WHO."[4] In a breathtaking departure from the otherwise well-reasoned and -argued report, the section on needle exchange in prisons is characterized by an absence of logic. Looking for reasons to refuse making sterile injection equipment available to inmates, the group argued that since access to sterile needles was limited outside prisons, the prison system should not make them available to inmates. The group rightly states that injection drug use among those using outside diminishes in prison. But no reference is made, for example, to the results of a study undertaken in a prison in Québec that showed that 11 of the 12 inmates in the study who admitted injecting in prison also admitted to sharing syringes – with obvious transmission risks.[5] Nevertheless, the report, which unfortunately is available in French only, should be read by staff and officials of prison systems in Canada and outside.

## Counselling and Testing Services in Two Provincial Prisons in Québec[6]

This report on the evaluation of the counselling and testing services offered in two provincial prisons in Montréal - a prison for men and a prison for women – concludes that "maintaining, even improving, access to HIV testing and counselling services is justified ... in all provincial correctional establishments." In the two prisons studied, testing and counselling services have been offered since 1994 by the local public health clinic.

Between November 1995 and June 1996, the period covered by the evaluation, 197 inmates used the counselling service. Sixty-five percent of them responded to a questionnaire developed for the evaluation and 24 inmates also participated in an individual interview. In addition, focus groups were undertaken with inmates who did not use the services offered, to identify barriers to use.

The evaluation showed that the services reach a clientele at high risk of HIV infection:

- 52 percent of the men and 56 percent of the women who used the services had injected drugs during the 12 months before imprisonment;

- 10 percent of the men and 67 percent of the women had engaged in prostitution;

- 8 percent of the men and 46 percent of the women had both risk factors; and

- 41 percent of the men and 34 percent of the women had sexual partners who were IDUs.

In addition, the evaluation showed that many of the clients reached had not used counselling and testing services on the outside: 63 percent of the male and 43 of the female clients were at their first HIV test.

The report suggests ways to further improve testing and counselling service in prisons. It concludes that

> we need to reach those who continue, inside prison, to expose themselves to the risks of HIV infection. In particular, access to the means of protecting oneself (sterile syringes, condoms, methadone maintenance treatment, etc) have to be made available as part of a general HIV prevention strategy in prisons.[7]

### ***Report of the 3rd European Conference on Drug and HIV/AIDS Services in Prison***[8]

This is a very comprehensive report on what is probably the biggest conference exclusively devoted to HIV/AIDS and drug use in prisons – 226 participants from 27 countries came to the third edition, held in Amsterdam in February 1997.[9]

The report contains summaries in three languages (English, French and German) of 40 papers and six workshops on issues such as research on HIV/AIDS and on drug use, health promotion, needle exchange, drug strategies, drug-free treatment, preparation for release, interventions on HIV and hepatitis, dual diagnosis, services for female prisoners and prisoners' families, substitution treatment and diversion to treatment. For everyone with an interest in issues raised by HIV/AIDS and drug use in prisons, this is required reading.

Also available from Cranstoun Drug Services (and highly recommended: order copies from Francesca Ambrosini, European Project Administrator, Cranstoun Drug Services, 4th Floor, Broadway House, 112-134, The Broadway, London SW19 1RL, United Kingdom. Tel: (44-181) 543-8333; fax: (44-181) 543-4348; email: prs@easynet.co.uk): (1) *A Question of Equivalence: A Report on the Implementation of International Guidelines on HIV/AIDS in Prisons of the European Union*. By Oonagh O'Brien and Alex Stevens, 1997, 47 pp, £3.95 (a report comparing the reality of HIV/AIDS in European prisons with the recommendations made by the World Health Organization and the Council of Europe); (2) *Digest of Research on Drug Use and HIV/AIDS in Prisons*. By Clare Flanagan and Alison J Giaime, 1997, 57 pp, £2.50 (a document compiling abstracts from 85 international reports, books and articles).

### *Harm Reduction in Prison*[10]

Finally available under this title is a summary of the proceedings of the symposium on harm reduction in prisons that took place in Berne from 28 February to 1 March 1996.[11] At the symposium, the first results of the first scientifically evaluated needle exchange project in prison were presented and discussed to "prepare a scientific basis for subsequent political decisions." About the project, Dr J Nelles, who conducted the evaluation, writes in the introduction of the book:

> The results of this 12-month project are now available. The outcomes, entirely positive, allay all the fears described before the project start. Most importantly, the exchange of used syringes between drug dependents all but disappeared.[12]

According to Nelles and Fuhrer, what characterizes this project [and the heroin prescription project at Oberschöngrün institution, described elsewhere in this issue of the *Newsletter*]

> is the fact that they were both initiated by concerned prison personnel and subsequently won the commitment of an active public health authority which guaranteed systematic project design, scientific supervision, and funding of the project implementation. In the final analysis, it is this combination of *courageous action*, *circumspect support and scientific appraisal* that has made the projects politically acceptable and practicable.[13]

The book makes the results of the Swiss projects available for wider discussion and is essential reading for everyone interested in HIV/AIDS and drug use in prisons, particularly policymakers. It is to be hoped that the results will be taken into account in political decisions and in the planning and implementation of further projects.

### Belgian Report on AIDS in Prisons Released[14]

This is another of the growing number of reports on HIV/AIDS and drug use in prisons in a particular country that analyzes the situation in the prison system(s) of the country and makes recommendations about how to deal with the issues raised. In this case the country is Belgium. The recommendations are the same as in most of the other reports, including that a pilot study of distribution of sterile injection equipment be undertaken. The problem, in Belgium as elsewhere, will be to convince prison authorities to implement the recommendations.

### Further Publications Noted

*L'infection à VIH en milieu carcéral: épidémiologie, prévention, aspects éthiques et juridiques*[15]

The proceedings of the first seminar of the European Network for AIDS and Hepatitis Prevention in Prison, held in Marseille on 20 June 1996, contain a review of literature on HIV risk behaviours in prisons and an overview of the situation in six European countries: Germany, Scotland, France, Italy, The Netherlands, and Sweden. Order information: Service études de l'O.R.S., 23 rue Stanislas Torents, 13006 Marseille, France. Tel: (33-4) 91-59-89-00; fax: (33-4) 91-37-48-24.

*Understanding HIV-Related Risk Behaviour in Prisons: The Inmates' Perspective*[16]

This report contains the results of a small exploratory pilot study undertaken in 1994 to gain an understanding of the potential for HIV transmission among inmates in federal institutions in Canada. Although the small sample size (n=39, 20 men and 19 women) limits the extent to which conclusions can be drawn from the study, the information collected shows that

> inmates engage in high-risk behaviour and that many do not use the harm reduction tools available to them. The structure of prison life and prison culture are barriers to their use. If existing and proposed HIV interventions are to be more effective, they must be adapted to

> the unique prison environment.[17]

Since the study was undertaken, the Correctional Service of Canada released the results of its survey of 4285 inmates, providing evidence that at least 26 percent of inmates had engaged in "risky practices" at their current institution.[18]

For copies of the report, contact the National AIDS Clearinghouse. Tel: (613) 725-3769; fax: (613) 725-1205; email: aids/sida@cpha.ca

- reviewed by *Ralf Jürgens*

---

Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTES

[1] *Prisons and AIDS: UNAIDS Point of View* (UNAIDS *Best Practice* Collection: Point of View). Geneva: UNAIDS, April 1997; and *Prisons and AIDS: UNAIDS Technical Update*. Geneva: UNAIDS, April 1997.

[2] Gouvernement du Québec, Ministère de la Sécurité publique, Direction générale des services correctionnels. *Les moyens de prévention de la transmission du VIH en milieu carcéral en regard de la clientèle UDI: Rapport du groupe de refléxion.* Québec: Direction du partenariat et du conseil en services correctionnels, 19 June 1997.

[3] Ibid at 8.

[4] Ibid.

[5] A Dufour et al. HIV Prevalence Among Inmates of a Provincial Prison in Québec City. *Canadian Journal of Infectious Diseases* 1995; 6(Suppl B): 31B.

[6] J Beauchemin, JF Labadie. *Évaluation de l'utilité et de l'accessibilité des services de counselling et de dépistage du VIH en milieu carcéral – Services offerts par le CLSC Ahuntsic à la Maison Tanguay et à l'Établissement de détention de Montréal. Rapport final: août 1997*. Montréal: Direction de la santé publique de Montréal-Centre et CLSC Ahuntsic, 1997.

[7] Ibid at 6.

[8] London, UK: Cranstoun Drug Services, 1997.

[9] The 4th conference, Prison & Drugs 1998 – A Conference for European Guidelines, will take place in Oldenburg, Germany, from 12 to 14 March 1998. The conference will concentrate on drug-free treatment, peer support, needle exchange, and substitution treatment in prisons. Participants will develop guidelines for work on HIV/AIDS and drug use in prisons, for presentation to the ministers of justice and ministers of internal affairs of the European Union.

[10] J Nelles, A Fuhrer (eds). *Harm Reduction in Prison: Strategies Against Drugs, AIDS and Risk Behaviour*. Berne: Peter Lang AG, 1997.

[11] See Symposium on Harm Reduction Strategies in Prisons. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 2(2): 25.

[12] Nelles & Fuhrer, supra, note 10 at 9.

[13] Ibid at 21 (emphasis in the original).

[14] Agence de Prévention du Sida, Ministère de la Santé de la Communauté française de Belgique. *Sida et Prison*. Brussels: The Agency, September 1997.

[15] European Network for AIDS and Hepatitis Prevention in Prison, 1997.

[16] L Calzavara et al. *Understanding HIV-Related Risk Behaviour in Prison: The Inmates' Perspective*. Toronto: HIV Social, Behavioural and Epidemiological Studies Unit, Faculty of Medicine, University of Toronto, 1997.

[17] Ibid at 33.

[18] CSC. *1995 National Inmate Survey: Final Report*. Ottawa: The Service (Correctional Research and Development), 1996, N$^0$ SR-02.

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

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## CRIMINAL JUSTICE

# Justice Delayed and Denied in Biting Case

**In May 1996, an HIV-positive transgendered sex worker was sentenced by an Ontario court to two years less a day in prison for biting a police officer on the hand.**

The incident had happened during a scuffle when the police officer arrested the sex worker on a downtown Toronto street for communicating for the purposes of prostitution.[1] After the bite, the sex worker said to the officer she had AIDS. On the theory that the bite had "endangered" the officer's life, she was charged with "aggravated assault." She pleaded guilty.

Although there was no evidence before the court that the bite in fact ever endangered the officer's life, the court noted the married officer's statements that he has had regular counselling, HIV testing every three months, and that he and his distraught wife had postponed their plan to start a family "in view of the danger he faces to his life." (The officer continued to test HIV-negative as of the sentencing, eight months after the bite.) The judge also adverted to the enormity of the "worldwide health menace" of the global AIDS epidemic, in agreeing with the Crown that a sentence of two to three years was appropriate for the bite. However, in light of evidence that federal penitentiaries lack facilities to adequately care for inmates with HIV/AIDS, the court reduced the sentence to 2 years less a day so the term could be served in a provincial prison. An additional three years' probation after release was imposed, including the condition that the sex worker not engage in unprotected sex.

The sex worker's appeal was delayed and was supposed to be heard in October 1997. She was released in September 1997, after 16 months spent in prison before an appellate court could review the justice of the conviction and the sentence imposed. The appeal has since been further delayed.

- *R Elliott*

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Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTE

[1]*R* v *Thissen*, unreported decision, 16 May 1996, Ontario Court (Prov Div), Toronto, Cadsby J. See also R Elliott. Sex Trade Worker Sentenced to Two Years for Biting. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 3(1): 20-21.

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

---

# BC Court of Appeal Rules on Detention of HIV-Positive Prostitute

**In a judgment filed on 25 June 1997, the British Columbia Court of Appeal held that an HIV-positive, drug-using prostitute "should not be detained under the *Criminal Code* because she is physically ill."[1]**

The HIV-positive woman (the appellant) appealed a decision of a Review Board pursuant to sec 672.54 of the *Criminal Code*. The Review Board had refused to allow her request for a discharge, ordering that she continue to be detained.

## The Facts

The appellant had been charged with assault and two counts of fraudulently obtaining food in July 1995. She had attacked the owner and an employee of a restaurant who were attempting to restrain her from escaping. The appellant, who was aware of her positive HIV status and was 27 years of age at the time, was found not criminally responsible by reason of a mental disorder in September 1995. She had previously been certified pursuant to the Mental Health Act of British Columbia,[2] and in August 1995 was hospitalized at the Forensic Psychiatric Institute (FPI) for her own protection and that of others.

At a first Review Board hearing on 3 November 1995, the appellant was conditionally discharged; she was released on 8 November 1995. Once back in the community, she returned to the use of illicit drugs and engaged in prostitution. She was subsequently brought back to the FPI. At a second hearing, on 24 January 1996, the Review Board made a custody order allowing the appellant unsupervised access to the community. On 2 February she left the FPI without authorization and was returned by the police on 3 February. At a third hearing on 17 April 1996, the custody order of 24 January was confirmed.

The appellant contested the fourth order of the Review Board, made at a hearing in October 1996. At that hearing, the Board reviewed evidence that indicated improvements in the appellant's mental condition. However, evidence also indicated the appellant's inability to refrain from the use of drugs and alcohol and her continued engagement in prostitution.

Section 672.54 of the *Criminal Code* reads as follows:

> Where a court or Review Board makes a disposition pursuant to subsection 672.45(2) or section 672.47, it shall, taking into consideration the need to protect the public from dangerous persons, the mental condition of the accused, the reintegration of the accused into society and the other needs of the accused, make one of the following dispositions that is the least onerous and least restrictive to the accused:
>
> (a) where a verdict of not criminally responsible on account of mental disorder has been rendered in respect of the accused and, in the opinion of the court or Review Board, the accused is not a significant threat to the safety of the public, by order, direct that the accused be discharged absolutely;
>
> (b) by order, direct that the accused be discharged subject to such conditions as the court or Review Board considers appropriate; or
>
> (c) by order, direct that the accused be detained in custody in a hospital, subject to such conditions as the court or Review Board considers appropriate.

At the fourth hearing, the Review Board did consider the appellant a threat to the community, saying that

> the accused is HIV positive and with this history, presents as a danger to the community, in the event that she uses a needle and then shares this needle with others. The record should reflect that she is possessed of sufficient intellectual capacity to know the danger she poses in this context, as well as the dangers associated with her having sex with others. (para 13)

The Board added that

> [a]lcohol in itself has not appeared to have featured largely in her posing a risk, but our concern is, that it is a disinhibiting substance. In this disinhibited state, we are concerned that she would pose a realistic risk of passing HIV virus [sic] to others, particularly as she was a prostitute and returns to that practice when in the community. (para 13)

It further stated that "[h]er sobriety is what keeps her safe, and her sobriety can only be ensured at the current level of understanding through custodial care." (para 13).

## The Appeal

The main question for the British Columbia Court of Appeal was whether the Review Board reached a custody disposition that is unreasonable or cannot be supported by the evidence in the case. Counsel for the appellant argued that:

> • the Review Board had no authority to confine a person because of a physical condition (such as HIV infection); and
>
> • the term "significant threat" in section 672.54 of the *Criminal Code* refers only to "a threat to the community of doing some act which constitutes an offence under the Criminal Code." As stated by counsel: "Because the appellant is HIV Positive, and because she is a prostitute, does not cause the appellant to be a significant threat within the meaning of the Criminal Code. It is not a crime to be a prostitute neither is it a crime to be a prostitute who is HIV Positive [sic]." (para 19)

## The Decision

The Court of Appeal agreed with the arguments of counsel for the appellant. In particular, after examining whether the term "significant threat" in section 672.54 of the *Criminal Code* refers to criminal conduct only or whether it can include the risk of spreading a communicable disease, it concluded that the threat must refer to *criminal* conduct or activity since the review procedure in this case is part of the *Criminal Code*: "Parliament never intended to deal with (detain) persons with physical (health) problems which are neither mental conditions nor mental disorders within these sections of the *Criminal Code*." (para 22)

The Court noted that the appellant's medical record indicated that her mental condition had been stabilized. And while it conceded that the appellant could at times pose a risk to herself or to others if she engages in unsafe sex or shares needles, the Court stated that "disinhibiting behaviour or acting on impulse when using alcohol or drugs are not in and of themselves offences under the *Criminal Code*." (para 24)

The Court concluded that the appellant

> should not be detained under the Criminal Code because she is physically ill. If a mental problem arises upon release, s. 20 of the Mental Health Act is the appropriate legislation to deal with the situation. If she is considered a menace because of her physical condition, s. 7 of the Health Act may be invoked. It was not the intent of Parliament that the Criminal Code be used to confine persons who may develop AIDS or for that matter any other communicable disease. (para 26)

Considering that the Attorney General conceded on appeal that the appellant was being detained because she was HIV-positive, the Court ruled that the Review Board's decision was, in law, unreasonable since there was no evidence or persuasive argument that the appellant was a significant threat within the meaning of the *Criminal Code*.

– *Bruno Guillot-Hurtubise*

Top of this page

Return to Table of Contents

Return to Home Page

ENDNOTES

[1] *Chambers v British Columbia (Attorney General)*, [1997] BCJ No 1497.

[2] RSBC 1978, c 256.

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

---

# HIV-Positive Man Faces Criminal Charges

According to a newspaper report of 30 November 1997, a man in Gatineau, Québec, was charged with criminal negligence and sexual assault endangering life for allegedly having had unprotected sexual intercourse with his partner between 1993 and 1997, knowing that he was HIV-positive.[1]

For more information on other similar cases, consult the six criminal law bulletins produced by the Canadian HIV/AIDS Legal Network and the Canadian AIDS Society, and *Criminal Law and HIV/AIDS: Final Report*.[2] These documents can be retrieved at www.aidslaw.ca. Copies can also be ordered through the National AIDS Clearinghouse. Tel: (613) 725-3434; fax: (613) 725-9826; email: aids/sida@cpha.ca

Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTES

[1] Un sidéen trop discret a été accusé de négligence criminelle. *Le Journal de Montréal*, 30 November 1997, at 19.

[2] R Elliott. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1997.

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

---

## HIV Considered Aggravating Factor in Sentencing

**A 36-year-old man was recently sentenced to 28 months, imprisonment for masturbating in front of a friend, after a fight with her and holding her at her throat.**[1]

The man pleaded guilty to sexual assault. Although there was no risk of HIV transmission, Judge Laberge of the Court of Québec considered the fact that the man was HIV-positive an aggravating factor in sentencing, and sentenced him to 28 months.

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Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTE

[1]See P Richard. Un sidatique se masturbe devant son amie: 28 mois de pénitencier. *Le Journal de Montréal*, 19 November 1997, at 8.

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

# US – 10 Years for Unprotected Sex

**A man who had unprotected sex with several women over a period of years after learning that he was HIV-positive in 1991 was sentenced to ten years in prison on two counts of risking infection of another with HIV.**

Kansas City health workers testified that they repeatedly warned the man to use protection after he tested positive, but that he was treated for venereal diseases six times between 1992 and 1996. One of his sex partners tested positive in 1993.

The charges against the man were brought under an HIV-specific criminal statute enacted by the Missouri legislature in 1988. This is only the second case brought under that statute. The man claimed he did not intend to harm anybody and blamed his lapses on alcoholism.[1]

Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTE

[1] Reported in *Lesbian/Gay Law Notes* October 1997, at 154-55.

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Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

---

## US – Downward Sentencing Departures for Defendants with AIDS Refused

**In two recent decisions, US federal appeals courts reiterated their now well-established position that defendants with AIDS are not normally entitled to downward departures under federal criminal sentencing guidelines solely because of their AIDS diagnosis.**[1]

Both courts emphasized that a downward departure would be in order only where the district court concluded that the defendant's physical condition was so extraordinarily compromised that he could not possibly commit further criminal acts or present any danger to society. Reviewing the district courts under an abuse of discretion standard, the appeals courts found no basis for upsetting the sentences in either case.

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Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTE

[1] *Montanez-Anaya v US*, 1997 WL 351634 (1st Cir June 20, 1997) (unpublished disposition), and *US v Smith*, 1997 WL 346045 (4th Cir June 24, 1997) (unpublished disposition). Reported in *Lesbian/Gay Law Notes* Summer 1997, at 107.

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**Canadian HIV/AIDS Policy & Law Newsletter**

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

---

# Australia – Charges of Intentionally Transmitting HIV

**An HIV-positive man in the State of Victoria faces 80 charges of intentionally transmitting HIV, after allegedly having unprotected sex with eight people over a period of seven years.**[1]

The man is also charged with 21 counts of attempting to transmit HIV, 180 counts of reckless conduct endangering life, 13 counts of administering a drug (amyl nitrate, also known as "poppers") to enable sexual penetration, two counts of bestiality, and six counts of indecent assault.

The alleged victims are seven men and one women, aged 19 to 34. Three of them have been diagnosed HIV positive, and 4 are intellectually disabled. The defendant is contesting the charges.

The offence of "intentionally transmitting a very serious disease" was inserted into the *Crimes Act 1958* (Victoria)(s 19A) in 1993.

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Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTE

[1] Reported in [Australian] *HIV/AIDS Legal Link* 1997; 8(2): 5.

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Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

---

# Australia - Prison for Assisting Suicide

**An HIV-positive male-to-female transsexual who pleaded guilty to assisting in her lover's death has been imprisoned for two years by Queensland's Supreme Court in what is believed to be Australia's first conviction for the crime of assisting suicide.**[1]

Justice Moynihan found that the accused should be dealt with "in a region which falls between a joint suicide pact which didn't work and a detached assistance to help fulfil someone else's wish to commit suicide." On the day of her lover's death they sold a car to buy heroin, injected it, took other drugs, and went to bed. The deceased was found to have died from a drug overdose, while the accused recovered in hospital. The accused – who at the time of the court hearing was undergoing a sentence of 12 months for "unlawful wounding" – was convicted, sentenced and imprisoned as a male, with a recommendation for parole after nine months.

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Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTE

[1] Reported in [Australian] *HIV/AIDS Legal Link* 1997; 8(2): 4. In another case, an HIV-positive man who had helped his lover with HIV to die was convicted for aiding and abetting an *attempted* suicide. See, Australia – Lenient Sentence in Euthanasia Case. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 2(4): 25-26.

**Canadian HIV/AIDS Policy & Law Newsletter**

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

---

## Australia – Doctors Admit to Performing Assisted Suicide and Euthanasia

**In response to a survey conducted by the Melbourne paper *The Sunday Age*, 12 doctors stated they had helped terminally ill patients to die, knowing it was against the law.**[1]

Melbourne GP Dr Jonathan Anderson admitted to giving lethal injections to three patients dying from AIDS-related conditions. He told the paper he knew he had technically committed murder, but that he had acted out of obligation to his patients.

---

Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTE

[1] Reported in [Australian] *HIV/AIDS Legal Link* 1997; 8(2): 5.

© Canadian HIV/AIDS Legal Network, 1998

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

---

## IMMIGRATION

# European Court Prevents Deportation of Man with AIDS

**In a decision handed down on 2 May 1997, the European Court of Human Rights found that the Convention for the Protection of Human Rights and Fundamental Freedoms prevented the United Kingdom (UK) from deporting an alien drug courier with AIDS to his country of origin.**[1]

In a 9-0 decision, the Court held that if the man who was approaching death from AIDS-related complications were deported to the Caribbean island of St Kitts, it would amount to "inhuman treatment" and violate Article 3 of the Convention.

The man (D) had attempted to enter the UK as a visitor in January 1993, but permission was refused when he was found to be in possession of large quantities of cocaine. He was subsequently convicted of drug importation offences and received a sentence of six years' imprisonment. In August 1994, while in prison, D was diagnosed with AIDS. In January 1996, he was released and placed in immigration detention pending his removal to St Kitts.

D applied for permission to remain in the UK on compassionate grounds, as his removal to St Kitts would entail loss of the medical treatment he was receiving. The request was refused on the grounds that Immigration Department policy did not provide a right for a person with AIDS to remain in the UK exceptionally, when treatment was being carried out at the public expense under the National Health Service. On appeal against this refusal, the Court of Appeal found that the Department's decision was neither irrational nor unreasonable in view of the fact that had D not been trying to smuggle drugs, he might not have come to the UK at all.

D applied to the European Commission of Human Rights, arguing that as he was terminally ill, his removal to a place where inadequate medical treatment was available would shorten his life and deprive him of his right to life, in violation of various articles of the Convention. The Commission concurred with D, and the matter was referred to the Court of Human Rights.

Article 3 of the Convention states that "[n]o one shall be subjected to torture or to inhuman or degrading treatment or punishment." D argued that his removal to St Kitts would condemn him to spend his remaining days in pain and suffering, in conditions of isolation, squalor and destitution. As he had no accommodation, no money and no access to social support, his death would not only be accelerated, it would come about in inhumane and degrading conditions. The British government argued that D would not be *intentionally exposed* to any treatment by St Kitts that breached the standards of Article 3. He would be in the same position as other people with HIV/AIDS in a developing country with inadequate medical facilities. In the government's view, D's hardship and reduced life expectancy was due to his illness.

The Court found that Article 3 prohibits in *absolute terms* torture or inhuman or degrading treatment or punishment, and that its guarantees apply irrespective of the reprehensible nature of the conduct of the person in question. In light of the medical evidence, the Court found that the abrupt withdrawal of medical treatment caused by the removal of D to St Kitts would amount to inhuman treatment by the British government, in violation of Article 3. The Court pointed out that aliens who had served their prison sentences and who were subject to expulsion could not in principle claim entitlement to remain in the relevant country in order to benefit from medical, social or other forms of assistance provided by the state during their time in prison. It was only in the exceptional circumstances like this case that the Court would be prepared to uphold the protection afforded by Article 3.

---

Top of this page

Return to Table of Contents

Return to Home Page

---

ENDNOTE

[1]D v The United Kingdom (case number 146/1996/767/964). The full text of the decision can be found at www.dhcour.coe.fr. The following is an edited version of an article by Hseuh Mei Tan in the [Australian] *HIV/AIDS Legal Link* 1997; 8(2): 18-19.

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Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

---

## INTERNET NEWS

# The Internet, Drug Policies and Harm Reduction

**Renewed calls for pragmatism, many texts on new issues and recent developments, and on improved websites: there are abundant and impressive materials promoting the harm-reduction approach and fighting complacency and misinformation. The harm-reduction networking movement on the Internet is becoming a tidal wave.**

The Canadian Foundation for Drug Policy's Internet site at http://fox.nstn.ca/~eoscapel/cfdp/cfdp.html deserves a mention for being always up-to-date. Canada's most comprehensive and compelling resource about drug law and policy reform features online press releases and stories relating to a physician's 17 December 1997 application to Health Canada for legal access to medical marijuana, including the text of the application and a transcript of an *Ottawa Citizen* report (19 December) saying that Health Canada is ready to approve application if "technical flaws" in the application are corrected. You will find, among other things, links to research information and policy discussions about medical marijuana; to the medicinal marijuana section of the Lindesmith Center Library; to articles about marijuana in the *British Medical Journal* and *The Lancet*; to the comprehensive medicinal marijuana research site of Drs Lester Grinspoon and James Bakalar of Harvard Medical School; and to Canadian and foreign news articles and media reports on drug policy collected and updated daily on the Media Awareness Project website at www.mapinc.org/canada.htm.

The Canadian Centre on Substance Abuse has made some additions to its website at www.ccsa.ca, including a "special interest section" on cannabis issues where the first link leads – sign of the times? – to a [US] National Institute for Drug Abuse marijuana update capsule. The website features *HIV/AIDS and Injection Drug Use: A National Action Plan,* the report of the National Taskforce on HIV/AIDS and Drug Use; an April 1997 article about needle exchange and HIV; *Harm Reduction: Concepts and Practice – A Policy Discussion Paper* ; and *International Guidelines for Estimating the Costs of Substance Abuse*.

The Canadian Medical Association is not indifferent to the idea of harm reduction, but a site search of www.cma.ca/sitesearch/index.html may reveal more than intuitive browsing of this rich website, with titles like "Time for legalized distribution of illegal drugs?" and "Needle exchange programs: an economic evaluation of a local experience" leading to abstracts and online versions of the CMA's numerous publications.

For those interested in south-of-the-border developments (Canada's drug laws and policies are, of course, not free from US influence), the Drug Reform Coordination Network at drcnet.org publishes regular updates (*The week online*) and includes a section about "The Epidemic of Drug-Related AIDS." The National Drug Strategy Network at www.ndsn.org is an information-sharing network that provides "complete and up-to-date information about current events regarding drug issues. ... It does not take any official positions on policy matters" but includes an interesting "Newsbrief," as well as a very diversified links section where the Lindesmith Center's excellent website at www.lindesmith.org (always a must!) neighbours those of the FBI, the DEA and many more.

The International Harm Reduction Association at www.ihra.org.uk has uploaded a valuable addition under "Proceedings from the 8th International Conference on the Reduction of Drug Related Harm," where numerous papers from the plenary, major sessions and symposia have been archived: "What have we learnt from Drug Education?" by Niall Coggins; "Strategy of Change: The French Situation" by Anne Coppel; "Promoting harm reduction ideas in the international community" by Catherine Hankins; "Changing Drug Policy: Lessons from Eastern Europe and the USA" by Ethan Nadelmann; "Increasing Trends towards the reduction of drug related harm in Asia" by Manisha Singh; "Using Harm Reduction Policies within Drug Law Enforcement in the NSW Police Service, Australia" by Suzie Forell; "Women and Drugs: 25 years of Research and Policy" by Marsha Rosenbaum; and many more insightful pieces.

At www.oeko-net.de/ecdp, the website of European Cities on Drug Policy offers a newsletter and an online version of the Frankfurt Resolution, and it outlines the goals of this group that seeks to coordinate harm-reduction strategies among European cities.

- *Jean Dussault*

Top of this page

Return to Table of Contents

Return to Home Page

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

---

## PUBLICATIONS REVIEWED

### *Positively Women Living With AIDS*[1]

I have always been a big fan of Positively Women, the British organization serving women living with HIV/AIDS, which was created by HIV-positive women early on in the AIDS epidemic. When Kate Thomson, one of the founders of Positively Women, and Sue O'Sullivan, her co-editor, published *Positively Women Living With AIDS* in 1992, I read it avidly for its gutsy testimonials by women with HIV – testimonials that were so different from other portraits of women with HIV, written by people who sought to pity or blame, whose descriptions of the lives of HIV-positive women made us strangers to ourselves.

*Positively Women Living With AIDS* has recently been updated and reissued by Pandora / HarperCollins. Its strength remains its telling of the stories of women with HIV. The same twelve women who appeared in the 1992 Sheba Press edition updated their stories for this new edition. These women's stories remain compelling, even in the retelling. They are the backbone of the book. Sadly, though not surprisingly (and yet why was I shocked?), some of the stories now end with the death of their narrators, including the story of Sheila, who along with Kate Thomson founded Positively Women.

The remainder of the book – the women's stories occupy half of the book – is weak. It needs to be stated up front that when this book was "fully updated" (as its back cover tells us), its editors simply added a paragraph or so in italics at the end of essays and testimonials written for the first edition. This is not the same as a thorough revision, and the book suffers as a result.

The section entitled "How HIV/AIDS Affects Women's Lives" discusses human rights, clinical issues, research, complementary therapies, racism, sexuality, housing, legal issues, etc. Even in the first edition, I felt that this section was not particularly thoughtful or strong. Years later, much of this information reads as a tiresome and superficial reiteration of AIDS dogma: we need more research on women, AZT can be harmful, every woman experiences HIV differently, safer sex can be fun.... Sharp, provocative writing appears to have been sacrificed to principles of inclusivity, which probably made for a very exciting process in creating the book, but not for an informative, insightful read.

Worse, the clinical information included in the book is woefully out-of-date. The grounds of the debate on, for example, pregnancy have shifted considerably in the past years with proof that AZT therapy significantly reduces maternal transmission of HIV. Writers throughout the book seem dimly aware of the implications of this information. There is no information about protease inhibitors, but the reader will find outdated references to ARC [AIDS-related complex]. A pervasive lack of interest in grappling with the volatility of treatment issues is evident in the new edition of *Positively Women Living With AIDS*: instead of a chapter on medical treatment in HIV disease, which we lose in the new edition, we get a pedestrian chapter on grief and loss.

Issues of direct relevance to women with HIV continue to provoke dynamic responses: from women living with this disease; in community-based work; through activism; in research; in provision of health care and services. It is unfortunate that a new edition of *Positively Women Living With AIDS* did not provide an opportunity to describe some of these exciting experiences.

– reviewed by *Darien Taylor*

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Top of this page

Return to Table of Contents

Return to Home Page

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ENDNOTE

[1] Sue O'Sullivan, Kate Thompson. *Positively Women Living with AIDS.* San Francisco, CA: Pandora / HarperCollins, 1996 (303 pp, ISBN 0-04-440943-5, US$18).

Canadian HIV/AIDS Policy & Law Newsletter

Volume 3 Number 4 & Volume 4 Number 1 - Winter 1997/98

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# *Typhoid Mary: Captive to the Public's Health*[1]

**In 1907, Mary Mallon, an Irish immigrant working as a cook, became the first person to be identified as a healthy carrier of typhoid. The very concept of a healthy person carrying disease was new, a laboratory-defined concept that ran counter to public understanding. Mallon was arrested twice, and isolated on North Brother Island for twenty-six years of her life.**

In *Typhoid Mary: Captive to the Public's Health*, Leavitt traces various perspectives on Mallon's life, exploring how Mallon's story was shaped by science, public policy makers, the law, the media, and social prejudices of the period, as well as exploring Mallon's own point of view. The reader comes to see how Mallon's own identity was obscured by a symbol, and how that symbol, "Typhoid Mary," was a public construction, a dialogue about the transmission of disease that had less to do with Mallon herself than with those whose business it was to shape opinions and policies about health.

Mallon was not the only healthy carrier to be identified in the early 1900s. Others, such as Alphonse Cotils, Tony Labella, and Frederick Moersch, were also named as healthy carriers and, like Mallon, returned to occupations in the food service industry. Unlike Mallon, however, these individuals were not stigmatized in terms of their "ethnicity, sex, or personal appearance, [and] the news media remained nonjudgemental and unemotional about [their] culpability..." (153). As Leavitt points out throughout the text:

> The story of how Mary Mallon became "Typhoid Mary" underscores the necessity of looking at public health problems from different stances. In her stories, a powerful negative image replaced the human being very early on – a negative image constructed by public health officials, medical writers, and the media, all of whom helped it become entrenched in American culture. In turn, the cultural meaning of the popular but stigmatizing phrase "Typhoid Mary" influenced the actual treatment of Mary Mallon, as well as her own responses to the situation (232).

Throughout the text, Leavitt urges the reader to a gentler, more empathetic view of individuals who happen to be infected with a virus, pointing out that such an attitude is likely "to foster cooperation with public health measures and help stem dangerous epidemic crises" (238).

Leavitt also explores how the basic issues in Mallon’s story can help to clarify contemporary thought about the tensions between public health and individual rights and liberties. She finds similarities between Mallon’s story and present-day reactions to HIV infection, pointing out how "the infection’s initial association with gay men and Haitian refugees allowed the marginalization of homosexuality and race to shape an emerging disease-associated stigma and exacerbate what seemed to many an unfair distribution of blame" (247).

Throughout the text, Leavitt focuses the reader’s attention on the social aspects of our attempts to combat the spread of disease. Her lucid account of Mary Mallon's treatment is relevant to all persons engaged in public discourse about health.

- reviewed by *Anne Stone*

Top of this page

Return to Table of Contents

Return to Home Page

ENDNOTE

[1]Judith Walzer Leavitt. *Typhoid Mary: Captive to the Public's Health*. Boston: Beacon Press, 1996 (331 pp).