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Supreme Court Rules on Disability Discrimination

On 3 May 2000, the Supreme Court of Canada released a unanimous decision involving the interpretation of the term "handicap" in Québec's anti-discrimination legislation in three complaints filed with the province's human rights commission.[1] While none of the cases involved HIV-related discrimination, the Court's strong decision is of definite benefit in protecting and promoting the rights of people with HIV/AIDS, particularly for those living in Québec. The decision recognizes that people are protected against discrimination based on disability even if their condition does not give rise to any functional limitation and the discrimination is based on the perception that they are disabled.

The city of Montréal refused to hire one person as a gardener and another as a police officer because a pre-employment medical exam revealed an anomaly of the spinal column. In a third case, the city of Boisbriand dismissed a police officer diagnosed with Crohn's disease. In each case, the medical evidence indicated that the individuals could perform the normal duties of the position in question, and that they had no functional limitations. All three individuals filed complaints with the provincial human rights commission, alleging that

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Canadian Strategy on HIV/AIDS

Health Canada

HIV/AIDS and the Law: New Challenges

Regular readers of the *Canadian HIV/AIDS Policy & Law Newsletter* are well aware of the many legal, ethical, and human rights issues raised by HIV/AIDS in Canada. Although the *Newsletter* has always also included articles about developments in other countries, the time was ripe to ask some of the experts on HIV/AIDS law in other countries to reflect on past and current developments, as well as future challenges, in HIV/AIDS law. This issue of the *Newsletter* contains the first series of articles, with contributions from Australia, England & Wales, Switzerland, and India. Articles from Canada, South Africa, the United States, and Germany have also been solicited, and will be published in a future issue of the *Newsletter*. The articles reveal that there are many common issues, the most important of which may be ongoing discrimination at a time when the commitment to dealing with HIV/AIDS in its entirety, rather than seeing it as just a medical issue, is waning in most Western countries. In addition, in many countries the benefits from new treatments have been accompanied by complacency, misunderstanding, and new forms of discrimination. Rather than diminishing, the challenges for law, ethics, and human rights in the context of HIV/AIDS are increasing.

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Comments?

We would like to hear your views and opinions regarding the* Newsletter, *its content and format. We also encourage comments on or responses to individual articles, and letters to the editor, which will be published on a regular basis.

CANADIAN HIV/AIDS POLICY & LAW NEWSLETTER

The *Newsletter* is a summary of developments in HIV/AIDS policy and law in Canada and abroad. Its aim is to educate people about and inform them of policy and legal developments and to promote the exchange of information, ideas, and experiences. It is published quarterly by the Canadian HIV/AIDS Legal Network.

Contributions are welcome and encouraged. Please contact Éric Nolet, Publications & Project Coordinator, at the following address to discuss your article and to obtain a copy of our style guide:

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Canadian HIV/AIDS Legal Network
The Network is a charitable organization engaged in eduation, legal and ethical analysis, and policy development. We promote responses to HIV/AIDS that

- implement the international Guidelines on HIV/AIDS and Human Rights;
- respect the rights of people with HIV/AIDS and of those affected by the disease;
- facilitate HIV prevention efforts;
- facilitate care, treatment, and support to people with HIV/AIDS;
- minimize the adverse impact of HIV/AIDS on individuals and communities; and
- address the social and economic factors that increase the vulnerability to HIV/AIDS and to human rights abuses.

We produce, and facilitate access to, accurate and up-to-date information and analysis on legal, ethical, and policy issues related to HIV/AIDS, in Canada and internationally. We consult, and give voice to, Network members and a wide range of participants, in particular communities of people with HIV/AIDS and those affected by HIV/AIDS, in identifying, analyzing, and addressing legal, ethical, and policy issues related to HIV/AIDS. We link people working on or concerned by these issues. We recognize the global implications of the epidemic and incorporate that perspective in our work.

The Network is based in Montréal. We welcome new members. For membership information, contact Anne Renaud <arenaud@aidslaw.ca>.

EDITORIAL

Good news is rare in this issue of the *Newsletter*.

Yes, the Supreme Court of Canada has just released an important decision that, while it is not specifically on the issue of HIV/AIDS, is of definite benefit in protecting and promoting the rights of people with HIV/AIDS. The decision recognizes that people, including people with HIV/AIDS, are protected against discrimination based on disability even if their condition does not give rise to any functional limitation and the discrimination is based on the *perception* that they are disabled. (Supreme Court Rules on Disability Discrimination, page 1). But this is the very same Court that only 18 months ago decided that an HIV-positive person may be guilty of the crime of "assault" if they do not disclose their HIV-positive status before engaging in (unprotected) sexual activity, raising many unanswered questions for people with HIV/AIDS about disclosure in the context of sexual activity, but offering few clear answers. And it is a Court that is more and more frequently being bashed by right-wing Canadian newspapers (are there any other left?) for placing concerns of dignity at the centre of equality rights analysis and being proactive in interpreting the *Canadian Charter of Rights and Freedoms*. When it does what it should do, as in the case reported in this issue of the *Newsletter*, the Court often has few friends.

And yes, support for the development of a vaccine against HIV infection or AIDS is now finally gathering momentum, reflected in the articles in this issue of the *Newsletter* dealing with the human rights and ethical questions raised by the

development and eventual availability of a vaccine (see pages 16-24). It has become abundantly clear that the HIV epidemic continues to spread in the developing and, to a lesser but still worrisome extent, in the developed world, and that in the absence of the necessary funds and political will, prevent-ion efforts based on behaviour change alone will not stop it. Therefore, the new vaccine initiatives, and the efforts to ensure that, once developed, vaccines will become available to those most in need, are crucial and represent good news.

The search continues for quick fixes to problems that are social in nature and require more than medical (or legal) measures to solve.

The establishment of a Special Committee of Canada's Senate to conduct a comprehensive review of Canadian drug laws and policies (*Canadian Senate Committee to Review Drug Laws and Policies*, at page 59) also represents good news, although what is needed in this area more than anything else is swift action on the many recommendations made before, rather than more of the same recommendations.

There are, however, many reasons for concern. A private member's bill that proposes to permit forced blood testing of persons for HIV or hepatitis B or C where peace officers, firefighters, and other emergency services personnel or other health-care workers may have been exposed to the risk of infection, was introduced in the House of Commons (*Reform MP Proposes Compulsory Testing*, at page 25. Health Canada is considering making HIV testing mandatory for all potential immigrants to Canada, and to exclude all those testing HIV-positive (see info sheet 16 in the Legal Network's recently released series of info sheets on HIV testing, www.aidslaw.ca). And discrimination continues, or indeed seems to be on the rise, as a study undertaken in New Brunswick shows (*HIV-Related Discrimination in New Brunswick Increasing*, at page 52), and as is also confirmed by authors from Australia and England. Prevention efforts continue to be neglected in most prisons, although studies show that they work (*Evaluation of Needle Exchange Pilot Projects Shows Positive Results*, at page 60). In Canada, an evaluation of HIV/AIDS harm-reduction measures in the Correctional Service of Canada concluded that "[t]he review team has no confidence that the distribution of bleach alone will effectively reduce transmission of infection from Hepatitis or HIV" (*HIV/AIDS in Prisons: More New Developments*, at page 64). Nevertheless, a needle exchange pilot project that was to be undertaken in a federal and a provincial prison in British Columbia was stopped in its tracks by a new Solicitor General who seems to have little understanding of, but an aversion to, the concept and practice of harm-reduction measures.

Globally, the availability of new treatments has led to an acceleration of the trend toward a medicalization of HIV/AIDS, although these treatments are accessible to only five percent of all people with HIV/AIDS, and although there has been early recognition that the "old public health," with its focus on the individual, cannot appropriately deal with an epidemic fueled by social injustice, and that new approaches are needed. Nevertheless, the search continues for quick fixes to problems that are social in nature and require more than medical (or legal) measures to solve. This means that we need to work even harder to ensure that prevention efforts based on behaviour change, and promotion and protection of human rights, continue alongside the development of vaccines and treatments. Most important, behaviour change on the part of governments and policymakers is needed, because it is government action or inaction that determines more than anything else whether we will succeed in the fight against HIV/AIDS.

HIV/AIDS IN CANADIAN COURTS

This section of the *Newsletter* presents a summary of miscellaneous Canadian court cases relating to HIV/AIDS or that may be of significance to people with HIV/AIDS. It features cases reported since the last issue of the *Newsletter*, between October 1999 and April 2000. A search of Canadian electronic legal databases and some media sources yielded several cases in which reference was made to HIV/AIDS. However, only those cases dealing with HIV/AIDS or related litigation in any substantive way are reported here. (Readers aware of any unreported cases that would be of interest to the Network and to *Newsletter* readers are asked to draw these to our attention.) The cases reported below deal with: the medical treatment of children living with HIV/AIDS; the Supreme Court of Canada's interpretation of laws prohibiting discrimination based on disability; loss of insurance coverage; challenges to the criminalization of marijuana; a suit alleging harassment and discrimination in the workplace; a pharmaceutical company's unsuccessful attempt to have its patent extended; and a stay of a deportation order against a person with HIV. Criminal cases and cases relating to HIV/AIDS in prisons (both in Canada and other jurisdictions) are summarized elsewhere in this issue.

Medical Treatment of Children with HIV/AIDS

In the last issue of the *Newsletter*, we reported on the case of a Montréal woman who sought an injunction from the Québec Superior Court to prevent physicians from administering antiretroviral medication to her HIV-positive sons, of whom she had previously lost custody because of her refusal to consent to such medication.[1] In December 1999, the Court of Québec (Youth Division) heard the mother's application to regain custody and an application by the Director of Youth Protection for an order declaring that the children were in need of protection, as well as an order that the children be placed in the physical custody of another family for a period of two years, that the authority to make decisions regarding the children's medical care be removed from the mother and placed with the Director of Youth Protection, and that the children receive the necessary medications and diet. The Court issued its decision on 12 January 2000.[2]

In his decision, Ouellet J noted the following evidence: the mother does not herself take AZT; she relies on alternative medicines and on fasting to combat fevers and infections; she denies the validity of tests used to detect the presence of HIV; she refuses to administer "combination triple therapy" to her children, and resists any other medications such as antibiotics to combat or prevent opportunistic infections.

The Court cited the leading Supreme Court of Canada decision in *RB* v *Children's Aid Society of Metropolitan Toronto*.[3] In that case, the Supreme Court recognized that parents' interest in caring for their children is of "fundamental importance" and is protected by the right to liberty under the Charter (s 7); there is a presumption that parents ought to make important decisions regarding their children, and state intervention must be justified. But the Supreme Court cautioned that this is not an "unconstrained freedom"; children

> The Court concluded that, in the circumstances, it could not say that the mother's decision to refuse recommended treatment for her children was an "informed" one, made after "mature and objective reflection" in the children's interest.

are also entitled to the protection of their Charter rights, and the state may intervene to protect a child if necessary. The Court also reviewed additional Canadian decisions (including from Québec),[4] as well as other cases from both the UK[5] and the US,[6] in identifying the following guiding principles:

> translation](1) Parents have the primary responsibility with regard to the medical care to be provided to their children. The decisions they take in this regard must be respected when they are made following mature and objective reflection, and after having requested and obtained all the necessary information;
>
> (2) The right of parents to decide what medical care their children are going to receive is not absolute. Their decision must be dictated primarily by the best interests of their child and by a concern to ensure the child's welfare, not by inordinate personal considerations or convictions, be they religious, cultural or of some other nature;
>
> (3) The strictly medical aspect should not be the only one to be considered. The security and development of a child includes more than mere physical health. Emotional and psychological balance, emotional stability, one's surroundings and living conditions are also essential elements of a child's well-being.

Applying these principles to the case before it, the Court concluded that, in the circumstances, it could not say that the mother's decision to refuse recommended treatment for her children was an "informed" one, made after "mature and objective reflection" in the children's interest, taking into account their medical, social, emotional, and psychological needs. In the Court's view:

> [translation] The mother's decisions with respect to the required and recommended health care and treatment for her children ..., in order to be considered reasonable and in accordance with the children's interest, must be made in an informed way, upon reflection, and with maturity and objectivity, in the children's interest, taking into account their medical, social, emotional, and psychological needs. In all the circumstances the evidence has brought to light, the Court cannot conclude that the decisions made by the mother in this area meet the criteria set out above. Although the mother became well-informed and read many books, magazines, and other publications on AIDS and HIV, the mother's research was done only to confirm her own views and justify her own position.... The Court might have been able to consider her refusal to allow her children to receive antiviral medication not unreasonable – given the inherent risks of the therapy and the serious side effects – if, in other respects, she had taken all necessary steps to ensure close medical monitoring and recognized alternative therapies as valid.... On the contrary, the mother takes from the opinions of her own experts (eminently respectable, although very much in the minority of medical opinion) only those elements that support her position, but dismisses any conclusions or recommendations that differ from her own convictions. In effect, the evidence shows that, despite the vulnerability of the children, they have not had the benefit of regular medical monitoring, preventative care, or special attention. Furthermore, the mother objects to her children taking common medications such as antibiotics, and treats their infections with fasting.

Therefore, despite the Court's sympathy for the mother's difficult situation, it is not possible for the Court to consider that her decisions regarding the health care of her children ... have been carefully considered and taken maturely and objectively in their best interest. Based on the evidence submitted, it appears instead that the mother's choices are principally dictated by her own refusal to admit illness, her own as well as that of her children, and by her concern with maintaining and affirming her own convictions. For her, faithful adherence to her convictions seems, consciously or not, to come before her children's well-being and interest. To be convinced of this, one need only consider that she persisted in breastfeeding each of her two children, despite all advice to the contrary given to her. Perhaps, as she claims, it is not proven that HIV can be transmitted by breastfeeding, but why take a risk of such magnitude when the comparative benefits of breast-feeding remain, after all, relatively minor. [7]

In light of these considerations, the Court concluded that the "security or development" of the two children was "in danger" pursuant to Québec's *Youth Protection Act*, which provides that:

> For the purposes of this Act, the security or development of a child is considered to be in danger where ... (c) his physical health is threatened by the lack of appropriate care; [or]... (e) he is in the custody of a person whose behaviour or way of life creates a risk of moral or physical danger for the child.[8]

The Court therefore ordered that the authority to make decisions regarding the medical treatment of her children be removed from the mother and be placed with the Director of Youth Protection, and that the children receive the medical attention required, given their health condition. The Court noted that the children had already been receiving triple therapy for some time as a result of an earlier, interim decision, and that it would be illogical and unreasonable to interrupt this treatment before being able to assess its effect. The Court also ordered that the children be placed in the physical custody of their grandparents, who assured the Court they would abide by the Court's order, on the condition that they will facilitate contact between the children and their mother but will also take necessary steps to ensure that she does not interfere with the medication or diet of the children. Finally, the Court ordered that the mother be entitled to have access to her children as often as is "reasonably possible" and at least once a week. Noting that the state's intervention in such a matter should be as minimally intrusive as possible, the Court also ordered that its decision would be revisited in six months, after a medical assessment of the course of treatment and the possibility of the mother reevaluating her position.

– Richard Elliott

[1] *B.* v *Youth Protection Services et al.*, Québec Superior Court, District of Montréal, Court File No 500-05-052175-997. See Elliott R . HIV Testing & Treatment of Children. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 5(1): 1, 3-9.

[2] *Re IB*, [2000] JQ No 490 (Court of Québec (Youth Division)).

[3] [1995] 1 SCR 315.

[4] Eg, *Couture-Jacquet* v *Montreal Children's Hospital* (1986) RJQ 1221, 28 DLR (4th) 22 (Que CA).

[5] *In re C*, [1999] TNLR No 652. See Elliott, supra, note 1 for a summary of the case.

[6] *In re Nikolas E*, 1998 WL 80328 (Maine Supreme Court).

[7] *Re IB*, supra, note 2.

[8] RSQ, c P-34.1, s 38(c),(e).

Court Rejects Appeal for Safe Supply of Medical Marijuana

As previously reported, in a May 1999 decision in *Wakeford* v *Canada*,[1] the Ontario Superior Court of Justice granted an HIV-positive man an "interim constitutional exemption" from the provisions in the *Controlled Drugs and Substances Act*[2] that make it an offence to possess or to produce or cultivate marijuana.

While Wakeford has been granted permission to cultivate and possess marijuana, he has no guaranteed, legal access to a safe, clean, affordable supply of the drug.

The Court found that there was "no real and meaningful" process in place whereby the federal Minister of Health could consider a request for ministerial exemption from the criminal prohibition on the basis of medical necessity. Therefore, the violation of Wakeford's rights to "liberty and security of the person" was contrary to "principles of fundamental justice," which contravenes the *Canadian Charter of Rights and Freedoms* (s 7).

In June 1999, the federal Minister of Health issued the first ministerial exemptions permitting two men with HIV/AIDS to possess and cultivate marijuana.[3] (Additional exemptions were announced in October 1999.[4] But in March 2000, a Saskatoon man with a number of painful ailments, including severe arthritis, fibromyalgia, and irritable bowel syndrome, who was still waiting for a decision on his application for a ministerial exemption, was sentenced to one years' probation for growing 12 plants in his bedroom for personal, medicinal use; a term of the probation included not possessing marijuana.[5]) The Minister also announced in June 1999 that he would authorize clinical trials on the medicinal use of marijuana.[6]

However, while Wakeford has been granted permission to cultivate and possess marijuana, he has no

guaranteed, legal access to a safe, clean, affordable supply of the drug. He has unsuccessfully tried to cultivate his own plants, and must purchase his supply from others. But anyone selling him marijuana, or even caregivers procuring it on his behalf, remain open to possible criminal prosecution. (In a case unrelated to Wakeford, in February 2000, Montréal police arrested two employees of the city's chapter of the Compassion Club, which provides marijuana for medical purposes. The employees were charged with possession and trafficking of narcotics after a search of the club's premises. Police also seized the names of 27 doctors who had recommended marijuana as treatment for their patients; police were reported as saying that prosecutors will decide whether to charge those physicians with counseling someone to commit an offence.[7])

In light of this unsatisfactory situation, in January 2000 Wakeford instituted further legal proceedings in the Ontario Superior Court of Justice, seeking a court order that the federal government provide him with the drug he is entitled to use, and an order granting immunity to his caregivers who put themselves in legal jeopardy by supplying him with marijuana or helping him to cultivate it.[8] His claim was heard in mid April. In May 2000, the Court rejected his request. Blenus Wright J was of the view that Wakeford has "no real difficulty in obtaining marijuana" and that the drug is "not the only avenue" that could alleviate the side effects of his medications. Wakeford said he would appeal.[9]

The same week that Wakeford's claim was heard, the Senate voted to appoint a Special Committee "to reassess Canada's anti-drug legislation and policies," to consult broadly with Canadians about social problems and specific needs associated with the trafficking and use of illegal drugs, and "to make recommendations for an anti-drug strategy developed by and for Canadians under which all levels of government ... work closely together to reduce the harm associated with the use of illegal drugs."[10] (For more details, see the article "Canadian Senate Committee to Review Drug Laws and Policies" in this issue of the *Newsletter*.)

– *Richard Elliott*

[1] [1999] OJ No 1574 (QL). See Elliott R. HIV/AIDS in Canadian courts in 1999: part 1. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(4): 21-24 at 21-22.

[2] SC 1996, c 19.

[3] Health Canada. Health Canada's Research Plan on Marijuana for Medical Purposes, 9 June 1999; Health Canada. News Release: Minister Rock tables status report on medicinal marijuana research plan. 9 June 1999; Medical marijuana approved. *Globe and Mail*, 10 June 1999.

[4] Rock approves pot use for 14 more. *Canadian Press*, 5 October 1999.

[5] Perreaux L. "You've sentenced me to a fate that is really worse than death." [Saskatoon] *StarPhoenix*, 23 March 2000.

[6] Health Canada. News Release: Update on Health Canada's initiatives on marijuana for medical and research purposes, 6 October 1999; Health Canada. Production of marijuana in Canada for research purposes [fact sheet], October 1999; Health Canada. Research in Canada on marijuana for medicinal purposes [fact sheet], October 1999.

[7] Wyatt N. Two charged with trafficking after police investigate club giving marijuana to the sick. *Ottawa Citizen*, 12 February 2000; Peritz I. Medical marijuana club raided. *Globe and Mail*, 12 February 2000.

[8] McCarten J. Marijuana-smoker going to court for safe supply. *Canadian Press*, 20 January 2000; Man sues feds to supply him medical marijuana. *Canadian Press*, 20 January 2000; Arab P. AIDS patient wants Ottawa to supply pot. *Canadian Press*, 12 April 2000.

[9] Ontario court rules Ottawa doesn't have to supply AIDS patient with marijuana. *CP Wire*, 2 May 2000.

[10] *Debates of the Senate* (11 April 2000), 2nd Session, 36th Parliament, Hansard Vol 138, Issue 47. Available online via Parliament website (www.parl.gc.ca).

Appeals Heard on Both Medical and Non-Medical Marijuana

In October 1999, the Ontario Court of Appeal heard an appeal in the case of *R* v *Parker*.[1] Terry Parker was charged in 1996, after a police raid on his home in which the marijuana plants he was growing to ensure a supply in order to control his epileptic seizures were confiscated.

Charges against him were stayed by an Ontario trial court in 1997 on the basis that the law violated his constitutional rights, and his plants were ordered to be returned to him. But that decision has been appealed by the federal Crown. Parker, with the support of the Epilepsy Association of Toronto as intervener, argued that the process for applying for a ministerial exemption remains problematic and that this process was not even in place at the time that Parker was charged in 1996 or the charges against him were stayed in 1997.[2]

At the same hearing, the Court of Appeal also heard an appeal dealing with the non-medicinal use of marijuana in the *Clay* case.[3] Chris Clay appealed his 1997 conviction for possession and trafficking charges for selling cannabis to an undercover police officer. The trial judge's review of the evidence had led the judge to conclude that moderate use

of marijuana causes no serious physical or psychological damage, and that criminal sanctions against marijuana had been enacted in a "climate of irrational fear." Nonetheless, he ruled that it was up to Parliament to decide whether to decriminalize, and rejected Clay's argument that the prohibition against cultivation and possession violates the right to life, liberty, and security of the person under the Charter (s 7) in a manner inconsistent with the principles of fundamental justice. Clay has argued that it is a violation of these principles: to prohibit, upon threat of criminal sanction, conduct that is relatively harmless; to impose a term of imprisonment for such conduct; to maintain this sanction in the face of majority opinion in Canada favouring decriminalization; to interfere with an individual's bodily autonomy in the absence of any compelling reasons for the interference; and to infringe upon the private medical, recreational, or sacramental use of an intoxicating substance.

Canadian trial courts have previously rejected claims that prohibiting marijuana is a violation of religion,[4] that the prohibition infringes freedom of conscience, expression, and association, and the right to be free from cruel and unusual treatment or punishment,[5] and that the prohibition infringes on the right to liberty and security because it infringes on the autonomous decisions about one's own health and bodily integrity.[6]

The Supreme Court of Canada has also previously refused leave to appeal a decision by the Québec Court of Appeal that upheld the prohibition on cultivating and possessing cannabis as constitutional.[7] In the *Hamon* case, the Québec court had rejected challenges to the law as both a violation of the Charter's equality rights clause (s 15) and the right to not be deprived of liberty or security of the person except in accordance with the principles of fundamental justice (s 7). The appellate court ruled that the law does not violate the equality rights of cannabis users, as they are "not a class of persons covered" by the protection of the Charter's equality rights provision (s 15). It had also ruled that Parliament's decision to prohibit cannabis while permitting the use of alcohol and tobacco is not "arbitrary" or "irrational," and therefore could not be said to infringe liberty and security of the person in a manner inconsistent with the "principles of fundamental justice," but that even if this were the case, "our cultural traditions" would permit the state to prohibit marijuana use while still permitting the use of alcohol.

As of the time of writing, the Court of Appeal had not yet released a decision in either the *Clay* or *Parker* appeals.

– *Richard Elliott*

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[1] *R* v *Parker* (1997), 12 CR (5th) 251, [1997] OJ No 4923 (Prov Ct) (QL).

[2] Tyler T. Pot laws unfair to sick, court told. *Toronto Star*, 9 October 1999, A13.

3 *R* v *Clay* (1997), 9 CR (5th) 349, [1997] OJ No 3333 (Gen Div) (QL).

[4] *Tucker* v *Canada*, [1999] FCJ No 1947 (TD) (QL) (13 December 1999).

[5] *R* v *Malmo-Levine*, [1998] BCJ No 1025 (BCSC) (QL).

[6] *R* v *Caine*, [1998] BCJ No 885 (Prov Ct) (QL).

[7] *R* v *Hamon* (1993), 85 CCC (3d) 490, leave to appeal to SCC refused 85 CCC (3d) vi, [1994] 1 SCR viii.

BC Appellate Court Dismisses Insurance Appeal

As reported in the last issue of the *Newsletter*, in September 1997 a British Columbia trial court had dismissed a "wrongful dismissal" claim by the estate of a gay man who died of AIDS against his former employer for damages arising out of his termination, including the loss of his life insurance coverage.[1] The man's estate appealed that decision to the BC Court of Appeal. The Canadian AIDS Society and the BC Persons with AIDS Society were denied leave to intervene before the appellate court to make submissions.[2] The case was heard in October 1999 by the British Columbia Court of Appeal. In December 1999, the Court released its judgment dismissing the appeal.[3]

The employer, BC Rail, terminated A "without cause" in part because of his declining performance and a seeming loss of interest in his job in the two years preceding his termination. A did not tell his employer that he had HIV disease, although his health began to deteriorate in the 18 months prior to his termination. It was agreed that BC Rail had dismissed A without cause, and that he was entitled to five months' notice of termination (or pay in lieu thereof), and the employer agreed to pay A's estate five months' salary as compen-

sation. However, the point of contention that was the subject of the litigation was A's loss of employment benefits – in particular, life insurance coverage under two policies. A's condition deteriorated quickly following his dismissal, and he died within the five-month notice period. Had the employer given A the five months' notice of termination to which he was entitled, his estate would have received the proceeds under these policies.

However, there is a legal principle that a wronged plaintiff may not recover avoidable losses. In other words, as a general rule, anyone suing for damages for a breach of contract (such as an employment contract) is under an obligation to take reasonable steps to mitigate their losses (eg, look for another job), and is not entitled to be compensated for any losses they could have avoided by taking such reasonable steps. The issue before the Court of Appeal, therefore, was whether, after being wrongfully dismissed, A made these reasonable efforts to mitigate his losses.

A had roughly two months after the date of his dismissal in which he could apply to convert his group life insurance policies to individual policies. However, A's health worsened quickly after his termination. About two weeks before the end of this "conversion period" he was diagnosed with HIV-related dementia and was determined by his physician as no longer being capable of making decisions of this sort. He died ten days after this diagnosis, without having filed an application with the insurance company to convert his policies.

It was agreed that, had A converted his policies before he died, his estate would have received $200,000 in proceeds from the insurance company. However, the defendant, BC Rail, argued that it should not be liable for this amount because, had A taken the reasonable step of converting his life insurance policies, this loss would have been avoided. The trial judge agreed with the employer. On appeal, A's estate argued that the court should take both A's "diminishing mental capacity" and the employer's conduct into account in considering the reasonableness of A's efforts to mitigate his damages from having been terminated.

First, A's estate argued that an employer should be required to take steps to ensure that an employee with diminished mental capacity protects his own interests with respect to employment benefits. In this case, this would have required BC Rail to assist A in mitigating his losses by providing the necessary assistance to ensure that A had applied to convert his life insurance policies. However, writing for all three judges on the BC Court of Appeal panel, Huddart JA dismissed this argument because of the

> lack of evidence that the employer had knowledge of A's physical and mental condition as opposed to suspicions based on his work performance and physical appearance.... In the absence of circumstances giving the employer reason to monitor an employee's capacity to make decisions about benefits or actual knowledge of such incapacity, I would leave for another day consideration of whether an employer's conduct is a factor relevant to the assessment of damages in cases with avoidable losses.[4]

Second, A's estate argued that the trial judge erred when considering what A would likely have done had he remained capable of making choices. Since A lost his mental capacity before the period for converting his insurance policies had expired, his estate argued that his duty to mitigate his losses from his dismissal ended at the point when he lost his capacity. And, the estate argued, looking at A's conduct between the date of his dismissal and the date he was diagnosed as incapable, the trial judge should have concluded that he was taking reasonable steps to protect his interests, taking into account his physical, emotional, and mental condition at that time.

However, the Court also rejected this argument, saying that before he became incapable, A did meet with someone in the benefits and compensation department at BC Rail and also met with a lawyer regarding the preparation of his will. But he did not, before he became incapable, convert his insurance policies. In the Court's view,

> there can be little doubt that a reasonable person in A's position would have converted his life insurance policies at the first available opportunity. A did not do so for as long as he was capable.... For whatever reason, perhaps simple inattention, A did not minimize his damages. His failure to take a simple step in mitigation of them in the face of his rapidly declining health when he was dealing with his will and his claim for a severance payment was the cause of the loss."[5]

– Richard Elliott

[1] *EE* v *ER*, [1997] BCJ No 1966 (SC) (QL). See Elliott R. AIDS organizations denied leave to intervene in insurance case. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 5(1): 11.

[2] *A Estate* v *BC Rail Ltd*, [1999] BCJ No 2243 (CA) (QL).

[3] *A Estate* v *BC Rail Ltd* [*BCSC sub nom EE* v *ER*], 1999 BCCA 773, [1999] BCJ No 2941 (QL).

[4] Ibid, paras 9-15.

[5] Ibid, paras 20, 23.

Man with HIV Gets Reprieve from Deportation

On 4 November 1999, the Federal Court (Trial Division) lifted a "removal order" just hours before a man with AIDS was to be deported to El Salvador, his country of origin.[1]

Jose Mauricio Jimenez came to Canada in 1989 and claimed refugee status, after having lived several years in California, where he worked as a prostitute. During that time, he was convicted of at least three prostitution-related offences, as well as resisting arrest. He did not disclose his convictions when he applied for refugee status, fearing they would make him ineligible. During a medical examination required by immigration officials, Jimenez was diagnosed as HIV-positive. In 1990, he was convicted of assault with a weapon after using a knife to threaten a man who had disclosed his status to others. He received a suspended sentence and two years' probation, but immigration officials issued an order that he be removed from Canada. He appealed that order, eventually filing an application for permission to remain in Canada on "humanitarian and compassionate grounds."[2]

In August 1999, Jimenez was informed by the federal Department of Citizenship and Immigration that his application had been denied. He filed an application for leave to have this decision judicially reviewed by the Federal Court, arguing that he had been given no written reasons for the decision to deny his "humanitarian and compassionate grounds" application, and that he had no knowledge of, or access to, a physician's report relied upon by the review officer who denied his application. In early October 1999, he was issued an order to report on 2 November 1999 to be removed from Canada. At the end of October 1999, he filed a motion to stay the removal order pending the outcome of his application for judicial review.

Applying the three criteria for determining whether to grant a stay, Justice Blais agreed that (1) Jimenez had a "serious issue" to raise at the judicial review hearing, namely the lack of written reasons and no access to evidence relied upon in denying his application; (2) given the contradictory evidence regarding the availability of medication in El Salvador and the grave consequence the lack of medication would have on him, Jimenez could suffer "irreparable harm" if deported; and (3) because Jimenez would experience rapid clinical decline and early death if his access to antiretroviral therapy and treatment for opportunistic illnesses were compromised, the "balance of convenience" favoured staying the deportation order pending disposition of the application for leave and judicial review.

– Richard Elliott

[1] *Jimenez* v *Canada (Minister of Citizenship and Immigration)*, [1999] FCJ No 1668 (TD (QL)).

[2] Duffy A. Ex-prostitute with AIDS wins deportation delay. *Windsor Star*, 20 November 1999, A11.

Discrimination in Employment Alleged

In April 2000, former stockbroker DeWolf Shaw filed a $340-million civil suit in the Québec Superior Court against First Marathon Inc.

Shaw accuses his former employer (and several former bosses and colleagues) of harassment and discrimination. He had already filed complaints in April 1999 with the Québec Labour Standards Commission and the provincial Human Rights Commission.

Shaw alleges that First Marathon began harassing him and discriminating against him in 1996, and then fired him in January 1999, because of his sexual orientation and because he is HIV-positive. First Marathon's position is that he was fired because of his "erratic" work behaviour.[1]

[1] Blackwell R. Fired First Marathon broker files $340-million lawsuit. *Globe and Mail*, 12 April 2000, B8.

Federal Court of Appeal Strikes Claim for Extending Patent Term

In a short October 1999 decision, *Pfizer Inc* v *Canada*,[1] the Federal Court of Appeal affirmed a lower court decision that Canadian law currently provides only 17 years protection for drug patents filed before October 1989, and that the 20-year minimum period stated in intellectual property treaties negotiated under the auspices of the World Trade Organization have not (yet) taken effect in Canada with respect to these drugs.

Glaxo Wellcome's patent on AZT was applied for, and issued, in June 1988, so it too should only be of 17 years' duration.

While the case did not concern an antiretroviral medication or other drug commonly prescribed for opportunistic infections, it did concern the antidepressant drug marketed by Pfizer Inc under the trade name Zoloft™ and so is of significance to people with HIV/AIDS in Canada, both because of the medication in question and because of what the case says generally about Canadian patent law for pharmaceutical products.

Pfizer Inc owns the Canadian patent on the compound *sertraline hydrochloride*, marketed as Zoloft™ for the treatment of depression. It received its patent in August 1982. In 1992, Pfizer received a Notice of Compliance ("NOC") from the federal Minister of Health, the authorization required under the *Food and Drugs Act*[2] to legally market the drug in Canada. The *Patent Act*[3] provides that, where any patent application was filed before October 1989, the expiry date of that patent is 17 years from the date of issuance. (Where the patent application has been filed after October 1989, the term of patent protection is 20 years from the date of filing the application.) This meant that, under the *Patent Act*, Pfizer's patent on Zoloft™ would expire at the end of August 1999, 17 years after its patent was issued. (As an aside, Glaxo Wellcome's patent on AZT was applied for, and issued, in June 1988, so it too should only be of 17 years' duration. The outcome of Pfizer's case is therefore of relevance to people receiving AZT.[4])

Pfizer began a civil action in April 1999, seeking a court declaration that its patent on Zoloft™ be extended until the end of October 2000 (another 14 months), and interim and permanent injunctions prohibiting the Minister of Health from issuing an NOC to any other drug manufacturer until the expiry of Pfizer's patent. (Once the patent has expired, the Minister is free to issue an NOC that would permit another manufacturer to sell that pharmaceutical product.) Pfizer based its action on the Agreement on Trade-Related Aspects of Intellectual Property Rights ("TRIPS Agreement"), an international agreement to which Canada is a party and which is administered and enforced by the World Trade Organization (WTO). Article 33 of the TRIPS Agreement requires member countries to provide for all patents a minimum 20-year term of protection from the date of filing a patent application. Since Pfizer applied for its Zoloft™ patent at the end of October 1980, it claimed that, under the TRIPS Agreement, its patent does not expire until the end of October 2000.

The Canadian Drug Manufacturers Association, an industry association representing generic drug manufacturers, was given leave to intervene in the case.[5] Apotex, a generic drug manufacturer, had sought to receive an NOC for its generic version of Pfizer's patented drug, solely for the purpose of beginning the necessary paperwork to have the generic version placed on provincial "formularies" so that it could begin sales immediately upon Pfizer's patent expiring. Apotex had undertaken that it would not sell its generic drug until that time. However, this move by Apotex was what prompted Pfizer's application for an injunction to prohibit the Minister from issuing any NOC to any other manufacturer. Apotex

argued that this application for an injunction was "frivolous, vexatious and otherwise constitutes an abuse of process," but was unsuccessful in having Pfizer's application struck out.[6]

The federal government, however, also moved to strike out Pfizer's entire claim, and the case was heard in June 1999. Pfizer argued that Canada agreed to submit to the provisions of the TRIPS Agreement when it signed off on the agreement that established the WTO.[7] The WTO Agreement states that each member shall ensure that its laws, regulations, and administrative procedures conform to its obligations – including obligations under the TRIPS Agreement, which is annexed to the WTO Agreement. In 1994, Parliament enacted the *World Trade Organization Agreement Implementation Act*[8] to amend certain Canadian statutes "in order to give effect to the Agreement," including the annexed TRIPS Agreement.

In his July 1999 decision,[9] Lemieux J of the Federal Court (Trial Division) examined the *World Trade Organization Agreement Implementation Act* carefully, noting that while it amended a host of other statutes, it did not make any amendments to the *Patent Act* that were relevant to this case before the Court – in particular, it says nothing about the term of patent protection. He concluded that "it is plain and obvious" that Parliament had not legislated the TRIPS Agreement –including Article 33, which was the basis of Pfizer's claim for extending the term of its patent – into federal domestic law:

> The term of a patent is a matter governed by the *Patent Act*. Parliament did not change the provisions of ... that Act to provide what Pfizer is seeking. Statutory change was required and Parliament did not make that change. Whether Parliament, in doing so, was in breach of its international obligations is not material to the question before me. The WTO Agreement has procedures, government to government, to deal with a question of that nature.[10]

Lemieux J therefore struck out Pfizer's claim, as it had no basis in Canadian law.

Lemieux J also considered briefly two provisions in the *World Trade Organization Agreement Implementation Act* that provide statutory bars to Pfizer's claim. Sections 5 and 6 of the Act state that no cause of action exists, and no proceeding of any kind may be taken, without the consent of the Attorney General of Canada, to enforce or determine any right or obligation that arises solely under, or by virtue of, the WTO Agreement or of the federal government's approval of the WTO Agreement. The Court ruled that these barred Pfizer's claim.

Pfizer argued that these sections are unconstitutional because they violate the section of the *Canadian Bill of Rights* that says that "no law of Canada shall be construed or applied so as to ... deprive a person of the right to a fair hearing in accordance with the principles of fundamental justice for the determination of his rights and obligations."[11] Lemieux J dismissed this argument, finding that this clause was of no application to this case and did not confer the kind of substantive rights that Pfizer was claiming.

In its short ruling in October 1999, the Federal Court of Appeal agreed with Lemieux J that it is "plain and obvious" that Pfizer's case could not succeed. They dismissed Pfizer's appeal.At the time of writing, no application for leave to appeal to the Supreme Court of Canada was reported as having been filed.

– Richard Elliott

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[1] [1999] FCJ No 1598 (FCA) (QL).

[2] RSC 1985, c F-27.

[3] RSC 1985, c P-4, s 45.

[4] For a discussion of litigation regarding a patent dispute between Glaxo Wellcome and generic drug manufacturers in Canada, see: Elliott R. HIV/AIDS in Canadian courts in 1998: an overview. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(2/3): 9 at 11-12 ("Court Rules on Patent Dispute over AZT – Appeal Still Outstanding").

[5] [1999] FCJ No 957 (TD) (QL).

[6] *Pfizer Canada Inc* v *Apotex Inc*, [1999] FCJ No 959 (TD) (QL).

7 Marrakesh Agreement Establishing the World Trade Organization, 15 April 1994, Marrakesh, 1867 UNTS 3.

[8] SC 1994, c 47.

[9] *Pfizer Inc* v *Canada*, [1999] 4 FC 441, [1999] FCJ No 1122 (TD) (QL).

[10] Ibid at para 46.

[11] RSC 1985, Appendix III, s 2(e).

Supreme Court Rules on Disability Discrimination

cont'd from page 1

they had been discriminated against on the basis of "handicap."

The Québec *Charter of Human Rights and Freedoms*, the provincial anti-discrimination statute, prohibits discrimination in employment on the basis of "a handicap or the use of any means to palliate a handicap."[2] It also provides that "a distinction, exclusion or preference based on the aptitudes or qualifications required for employment ... is deemed non-discriminatory."[3] Another provincial statute intended to ensure the equality rights of those with disabilities defines a "handicapped person" as "a person limited in the performance of normal activities who is suffering, significantly and permanently, from a physical or mental deficiency, or who regularly uses a prosthesis or an orthopedic device or any other means of palliating his handicap."[4]

Brossard J of the Human Rights Tribunal dismissed two of the complaints.[5] He rejected the notion that a handicap could be subjectively perceived. While anti-discrimination statutes in other provinces specifically prohibited discrimination based on "perceived" disability, he found that the language in the Québec statute was not to be interpreted this way (even though he acknowledged that a purposive interpretation of the legislation was required, one that would promote the integration of people with disabilities into society). He therefore concluded that, without functional limitations, the complainants did not have a "handicap" under the law and so could not file a complaint of discrimination. He also took the view that a person's state of health cannot be a "handicap" because he felt that recognizing a handicap where there is no functional limitation would somehow "trivialize" the anti-discrimination statute.

In contrast, in the third case, Rivet J of the Human Rights Tribunal favoured a "broad interpretation of the term handicap." She therefore concluded that an assessment or identification of a handicap could be objective or purely subjective, and that excluding a person from employment based on the *perception* that they are disabled still amounts to discrimination based on "handicap." She therefore upheld the human rights complaint of this third complainant.[6]

The Québec Court of Appeal agreed with Rivet J that a broad interpretation of "handicap" was required, noting that this was consistent with the constitutional standards set out in the *Canadian Charter of Rights and Freedoms*, and with extensive case law affirming that human rights legislation is to be given a liberal, purposive interpretation that is flexible and allows the law to be adapted to changing social conditions and evolving concepts of human rights.[7] The employers appealed this decision even further, to the Supreme Court of Canada – a surprising decision, given the clear weight of the case law supporting the Court of Appeal's decision.

Indeed, the Supreme Court of Canada resoundingly affirmed this approach. Writing for a unanimous court, Madam Justice L'Heureux-Dubé repeated the fundamental point that:

> The objectives of the [Québec] Charter, namely the right to equality and protection against discrimination, cannot be achieved unless we recognize that discriminatory acts may be based as much on perception and myths and stereotypes as on the existence of actual functional limitations. Since the very nature of discrimination is often subjective, assigning the burden of proving the objective existence of functional limitations to a victim of discrimination would be to give that person a virtually impossible task. Functional limitations often exist only in the mind of other people, in this case that of the employer.
>
> It would be strange indeed if the legislature had intended to enable persons with handicaps that result in functional limitations to integrate into the job market, while excluding persons whose handicaps do not lead to functional limitations. Such an approach appears to undermine the very essence of discrimination.

> ... [T]he Charter's objective of prohibiting discrimination requires that "handicap" be interpreted so as to recognize its subjective component. *A "handicap", therefore, includes ailments which do not in fact give rise to any limitation or functional disability.*[8]

The Supreme Court noted that a number of ailments have been recognized as sustaining a claim of discrimination based on disability, even though they may not (at the time) result in functional limitations. This includes the status of being HIV-positive, as was recognized in the *Thwaites* case of an HIV-positive member of the armed forces.[9]

The Court also expressly ruled that, while the biomedical basis of "handicap" must be considered, for the purposes of anti-discrimination legislation

> we must go beyond this single criterion. Instead, a multi-dimensional approach that includes a socio-political dimension is particularly appropriate. By placing the emphasis on human dignity, respect, and the right to equality rather than a simple biomedical condition, this approach recognizes that the attitudes of society and its members often contribute to the idea or perception of a "handicap". In fact, a person may have no limitations in everyday activities other than those created by prejudice and stereotypes.... [A] "handicap" may be the result of a physical limitation, an ailment, a social construct, a perceived limitation or a combination of all of these factors. Indeed, it is the combined effect of all these circumstances that determines whether the individual has a "handicap" for the purposes of the Charter.... The aim of the multi-dimensional analysis ... is not only to eliminate discrimination against persons with handicaps; its goal is also to put an end to the "social phenomenon of handicapping" ... and to eliminate discrimination and inequality, generally.[10]

A "handicap "includes ailments which do not in fact give rise to any limitation or functional disability.

Such a clear direction from the Court is to be welcomed, particularly because it continues to place concerns of dignity at the centre of equality rights analysis, and focuses on the social context in which discrimination occurs, avoiding technical, narrow interpretations of the law that leave people without adequate protection against discrimination.

– *Richard Elliott*

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[1] *Québec (Commission des droits de la personne et des droits de la jeunesse)* v *Montréal (City)*; *Québec (Commission des droits de la personne et des droits de la jeunesse)* v *Boisbriand (City)*, 2000 SCC 27, [2000] SCJ No 24 (QL).

[2] RSQ c C-12, ss 10, 16.

[3] Ibid, s 20.

[4] *An Act to ensure the handicapped in the exercise of their rights*, RSQ, c E-20.1, s 1(g).

[5] (1996), 25 CHRR D/407 and D/412, [1995] JTDPQ No 4 and No 5 (QL) (Que Hum Rts Tribunal).

[6] (1996), 25 CHRR D/474 (Que Hum Rts Tribunal).

[7] [1998] RJQ 688, 33 CHRR D/149, [1998] QJ No 369 (QL) (CA).

[8] *Québec (CDPJ)* v *Montréal; Québec (CDPJ)* v *Boisbriand*, supra, note 1 at paras 39-41 (QL). [emphasis added]

[9] *Thwaites* v *Canada (Armed Forces)* (1993), 19 CHRR D/259 (Can Hum Rts Tribunal).

[10] *Québec (CDPJ)* v *Montréal; Québec (CDPJ)* v *Boisbriand*, supra, note 1 at paras 77, 79, 83 (QL).

AIDS VACCINES

HIV Vaccine: Ethics and Human Rights

The ethical dilemmas of vaccine development are particularly acute with respect to HIV because of the nature of the virus itself and the social setting of prejudice and stigma in which the virus operates, argues Justice Michael Kirby in an article first printed in the [Australian] *National AIDS Bulletin*,[1] reprinted here with permission.

Ethical perceptions will be in a constant state of evolution. Like the virus itself, they are unstable and continuously mutating.

It is exactly two hundred years since Edward Jenner released his study on the first vaccine against smallpox.[2] One by one, other conditions have responded to immunisation: yellow fever, plague, polio, diphtheria, tetanus, typhoid, whooping cough, rabies. Most of these conditions are produced either by bacteria (such as typhoid) or by a comparatively stable virus (such as smallpox). HIV/AIDS presents particular challenges to vaccine development. Those challenges stem from the features of HIV itself and of the social context in which this particular virus manifests itself.

One of the first lessons I learned in evaluating the ethical issues presented by HIV/AIDS, the prevention of its spread and response to its outcomes, was taught to me fifteen years ago by Dr June Osborn. Good ethics on this, as on most similar issues, will grow out of good science – a thorough understanding of the scientific facts. Because our knowledge about the HIV virus, and the particular strains[3] by which it differentially manifests itself, is constantly expanding, it is inevitable that ethical perceptions will also be in a constant state of evolution. Like the virus itself, they are unstable and continuously mutating.

Some elements of stability can, however, be introduced into ethical discourse on this subject by constantly returning to fundamental principles. Relevantly, these may be found in the great charter of human rights known as the Universal Declaration of Human Rights and in the Declaration of Helsinki.[4] These and other international statements of principle establish three central requirements to govern the ethics of prophylactic or therapeutic research into HIV involving human beings:

- First, respect for persons: their autonomy in decision-making and self-determination;
- Secondly, beneficence: maximising benefits and minimising harms; and
- Thirdly, distributive justice: that is, equitable distribution of both the burdens and benefits of participation in research.[5]

The defects and suggested inadequacies of the Helsinki Declaration to respond to the complex problem of HIV/AIDS, the human genome and so on has led to controversial suggested changes in the Declaration which are before the World Medical Assembly.[6] The late Jonathan Mann pointed out that the Helsinki Declaration makes no specific reference to issues related to patients' rights or to medical treatment as a fundamental human right.[7] But he also taught that the HIV/AIDS pandemic has, from the start, been concerned with ethics. Ethics at a national level by reason of the modes of transmission of this virus and the stigma, shame, prejudice and legal sanctions which acquisition of the virus involves. But also macro-ethics: looking at the pandemic from a global perspective. Such a perspective demands access to HIV prevention and therapy in developing countries as a global issue of equity and basic human rights.[8]

The Basic Principles

In considering the ethical issues presented by HIV vaccines, it is easy to lose one's way. These two

guideposts should therefore be remembered:

- Base your judgements on the best available science, recognising that science is constantly changing and that its subject matter, HIV/AIDS, not only produces different pathological strains of the virus in different countries but also different pathologies of social prejudice, fear and stigma; and
- When in doubt about a particular issue, return to universal norms. There are not two global statements of fundamental human rights – one for the developed world and another for developing countries.[9] There are only universal principles, although their application may sometimes vary in different environments.

Out of recognition of the need to develop global principles which will be in place as vaccine trials are multiplied in both developing and developed countries, UNAIDS has been preparing a "Guidance Document" on Ethical Considerations in HIV Preventive Vaccine Research.[10] The preparation of this document has involved a long and complex process reflecting the controversies which such an attempt inevitably produces. We should not be surprised about such controversies and the differences they reflect. They arise out of the many tensions that exist in this area:

- Between the perspectives and sense of urgency of developing countries and those of developed societies that feel that the worst phase of the pandemic may be behind them;
- Between those who see the priority as the development of a prophylactic vaccine and those who view vaccines as part of the strategy of therapy to help those already infected with HIV;
- Between governments and agencies that want immediate action and pharmaceutical corporations fearful of civil liability, dubious of short-term profits, inclined to hasten slowly, and vice versa;
- Between old-time vaccinologists looking for an answer to HIV/AIDS in the tried and trusted medical model and the communities with long-term experience of this pandemic who fear any diversion of funds and energy from education, behaviour modification and prevention of spread, which has been the strategy to date in default of an effective vaccine and affordable therapy; and
- Between the politicians and others looking for a quick fix that will relieve them from having to deal with stigmatised groups – homosexuals, sex workers, injecting drug users and the like. And those groups, energised by the pandemic, into demands for wider reforms of the law and of social attitudes.

The resolution of these debates will yield the answers to some of the ethical questions presented by the development, testing and use of HIV vaccines.

A Threshold Question: A Vaccine at All?

A threshold question is whether the development and trial of an HIV vaccine at this stage can be supported on ethical principles. There are those who express doubts. They suggest, for example:

- That we do not know enough about this unstable virus to be progressing to the risky undertaking of a trial of a vaccine to prevent its spread. Already the attempt of French vaccine researchers in the former Zaire indicated the risks of premature intervention.[11] There is also the peril of researcher egos and political pressure[12] and the special complications with this virus because of its mutations and local variations.[13]
- That trials in the United States have been discontinued because legal liability for mishaps would be scrupulously enforced in the courts.[14] They look suspiciously on the shift to developing countries where official approvals are more readily secured, individual consent can be obtained by community deals and legal liability if things go wrong is no big problem;[15]
- That we may see a repetition of the scientific imperialism which marked the Tuskegee study that denied penicillin to indigenous victims of syphilis even after it was widely available in the United States[16] or the radiation of human subjects which exposed living people to unknown and dangerous risks;[17]
- That there is a peculiar possibility that this virus, because of its high volatility, may "unattenuate" from an attenuated strain, such that a dead virus may come back to life, threatening the person vaccinated with it.[18]

These are legitimate ethical concerns that have to be answered. The response to some of them will depend upon the best available scientific knowledge. Clinical trials on animal subjects must first be attempted. Yet these have clear limits in HIV because, as in the past, the human response cannot be exactly replicated, or replicated at all, even in the animal closest to the human

species, the chimpanzee.[19] In the end, it is essential to take some measured risks.[20] These should be taken with a clear appreciation of the urgency which faces humanity. That urgency derives from three basic factors:

- HIV is the fastest spreading new pathogen threatening life in the world today. It is estimated that every day 16,000 new HIV infections occur;[21]
- Behaviour modification is a very slow and imperfect process. For any degree of effectiveness, it is necessary to challenge entrenched religious, moral, social and other sources of resistance and this is never easy or wholly successful; and
- In developing countries there is no time to overcome social resistance. As one Health Minister observed: "If you don't get on with this soon ... there will be no one left to test."[22]

This is why, on a macro level, it has been declared that the only "realistic" way to deal with the HIV/AIDS epidemic in many parts of the world is by vaccines.[23] It is why in recent years there has been a renewed commitment of governmental leaders to the development of HIV vaccines.[24]

We must recognise that not to take a decision to trial scientifically promising vaccines is itself to make an ethical decision. Even a low-efficiency limited-impact vaccine, used in places of major spread of HIV and protecting some individuals at primary risk to spread and receive the virus would, on mathematical population models, have a huge impact on this particular pandemic.[25] In any case, vaccine trials are now beginning. If too long delayed, the energy, investment and interest of the private sector entrepreneurs, essential for their practical success, might be lost.[26] In these circumstances, some risks may ethically be taken. Indeed, they will be taken as the trials progress. However, especially because many or most of the trials will take place in developing countries,[27] it is essential that those countries themselves, UNAIDS and voices of principle everywhere should insist upon the observance of fundamental ethical principles that respect the human dignity and rights of those involved in the trials, without forgetting the human dignity and rights of those who will benefit, even only partially at first, should the trials (or some of them) prove successful.

> It is essential that every HIV trial should have a guardian, a human rights ombudsman, to remind the politicians, scientists, investors and all concerned that HIV is a virus with special implications and dangers for human rights and ethics.

Ethical Rules for the Conduct of Trials

It is impossible to outline more than the main ethical considerations which must inform trials of HIV vaccines. Useful checklists for the conduct of vaccine trials in developing countries have been produced.[28] In approaching these questions, we can learn from the responses to analogous ethical quandaries:

- From the testing of HIV drugs in developing societies where there is no real prospect that such drugs will become commonly available in the societies concerned;[29] and
- From the suspension of the Human Genome Diversity Project because some of the developing societies subject to experimentation and study felt that they would be unfairly excluded by patent laws from any benefit as a result of their cooperation.[30]

At the risk of arbitrary choice of some only of the priorities for ethical reflection, in this context I would mention five:

- The need for close community involvement and education in vaccine development to ensure the recruitment of informed volunteers, true informed consent of those involved, continuing HIV education and health and other support for those participating in trials, particularly should they seroconvert;
- The development of health infrastructures generally, to improve the provision of basic healthcare to those in the target populations in developing countries. In short, host countries that participate in such trials, as well as the people who take part in them, must reap a just return ("the vaccine dividend") if, as a result of the trials, commercial vaccine development goes ahead;
- Those who participate in trials must continue to receive the HIV education messages because such messages are the only certain and available means of reducing their risk. Indeed, education of the community generally is essential as vaccine trials are carried out. There must be no let-up in the general effort to promote behaviour modification generally, as well as in the trial group, which has produced measurable results in countries such as Thailand and Uganda;
- Informed consent for entry into trials requires sensitive attention to local customs and values. It is here that, in developing countries, the involvement of community repre-

sentatives in the development of protocols will sometimes take a different direction than occurs in developed societies. Yet the individual is precious and has fundamental human rights in every society. The same basic norms must be observed. This will require an ethical commitment which is unwavering for the support and welfare of vaccine trial participants and their families;

- For those trial participants who seroconvert during the trial, it is essential that they then be offered the best-proven standard of treatment (although exactly what this means is debatable). In advance of the trial beginning, those in charge should fix and publish the circumstances of termination of their trial and the provisions they will make for any that may suffer or be disappointed.[31] They must address the compensation package for those who seroconvert. They must specifically address the problems of discrimination against, and stigma towards, people participating in trials[32] and people who, after the trial, present as HIV-positive (even if not seroconverted), with all of the practical and legal disadvantages that that can entail.[33]

It is essential that every HIV trial should have a guardian, a human rights ombudsman, to remind the politicians, scientists, investors and all concerned that HIV is a virus with special implications and dangers for human rights and ethics.

A Further AIDS Paradox

What is the basic reason for renewed vigilance about ethics in connection with the trials of an HIV vaccine? To answer that question requires us to acknowledge a new AIDS paradox. Years ago, before vaccines, we came to know the first AIDS paradox. This is that, paradoxically, the most effective way to promote behaviour modification essential to reducing transmission of HIV is not criminal law and punishment. It is protection of the vulnerable who are at risk, and effective defence of their basic human rights. Only then will such persons be receptive to the messages and means necessary for self-protection and the protection of others.

An ethical respect for the human rights of trial participants must place life before quick results; informed consent and thorough counselling before long-term profits; the uninfected today before the uninfected tomorrow.

Now we have a new HIV paradox. Ethics requires that those participating in HIV vaccine trials must be alerted, counselled and reinforced in the lessons of behaviour modification. They must not put their faith in the vaccine. Whether receiving the experimental product or the placebo, they must be constantly reminded of the messages about avoiding exposure to the virus. Yet, paradoxically, the effectiveness of the trial will only be proved if some participants do not receive or ignore these messages and become infected.[34] In this sense those promoting a vaccine have, potentially, an interest in the seroconversions of those receiving the placebo. They have an interest in the exposure to risk of those who have received the vaccine. In non-life threatening vaccine trials (mumps, measles and so on)[35] such potential conflicts of interest may be tolerable. Where HIV/AIDS is concerned, they are not. They require the greatest possible vigilance. An ethical respect for the human rights of trial participants must place life before quick results; informed consent and thorough counselling before long-term profits; the uninfected today before the uninfected tomorrow.

HIV/AIDS is a challenge full of dilemmas and paradoxes, scientific and ethical. Whoever we are, scientists or laity, we have imperfect understanding. We see the road ahead, including the ethical road, through a glass darkly; yet we must respond to the puzzles urgently face to face. Our hopes and prayers must be that we have "enough wisdom to make the right decisions, strength and courage to continue to discuss and confront the hard issues and luck to make it all work."[36]

– Michael Kirby

Michael Kirby is a Justice of the High Court of Australia, a member of the UNESCO International Bioethics Committee and the Human Genome Organization, and a former member of the WHO Global Commission on AIDS.

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[1] *National AIDS Bulletin* [Australia] 1999; 13(2): 16-19.

[2] Jenner E. *An Inquiry into the Causes and Effects of the Variolae Vaccinae* (1798); *Further Observations on the Variolae Vaccinae* (1799).

[3] United Kingdom. National AIDS Manual, AIDS Reference Manual. Keith Alcorn (ed), 1998- 99, at 276.

[4] Declaration of Helsinki. Recommendations Guiding Physicians in Biomedical Research Involving Human Subjects, adopted by 18th World Medical Assembly, Helsinki, Finland, 1964; amended 29th World Medical Assembly, Tokyo, Japan, 1975; 35th World Medical Assembly, Venice, Italy, 1983; 41st World Medical Assembly, Hong Kong, 1989. Cf Thomas J. Ethical challenges of HIV clinical trials in developing countries. *Bioethics* 1998; 12: 320 at 322.

[5] Thomas, ibid at 322.

[6] Schuklenk U. The ethics of clinical AIDS vaccine trials in developing countries – a critical commentary. *Monash Bioethics Review* 1994; 13: 13. The author criticises the views of Christakis N. The ethical design of an AIDS vaccine trial in Africa. *Hastings Center Report* 1988; 18(3): 31.

[7] Mann JM. HIV/AIDS, micro-ethics and macro-ethics. *AIDS Care* 1998; 10(1): 5-6. See also Thomas, supra, note 4 at 322.

[8] Thomas J. Access to AIDS treatment in developing countries: a global issue of equity and human rights. *AIDS Analysis Asia* 1998; 4(2), noted in Thomas, supra, note 4 at 325.

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[9] Thomas, supra, note 4 at 326.

[10] See the summary and comment by David Patterson in this issue of the *Newsletter*.

[11] Lurie P and Ors. Ethical, behavioral and social aspects of HIV vaccine trials in developing countries. *Journal of the American Medical Association* 1994; 271: 295 at 296.

[12] Schuklenk U. Unethical Perinatal HIV Transmission Trials Establish Bad Precedent. *Bioethics* 1998; 12: 312 at 315; Lurie & Ors, supra, note 11 at 296.

[13] Ibid.

[14] Schuklenk, supra, note 6 at 13.

[15] Ibid at 14.

[16] Resnik DB. The ethics of HIV research in developing nations. *Bioethics* 1998; 12: 286 at 301ff.

[17] Ibid at 306.

[18] *The Economist*, 4 July 1998.

[19] Grady C. HIV Preventive vaccine research: selected ethical issues. *Journal of Medicine and Philosophy* 1994; 19: 596 at 598.

[20] See US Code of Federal Regulations, 45 CFR 46.116(4) [the subject must be "informed of appropriate alternative procedures or courses of treatment if any that may be advantageous to the subject"] and 45 CFR 46.111(2): ["the risks to subjects [must be] reasonable in relation to the anticipated benefits, if any, to subjects and the importance of the knowledge that may reasonably be expected to result"]. See Grady, supra, note 19 at 607.

[21] *AIDS Policy & Law* 30 September 1994 ; 9(18): 1, 8.

[22] Cited in Grady, supra, note 19 at 599.

[23] Dr W Paul (Director, Office of AIDS Research, NIH) quoted in *AIDS Policy & Law*, supra, note 21 at 1.

[24] National AIDS Manual, supra, note 3 at 280. See also Goddard. The great vaccine race. In: Positive Living (supplement to *Sydney Star Observer*), 16 July 1998, 7.

[25] National AIDS Manual, supra, note 3 at 284.

[26] Grady, supra, note 19 at 600.

[27] C Del Ro. Is ethical research feasible in developed and developing countries? *Bioethics* 1998; 12: 328 at 329.

[28] Lurie & Ors, supra, note 11 at 299.

[29] Ibid at 330. See also Quan A. Drug access. *National AIDS Bulletin* [Australia] 1999; 13: 23.

[30] Cf Symposium. The World of Research Subjects. *Hastings Center Report* 1998; 28: 25ff; HUGO, Genome Benefit Sharing (Discussion Paper 1/1999) (forthcoming).

[31] Cf Murphy D. Visions of a vaccine. *National AIDS Bulletin* [Australia] 1999; 17: 10; Kippax S. The Role of Social Research in Vaccine Trials. Unpublished paper for HIV Vaccines Meeting, Sydney, 26 March 1999, 4.

[32] Grady, supra, note 19 at 608.

[33] Ibid; Kippax S, Crawford J. Prophylactic vaccine trials: what is different about HIV? *Venereology* 1995; 8: 178 at 179.

[34] Kippax, supra, note 29 at 2.

[35] Grady, supra, note 19 at 598, 608.

[36] D Gold, quoted in Grady, supra, note 19 at 609.

New Guidelines on Ethical Considerations in HIV Preventive Vaccine Research

In March 2000, UNAIDS released annotated guidance points on the ethical considerations of HIV vaccine research (the "Guidance Document").[1] The guidance points, reproduced at the end of the article, are the product of two years' consultation and debate around the world, yet key questions remain unsettled. This article reviews the process, the outcomes, and the challenges that remain.

The HIV epidemic continues to spread in the developing world and, in the absence of the necessary funds and political will, prevention efforts based on behaviour change alone will not stop it. Belated support for the development of a vaccine against HIV infection or AIDS is now gathering momentum. Although most new vaccines will be developed in Western laboratories, it is essential that they be tested in the countries where they are most needed to ensure they are effective against the types of HIV that are most prevalent locally, and under local conditions. Such "Phase III" trials may involve thousands of (initially) HIV-negative volunteers over several years.

In the field of medical research and experimentation, strict international standards apply to protect all research subjects from unethical practices and abuse. Yet urgent pressure to develop an HIV vaccine and the proposals for clinical trials in developing countries have thrown into question basic principles and raised new issues. In 1998, UNAIDS sponsored a series of international consultations to address these challenges.

The Regional Meetings[2]

Regional meetings were held in Brazil, Thailand, and Uganda in April 1998. They had three stated objectives: to familiarize participants with the science and design of vaccine trials; to discuss relevant social, political, and economic conditions with ethical implications for the proposed research; and "to establish a continuing discourse on HIV vaccine ethics both locally and in the international community."[3]

In order to understand the conclusions of these meetings, it is useful to know who participated and how the meetings were conducted. Participants (between 16 and 20 for each meeting) were invited by UNAIDS and regional planning committees. They included lawyers, activists, social scientists, ethicists, vaccine scientists, epidemiologists, NGO representatives, people with HIV/AIDS, and health policy experts. UNAIDS staff and expert consultants also attended. The meetings opened with briefings on vaccine research science and biomedical ethics, and a hypothetical research proposal was then presented for discussion. Throughout this process, no

ethical guidance documents or statements were referred to unless they were introduced by the participants.

The design of the meetings thus expressly excluded the existing body of legal and ethical principles regarding medical and scientific research, such as the Nuremberg Code, the Declaration of Helsinki, and the International Ethical Guidelines for Biomedical Research Involving Human Subjects (amended in 1992 with specific reference to HIV).

The Final Report, which contains the conclusions of the three meetings, sets out areas in which consensus was reached or controversy continued, for each region. For example, there was a consensus that the terms "developed" and "developing" are not adequate for comparing the characteristics of a population, community, or country that lead to vulnerability in relation to vaccine trials. There was also agreement that individual informed consent must be obtained for all HIV vaccine trials, and that trial participants must have access to high-quality counseling. The Thai group added access to condoms and syringes, where appropriate.

Differences existed between the regions on whether trial participants who become infected during a vaccine trial should be provided with top-level HIV treatment (eg, triple antiretroviral therapy) that is not generally available in the "host" country (ie, the country in which the trial is taking place). There was a strong consensus at the Brazil meeting that such treatment should be provided at the standard of that offered in the "sponsoring" country (ie, the industrialized country in which the research institution or pharmaceutical company funding the trial is based), at least for the duration of the trial. This is consistent with the Declaration of Helsinki, which requires that the "best proven diagnostic and therapeutic method" be provided.

All regions agreed that historical examples of "developing country" participation in vaccine research where access to the final product has not occurred must not be repeated in HIV vaccine research. They also agreed that an effective vaccine must be free and available at least to those who participated in the trial (ie, the placebo group) and other groups most vulnerable to HIV infection. Further, a discussion on availability should take place *prior* to the trial. There was related agreement that as the contribution of host countries to the success of HIV vaccine trials is substantial, discussion on intellectual property claims should take place before each trial and agreements specified in a contract.

The Geneva Consultation

The outcomes of the workshops and a draft set of "ethical guidance statements" were presented at a meeting in Geneva in June 1998, just prior to the XII International Conference on AIDS. This meeting included representatives of the regional workshops, UNAIDS, WHO, Council of International Organizations of Medical Sciences, research funding agencies, activists, scientists, ethicists, and the media. There was strong disagreement at this meeting over a number of proposals – in particular the "standard of care" issue – and a UNAIDS statement prematurely announcing that a consensus had been reached had to be withdrawn following the protests of a number of participants. UNAIDS then undertook to rewrite the document, which was released after some delay in early 2000.

The Guidance Document

The Guidance Document is UNAIDS policy, and is controversial because of the process leading up to it, what it contains, and what it omits.[4] Most significantly, although it purports not to "duplicate or replace" key ethical documents such as the Declaration of Helsinki, it proposes a shift from previously agreed universal standards of ethical research to locally determined standards. This is perhaps most evident in Guidance Point 16, which addresses the issue of care and treatment of trial participants infected during a trial. While the "ideal" should be to provide the best proven therapy, the Guidance Document would accept a lower standard, based on a consideration of local factors to be agreed upon through a "host/community/sponsor dialogue" prior to a vaccine trial.

However, there is an obvious contradiction between:

- the acknowledgement of communities as vulnerable due to a range of economic, social, legal, and other factors (and hence the increased risk of HIV infection and impact of AIDS); and
- the expectation that such communities can readily negotiate the terms and conditions of complex vaccine trials to their benefit and the benefit of others vulnerable in their country and even other developing countries.

The terms of the first Phase III vaccine trial in a developing country, among injection drug users in Thailand, is a case in point.

Participants are not provided with clean injecting equipment, will receive the local standard of care (not the best proven therapy) if they become infected during the trial, and there are only vague assurances from VaxGen, the pharmaceutical company behind the trial, that any successful vaccine will be made "as inexpensive as possible" for Thailand.[5]

Moreover, although intellectual property issues were roundly debated at the regional meetings and there was a consensus in each region that host countries may have a special claim in the context of HIV vaccine research, the Guidance Document contains only a passing reference to this issue. The practical recommendation that such matters be negotiated and set out in writing *before* the start of the trial was replaced by the recommendation that parties "should begin this discussion before the trials commence" (Guidance Point 2).

At the end of the day, does the Guidance Document really provide much guidance? Although it is not intended to duplicate existing texts, much of the contents reflects already well-established standards. Perhaps the main contribution is to locate these issues squarely in the context of HIV vaccine research in developing countries. For example, it rules out any possibility that third party consent (eg, a village elder or even a male partner) could be an acceptable substitute for truly individual and free consent – this is concrete and useful guidance.

The Bigger Picture

If strictly applied, current ethical standards would stop vital research in developing countries on many health conditions, including those specific to developing countries. In the opinion of this author, the challenge is not to impose the highest possible standards, but to permit essential research to go forward while protecting vulnerable populations from abuse and ensuring that the products of such research are available to developing world communities.[6] This issue is not limited to HIV vaccines: as developing-country health patterns evolve to reflect health problems (eg, heart disease, diabetes) found in the industrialized countries, pharmaceutical companies are eager to test many new drugs in a cheaper, less exacting, and less litigious environment.

If strictly applied, current ethical standards would stop vital research in developing countries on many health conditions, including those specific to developing countries.

A key issue in coming years will be whether international standards prevail or are replaced by locally negotiated terms and conditions. If locally negotiated conditions become the norm (and this now seems likely), communities will need to develop a better understanding of the issues, and build strong local and international networks to rapidly share information about draft protocols and emerging standards. There is little doubt that researchers and pharmaceutical companies will have this information, and will be shopping around for the best deals.

– David Patterson

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Note: Legal and ethical aspects of HIV vaccine research in developing countries will be examined in greater depth at the Satellite Meeting "Putting Third First – Critical Legal Issues and HIV/AIDS" to be held on 7 July 2000 in Durban, South Africa, just prior to the XIII International Conference on AIDS. A discussion paper prepared for the meeting will be published in the next issue of the *Newsletter* and will become available on the Legal Network's website just prior to the meeting. In the Canadian context, the Legal Network and the Centre for Bioethics of the Clinical Research Institute of Montréal will publish a joint paper later in 2000 on the legal, ethical, and human rights issues raised by the development and eventual availability of a vaccine for HIV/AIDS.

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[1] UNAIDS. Ethical Considerations in HIV Preventive Vaccine Research: UNAIDS Guidance Document. Geneva: UNAIDS, prepublication version, March 2000 (available at www.unaids.org).

[2] For a full description of the process and participants, see "Final Report, UNAIDS-Sponsored Regional Workshops to Discuss Ethical Issues in Preventive HIV Vaccine Trials," available from UNAIDS.

[3] Gunter G, Esparza J, Macklin R. Ethical considerations in international HIV vaccine trials: summary of a consultative process conducted by the Joint United Nations Programme on HIV/AIDS (UNAIDS). *Journal of Medical Ethics* 2000; 26(1): 37-43 at 38.

[4] Letter of 11 February 2000 from P Lurie, S Wolfe, Public Citizen, to Peter Piot, UNAIDS, (HRG publication #1508) (available at www.citizen.org).

[5] See: Questions and Answers on the Thailand Phase III Vaccine Study and CDC's Collaboration. *CDC Update*, February 1999; Wehrwein P, Morris K. HIV-1 vaccine trial go-ahead reawakens ethics debate. *Lancet* 13 June 1998; 351: 1789.

[6] A working group is to provide an interim report on proposed amendments to the Declaration of Helsinki, which may address these issues, to the World Medical Association Council in May 2000. See Brennan T. Proposed revisions to the Declaration of Helsinki – will they weaken the ethical principles underlying human research? *Lancet* 1999; 341(7): 527-530; Levine R. The need to revise the Declaration of Helsinki. *Lancet* 1999; 341(7): 531-534.

The 18 Guidance Points

We reproduce here the 18 guidance points contained in the UNAIDS document on Ethical Considerations in HIV Preventive Vaccine Research[1] discussed in the article above.

Guidance Point 1

Given the severity of the HIV/AIDS pandemic in human, public health, social, and economic terms, sufficient capacity and incentives should be developed to foster the early and ethical development of effective vaccines, both from the point of view of countries where HIV vaccine trials may be held, and from the point of view of sponsors of HIV vaccine trials. Donor countries and relevant international organisations should join with these stakeholders to promote such vaccine development.

Guidance Point 2

Any HIV preventive vaccine demonstrated to be safe and effective, as well as other knowledge and benefits resulting from HIV vaccine research, should be made available as soon as possible to all participants in the trials in which it was tested, as well as to other populations at high risk of HIV infection. Plans should be developed at the initial stages of HIV vaccine development to ensure such availability.

Guidance Point 3

Strategies should be implemented to build capacity in host countries and communities so that they can practice meaningful self-determination in vaccine development, can ensure the scientific and ethical conduct of vaccine development, and can function as equal partners with sponsors and others in a collaborative process.

Guidance Point 4

In order to conduct HIV vaccine research in an ethically acceptable manner, the research protocol should be scientifically appropriate, and the desired outcome of the proposed research should potentially benefit the population from which research participants are drawn.

Guidance Point 5

To ensure the ethical and scientific quality of proposed research, its relevance to the affected community, and its acceptance by the affected community, community representatives should be involved in an early and sustained manner in the design, development, implementation, and distribution of results of HIV vaccine research.

Guidance Point 6

HIV preventive vaccine trials should only be carried out in countries and communities that have appropriate capacity to conduct independent and competent scientific and ethical review.

Guidance Point 7

Where relevant, the research protocol should describe the social contexts of a proposed research population (country or community) that create conditions for possible exploitation or increased vulnerability among potential research participants, as well as the steps that will be taken to overcome these and protect the dignity, the safety, and the welfare of the participants.

Guidance Point 8

As phases I, II, and III in the clinical development of a preventive vaccine all have their own particular scientific requirements and specific ethical challenges, the choice of study populations for each trial phase should be justified in advance in scientific and ethical terms in all cases, regardless of where the study population is found. Generally, early clinical phases of HIV vaccine research should be conducted in communities that are less vulnerable to harm or exploitation, usually within the sponsor country. However, countries may choose, for valid scientific and public health reasons, to conduct any phase within their populations, if they are able to ensure sufficient scientific infrastructure and sufficient ethical safeguards.

Guidance Point 9

The nature, magnitude, and probability of all potential harms resulting from participation in an HIV preventive vaccine trial should be specified in the research protocol as fully as can be reasonably done, as well as the modalities by which to address these, including provision for the highest level of care to participants who experience adverse reactions to the vaccine, compensation for injury related to the research, and referral to psycho/social and legal support, as necessary.

Guidance Point 10

The research protocol should outline the benefits that persons participating in HIV preventive vaccine trials should experience as a result of their participation. Care should be taken so

that these are not presented in a way that unduly influences freedom of choice in participation.

Guidance Point 11

As long as there is no known effective HIV preventive vaccine, a placebo control arm should be considered ethically acceptable in a phase III HIV preventive vaccine trial. However, where it is ethically and scientifically acceptable, consideration should be given to the use in the control arm of a vaccine to prevent a relevant condition apart from HIV.

Guidance Point 12

Independent and informed consent based on complete, accurate, and appropriately conveyed and understood information should be obtained from each individual while being screened for eligibility for participation in an HIV preventive vaccine trial and before s/he is actually enrolled in the trial. Efforts should be taken to ensure throughout the trial that participants continue to understand and to participate freely as the trial progresses. Informed consent, with pre- and post-test counselling, should also be obtained for any testing for HIV status conducted before, during, and after the research.

Guidance Point 13

Special measures should be taken to protect persons who are, or may be, limited in their ability to provide informed consent due to their social or legal status.

Guidance Point 14

Appropriate risk-reduction counselling and access to prevention methods should be provided to all vaccine trial participants, with new methods being added as they are discovered and validated.

Guidance Point 15

A plan for monitoring the initial and continuing adequacy of the informed consent process and risk-reduction interventions, including counselling and access to prevention methods, should be agreed upon before the trial commences.

Guidance Point 16

Care and treatment for HIV/AIDS and its associated complications should be provided to participants in HIV preventive vaccine trials, with the ideal being to provide the best proven therapy, and the minimum to provide the highest level of care attainable in the host country in light of the circumstances listed below. A comprehensive care package should be agreed upon through a host/community/sponsor dialogue which reaches consensus prior to initiation of a trial, taking into consideration the following:

- level of care and treatment available in the sponsor country;
- highest level of care available in the host country;
- highest level of treatment available in the host country, including the availability of antiretroviral therapy outside the research context in the host country;
- availability of infrastructure to provide care and treatment in the context of research;
- potential duration and sustainability of care and treatment for the trial participant.

Guidance Point 17

As women, including those who are potentially pregnant, pregnant, or breastfeeding, should be recipients of future HIV preventive vaccines, women should be included in clinical trials in order to verify safety, immunogenicity, and efficacy from their standpoint. During such research, women should receive adequate information to make informed choices about risks to themselves, as well as to their fetus or breastfed infant, where applicable.

Guidance Point 18

As children should be recipients of future HIV preventive vaccines, children should be included in clinical trials in order to verify safety, immunogenicity, and efficacy from their standpoint. Efforts should be taken to design vaccine development programmes that address the particular ethical and legal considerations relevant for children, and safeguard their rights and welfare during participation.

[1] UNAIDS, March 2000 (prepublication version). See the article by David Patterson, supra.

HIV TESTING & CONFIDENTIALITY

Reform MP Proposes Compulsory Testing

In October 1999, a Reform Party Member of Parliament introduced Bill C-244 (the *Blood Samples Act*) in the House of Commons as a private member's bill. The bill proposes to permit forced blood testing of persons for HIV or hepatitis B or C where peace officers, firefighters, and other emergency services personnel or other health-care workers, may have been exposed to the risk of infection. It also proposes imprisonment for up to six months of any person who refuses court-ordered testing. In January 2000, the Canadian HIV/AIDS Legal Network wrote to the federal Minister of Justice, explaining why such legislation is unnecessary, unethical, contrary to existing law regarding "informed consent," and unconstitutional. On 21 March 2000, the Bill passed second reading unanimously. It now awaits committee hearings. This article sets out the concerns the Network raised about the proposal for compulsory HIV testing.

The issue of compulsory HIV testing following possible exposure has been examined carefully in Canada. It has been recognized that, like other medical procedures, HIV testing should generally only be carried out with the specific, informed consent of the person being tested. In October 1998, following extensive national consultations, the Legal Network and the Canadian AIDS Society published a detailed analysis of HIV testing and confidentiality issues.[1] In March 2000, the Legal Network also released a detailed analysis of legal and ethical issues raised by the licensing of rapid HIV test kits in Canada – including the proposed use of such tests after occupational exposures to possible HIV infection.[2] Both reports concluded that HIV testing without consent was not justified.

There are four primary concerns with the proposed *Blood Samples Act* (Bill C-244).

Forced HIV Testing Is Impractical and of Little Practical Value

There is some evidence that, following an exposure to HIV, taking a short, intensive course of antiretroviral therapy may prevent actual infection with the virus. However, the available data indicate that this post-exposure prophylaxis (PEP) should be initiated as soon as possible, preferably within a few hours of possible exposure. Assuming the source person is physically available to be tested, judicial authorization following a hearing is unlikely to be obtained within such a short time frame. Furthermore, unless a rapid HIV test kit providing results within minutes is used, test results will simply not be available within the critical time frame for initiating PEP. (It should also be noted that rapid HIV screening tests provide unconfirmed results and, by design, yield a significant number of false HIV-positive results, particularly in populations with a low prevalence of HIV infection.)

But in any event, even if test results were available within hours, testing the "source person" does not answer the question of whether the exposed person should begin PEP. Testing may show the source person was HIV antibody-positive at the time of the exposure; obviously, having this information does not relieve the exposed person of making a decision about PEP. Or the source person may test negative for HIV antibodies. While this *may* indicate a lower likelihood that they are infected, it does not rule it out: they may be in the "window period" between

infection and seroconversion (the point at which they have produced antibodies to HIV detectable by the test). This window period is usually estimated at a maximum of three months, but in some cases may be as long as six months. The exposed person is still faced with a decision about initiating PEP.

Confidentiality of Test Results Is Not Protected

Not only does Bill C-244 propose to imprison people who refuse forced testing, it also fails to address the possible breaches of confidentiality about that person's HIV status that may occur following forced testing. Unfortunately, we know all too well that people with HIV/AIDS continue to face stigma and discrimination (and sometimes violence) in Canada. A positive test result may have adverse consequences in terms of employment, housing, access to insurance coverage or other services, and ostracism from family and community.[3] It is particularly difficult to maintain confidentiality in smaller communities.

Bill C-244 does not require anyone receiving the person's test results to keep those results confidential, nor is such an obligation clearly recognized elsewhere in law. Bill C-244 neither prescribes a criminal penalty nor clearly creates a civil cause of action against any person who breaches that confidentiality. Nor does it require a ban on publishing the person's identity, so as to prevent widespread dissemination of private information about their health status through, for example, media reporting on a court application for a warrant for compulsory testing.

Forced HIV Testing Is Unethical and Violates the Legal Doctrine of "Informed Consent"

Drawing blood without a person's consent is an unethical abrogation of personal autonomy. Respect for autonomy is the basis for the well-recognized legal principle, embodied in both common law and statute, that a person cannot be subjected to medical procedures without their informed consent, a principle that the Supreme Court of Canada and other appellate courts have repeatedly affirmed.[4] Furthermore, Bill C-244 compounds the original wrong to physical integrity by providing that the person tested pursuant to a warrant "shall" be informed of the test results. By removing from the person the choice of whether to receive test results, this legislation also damages a person's psychological integrity in its disregard for the principle of informed consent.

Forced HIV Testing Is Unconstitutional

We should also be concerned about the constitutionality of compulsory HIV testing. Not only does forced HIV testing violate the moral principle of respect for autonomy and the legal doctrine of informed consent; the state authorization of forced HIV testing proposed in Bill C-244 arguably breaches the right to security of the person guaranteed by the *Canadian Charter of Rights and Freedoms* and is not in accord with the "principles of fundamental justice" (section 7).

In addition, forced HIV testing violates the Charter right to be secure against "unreasonable search or seizure" (section 8). Canadian courts have clarified that the fundamental purpose of section 8 is "to protect individuals from unjustified state intrusions upon their privacy."[5] In *R* v *Dyment*, the Supreme Court of Canada ruled that

> the use of a person's body without his consent to obtain information about him, invades an area of personal privacy essential to the maintenance of his human dignity.... [T]he protection of the *Charter* extends to prevent a police officer, an agent of the state, from taking a substance as intimately personal as a person's blood from a person who holds it subject to a duty to respect the dignity and privacy of that person.[6]

The Court ruled that such a breach of the rights protected by section 8 of the Charter could not be permitted, as it would bring both the administration of health services and the administration of justice into disrepute. The Supreme Court has repeatedly affirmed the importance of protecting the privacy of personal information, ruling that the Charter protects "the right of the individual to determine for himself when, how, and to what extent he will release personal information about himself."[7]

The forced HIV testing of a person following occupational exposure of a peace officer, emergency services worker or other health-care worker is, in some ways, analogous to proposals to forcibly test persons accused of sexual assault. In *R* v *Beaulieu*, the only case in Canada to consider the issue of compulsory HIV testing of a person accused of sexual assault, the court concluded that such forcible testing is not permitted by law and would be at odds

with constitutional protections (noting the Supreme Court's ruling in *Dyment*).[8] The (federal) Interdepartmental Committee on Human Rights and AIDS, among others, has also concluded that this is "not the most effective way" of dealing with the concerns of sexual assault survivors, and is "misguided," in part because testing the offender does not provide timely or reliable information about the risk of HIV infection.[9] Then Minister of Justice Allan Rock accepted the Working Group's conclusion, rejecting calls for compulsory testing of persons accused of sexual assault. This conclusion is equally applicable in the case of occupational exposures, and stronger still in those cases where there is not even any allegation of criminal wrongdoing resulting in the possible exposure.

Under the Charter, legislation that infringes a right may be constitutionally permissible if the government can show the infringement is a "reasonable limit" that can be "demonstrably justified in a free and democratic society" (section 1). In the leading case of *R* v *Oakes*,[10] the Supreme Court set out the requirements for justifying measures that infringe Charter rights:

- the objective to be served by the measures that limit a Charter right must be sufficiently important to warrant overriding a constitutionally protected right or freedom, in that it must at least relate to societal concerns that are "pressing and substantial" in a "free and democratic society";
- the measures must be fair and not arbitrary, carefully designed to achieve the objective in question, and rationally connected to that objective;
- the measures should impair the Charter right as little as possible; and
- there must be proportionality between the effects of the limiting measure and the objective – the more severe the infringement of the right, the more important the objective must be if the measure is to be reasonable and demonstrably justified in a free and democratic society.

Applying this test, it is questionable whether legislation authorizing compulsory HIV testing following occupational exposures is constitutionally justifiable. While there is no doubt that preventing HIV infection of emergency services workers is a laudable and important objective, legislation such as Bill C-244 does not satisfy the other criteria for justifying the breach of Charter rights.

First, in light of the limited practical value of forced HIV testing, the connection between forced HIV testing of a "source person" and the objective of preventing HIV infection of a peace officer, firefighter, or health-care worker who may have been occupationally exposed to a risk of infection is tenuous at best. Second, there is more than a "minimal impairment" of Charter rights in forcing a person to be tested for HIV, and the seriousness of this Charter violation is compounded by possible imprisonment for refusal to be tested and the lack of any confidentiality protections for those subjected to forced testing. Finally, given the harm to the bodily and psychological integrity, and personal privacy, of a person subjected to forced HIV testing, and the absence of any significant benefit to be gained, there is no "proportionality" between the damage to Charter rights and the ostensible objective of permitting court-ordered, compulsory testing.

Conclusion

Preventing possible exposures to HIV must be the focus of health protection efforts. Compelling HIV testing after possible exposure does not undo any possible harm that may flow from the exposure. That damage (if any) has been done, and forced blood testing offers no remedy. More constructive solutions to the risks faced by emergency services personnel would both offer greater protection against possible exposure to communicable diseases and respect the rights of Canadians to privacy and bodily integrity. Proactive efforts to educate police, firefighters, and health-care workers about how HIV and hepatitis are transmitted (and how they are *not* transmitted), and encouraging the use of universal precautions to reduce the likelihood of infection, are preferable responses.

– Richard Elliott

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[1] Jürgens R. *HIV Testing and Confidentiality: Final Report*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998. Available at www.aidslaw.ca

2 Elliott R, Jürgens R. *Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*. Montréal: Canadian HIV/AIDS Legal Network, 2000. Available at www.aidslaw.ca

[3] de Bruyn T. *HIV/AIDS and Discrimination: A Discussion Paper*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998. Available at www.aidslaw.ca

[4] *Reibl* v *Hughes*, [1980] 2 SCR 880; *Hopp* v *Lepp*, [1980] 2 SCR 192; *Ciarlello* v *Schachter*, [1993] 2 SCR 119; *Malette* v *Shulman* (1990), 37 OAC 281 (CA); *Fleming* v *Reid* (1991), 82 DLR (4th) 298 (Ont CA); *Videto* v *Kennedy* (1981), 33 OR (2d) 497 (CA).

[5] *Hunter* v *Southam*, [1984] 2 SCR 145 at 160.

6 *R* v *Dyment*, [1988] 2 SCR 417 at 431-432.

[7] *R* v *Duarte*, [1990] 1 SCR 30 at 46. See also: *R* v *Plant* (1993), 84 CCC (3d) 203 (SCC).

[8] *R* v *Beaulieu*, [1992] AQ No 2046 (Court of Québec) (QL).

[9] *Report of the Working Group on Sexual Assault and HIV Antibody Testing*. Ottawa: The Committee, 19 April 1994.

[10] *R* v *Oakes* [1986] 1 SCR 103, 24 CCC (3d) 321.

Rapid HIV Screening at the Point of Care: Legal and Ethical Issues

In March 2000, the Canadian HIV/AIDS Legal Network released a comprehensive report entitled *Rapid HIV Screening at the Point of Care: Legal and Ethical Issues*.[1] The release of the report coincided with the issuing of the first licence to sell rapid HIV test kits in Canada for use by health-care professionals at the "point of care," and received considerable media attention. The report makes 23 recommendations to federal and provincial/territorial health officials, health-care professionals and their professional associations and regulatory bodies, and test kit manufacturers, with a view to ensuring that the potential benefits of this testing technology are maximized and the potential harms are prevented or minimized. We reproduce here the executive summary of the report.

Background

Early in the HIV/AIDS epidemic, a concerted effort was made to address the issues surrounding HIV-antibody testing and confidentiality in a way that would respect the human rights of individuals, yet at the same time promote the goals of protecting public health. In particular, in Canada a broad consensus emerged that, except in a few well-defined circumstances, people should be tested only with their informed, voluntary and specific consent; when counseling and education before and following testing are available and offered; and when confidentiality of results or anonymity of testing can be guaranteed. This consensus was expressed in recommendations such as those prepared by the National Advisory Committee on AIDS, which provided an ethical framework for evaluating testing policy based on a careful consideration of the inherent costs and benefits of testing to the individual and to society.

In the past years, new testing technologies, advances in HIV/AIDS treatments, and changing patterns of HIV infection have forced us to reconsider approaches to HIV testing. A comprehensive analysis of the new issues and challenges can be found in *HIV Testing and Confidentiality: Final Report*, released in the fall of 1998 by the Canadian HIV/AIDS Legal Network and the Canadian AIDS Society (and available at www.aidslaw.ca).

Now, in the spring of 2000, another new development forces us to again reexamine approaches to HIV testing in Canada: a rapid HIV screening test has been licensed for sale in Canada in 2000, for use by health professionals at the "point of care."

In order to minimize the reporting of false-positive results, until now, under the standard procedure for HIV testing, no positive result was given to the person being tested until confirmatory testing was undertaken. Because rapid test kits can provide results within 30 minutes, without being sent to a laboratory, this generally accepted practice is being questioned, although positive results will still need to be confirmed. This, and some of the proposed uses of rapid test kits, raise a number of legal and ethical questions that cannot and should not be ignored. Indeed, all decisions about the use and regulation of rapid HIV tests should be informed not only (and not even primarily) by what is technologically feasible, but by an appreciation of the real-life implications of testing technologies, by ethical considerations, and by an understanding of how Canadian law and policy may or may not adequately address these implications and reflect these ethical considerations.

Therefore, the Canadian HIV/AIDS Legal Network, after extensive consultations, including a two-day national workshop held in January 2000, has prepared a detailed analysis of the key legal and ethical questions raised by the use of rapid HIV test kits for point-of-care testing, in order to provide critical thinking and recommendations regarding their introduction in Canada.

Standard HIV Testing versus Rapid Testing

Currently in Canada, the *standard procedure* for HIV testing involves a trained health-care worker drawing a blood sample from the person getting tested in a clinical setting (usually a physician's office or a testing clinic), with the blood subsequently being tested in a clinical laboratory to detect the presence of HIV-specific antibodies using an enzyme immunoassay (EIA, or "ELISA" test) as a screening test. A negative result is reported if the EIA screening test is nonreactive. Any blood sample that tests positive, however, undergoes a second, confirmatory test (generally the "Western blot"). Only *confirmed* test results are given to the health-care provider who ordered the test. Although the actual

testing does not require much time, typically one to two weeks elapse before results are available. This is because blood samples are generally "batched" (ie, tested in groups) to decrease testing costs, and because time is needed to complete confirmatory testing. Every person getting tested, whether the test is positive or negative, must return to the testing site for a second visit to learn their results from the provider.

In contrast, *rapid tests* can be done onsite. A sample is collected and a result is available within 30 minutes after the sample is taken. When HIV antibodies are present in sufficient concentration in the blood of the person being tested, a colour reaction occurs along a test strip. Licensed rapid HIV test kits will have the same sensitivity, specificity, and performance characteristics as *screening* methods currently used in approved laboratories, ensuring a reliable negative test. This permits the health-care professional to complete the HIV testing and counseling at a single visit *for those testing negative*. However, false-positive results will occur, particularly among patients from populations with a low rate of HIV infection. This means that all positive results and all results that are equivocal must be confirmed, requiring that a blood sample be sent to an approved HIV testing laboratory, where it will undergo confirmatory testing.

At least for now, in Canada rapid HIV screening tests will only be licensed for use by health-care professionals at the "point of care." This distinguishes them from home test kits, which require a person to collect the sample themselves and either mail it to a laboratory and receive the test results by telephone (home sample collection or home-access testing), or obtain the results within a few minutes (true home tests, also called home self-tests or home validated tests).

Under the Medical Devices Regulations, "health-care professional" is defined as "a person who is entitled under the laws of a province to provide health services in the province." In Health Canada's view, it lacks the jurisdiction to draw any further distinctions within the category of "health-care professional." The result is that provincial/territorial legislation defining "health services" and those who are entitled to provide them may end up defining the parameters of who is legally permitted to administer rapid HIV screening tests. These provisions vary from jurisdiction to jurisdiction, giving rise to concerns about different standards of care.

The Scope of the Report

The report prepared by the Legal Network:

- explains rapid HIV testing technologies;
- describes the status of rapid HIV test kits in Canada;
- presents an overview of the Canadian regulatory framework applicable to the approval and use of rapid test kits;
- provides a comprehensive evaluation of the potential benefits of making rapid HIV testing at the point of care available in Canada;
- discusses some of the concerns raised by point-of-care use of rapid HIV screening tests, including potential misuses;
- considers how, in light of the potential benefits and the concerns raised, rapid HIV screening tests should be regulated; and
- presents conclusions and recommendations regarding the use of rapid tests in Canada, directed to federal and provincial/territorial policymakers, health-care professionals, professional associations and regulatory bodies of health-care professionals, and those providing HIV testing and counseling and working in the field of public health.

Potential Benefits of Using Rapid HIV Screening at the Point of Care

The following potential advantages of using rapid HIV screening at the point of care have been put forward:

- clients' satisfaction can be improved because they can receive their results sooner;
- rapid screening kits are easier and safer to administer;
- people would be able to chose between conventional testing and rapid testing, enhancing their autonomy;
- more people would receive their test results, since most would not have to return for their results and post-test counseling;
- access to HIV screening could be improved; and
- acceptance of HIV testing could be increased.

In addition, it has been argued that rapid screening

- could make it possible, for women whose HIV status is unknown at the time of labour, to undergo screening during labour and, for those screening positive, to initiate preventive measures to reduce the risk of mother-to-child transmission; and
- could provide more information for decisions about post-exposure prophylaxis (PEP).

However, closer scrutiny reveals that little is known about how significant some of these benefits would be in the Canadian context. In addition, some

potential benefits would be realized only in certain, limited circumstances:

- Whether there would be a benefit to faster delivery of results depends upon the outcome of the test. For those who tested negative, as most people would, their anxieties, worries, and fears could be relieved sooner; for them, there would be a definite benefit. But those who tested positive on the screening test would have to await the result of a confirmatory test, enduring psychological and emotional distress that could be greater than what they would have experienced with the mere uncertainty that accompanies standard testing.
- The argument that rapid point-of-care screening will significantly increase the number of people who receive their test results cannot be generalized. Rates of return will vary across the country, between regions, and/or between testing sites. United States data are not particularly relevant or easily applicable when the available Canadian data indicate a very different context. Without solid Canadian data about many aspects of HIV testing, the size – and thus the importance – of this potential advantage of rapid HIV screening at the point of care is hard to gauge.
- While increasing access to quality HIV testing is important, the potential benefits of providing rapid HIV screening in remote settings should not be overestimated. Rapid HIV screening, on its own, falls below the generally accepted standard of care, and must be accompanied by timely access to confirmatory testing. In remote areas, there is a worry that it could take a long time to get a confirmed result for a positive screening test and that the community might not have the resources to support a person with a preliminary positive result during that difficult period. Therefore, if rapid screening kits are to be used in rural or more remote areas, steps would have to be taken to ensure that those who test positive on rapid screening tests would have improved and quicker access to confirmed test results. Consultation with communities who currently have limited access to testing services, and those who provide HIV testing, counseling and support, or other health-care services to these communities, would also be required.
- Being able to rapidly obtain results of an HIV test could assist a woman in labour and her physician(s) make decisions regarding possible interventions during labour and following the birth of her infant to reduce the chance of transmission. However, whether a woman in labour is capable of making a morally autonomous choice about, or giving voluntary, specific and informed consent to, any form of HIV testing is contentious. In addition, the possibility of implementing preventive measures without making these conditional upon a woman consenting to rapid HIV screening requires further careful consideration and discussion.
- Finally, rapid HIV screening offers some potential benefit with respect to making decisions about *starting* post-exposure prophylaxis, but very limited benefit with regard to decisions about *continuing* the prophylaxis regime.

Concerns

While there are potential (albeit probably limited) advantages in using rapid HIV screening at the point of care, there are also many concerns. These range from concerns about the implications of disclosure of positive screening results when, particularly in low-prevalence settings, a significant number of false-positive results will occur; to concerns that people undergoing rapid HIV screening will not receive adequate counseling (particularly people who receive a positive screening result, for whom provision of best-practice counseling and support is essential); to concerns that some of the health-care professionals who may end up being authorized to administer the test kits would not adequately protect confidentiality; to concerns that women in labour whose HIV status is unknown may be screened without their informed consent; to concerns that in a variety of other situations there will be a push for testing without specific informed consent.

What Must Be Done to Address These Concerns?

The concerns raised are serious, and must be addressed. In particular:

- Wherever rapid HIV screening at the point of care is offered, it must be accompanied by accelerated access to confirmed test results, and support services must be easily accessible to people who receive a positive screening result.
- The availability of rapid HIV screening at the point of care will not remove the legal and ethical imperative that testing only be undertaken with pre-and post-test counseling. Indeed, it highlights the importance of counseling, in addition to posing some challenges that are specific to rapid screening and that will have to be addressed. It highlights the importance of

counseling because of the potential harm of disclosing a positive screening result. Today, much testing in Canada, particularly outside of designated HIV testing clinics with trained staff, is done with little or no pre-test counseling. While this is bad enough in the context of the current mechanism of HIV testing, it must not be allowed to happen in the context of rapid screening. Imagine a person receiving a positive screening result without having understood that a screening test is only a screening test, that the result may be a false-positive result, and that it is imperative that the person come back to receive a confirmed result, which could well be negative. Because of the need to ensure that all people who receive a positive screening result have received best-practice counseling, only health-care professionals who have undergone a training program, including on how to provide counseling in the context of rapid HIV screening tests, should be allowed to use such tests.

- Rapid screening should initially only be offered to women in labour whose HIV status is unknown, in those settings where its use can be monitored and its results can be evaluated; in addition, efforts need to be improved to ensure that *all women* have access to HIV testing services and that all women considering pregnancy or already pregnant be routinely offered voluntary HIV testing, with quality pre- and post-test counseling.
- There would be some benefits to be gained from the availability of a rapid screening test with respect to making post-exposure prophylaxis decisions. However, the benefit to the person potentially exposed to HIV of knowing the source person's rapid HIV screening test result does not and should not give rise to an entitlement to compel the source person to be tested without their consent. In particular, the federal government should not support legislation imposing compulsory testing for HIV, and neither should provincial and territorial governments introduce legislation to that effect, such as legislation authorizing compulsory testing in sexual assault cases. Instead, in cases where the source person is known and available, they should be encouraged to undergo voluntary testing. It seems that in cases where the source persons are known and available, the overwhelming majority of them already agree to undergo testing. Nevertheless, a variety of measures could and should be taken to encourage even those few who currently refuse to submit to testing, such as scrupulously protecting confidentiality and preventing test results from being admissible in legal proceedings. In addition, specifically in the area of sexual assault, to deal with the very real concerns of survivors of sexual assault, Health Canada, the Department of Justice, Status of Women, and their provincial counterparts must continue to ensure that best-practice counseling, short- and long-term care, treatment and other services are made available to sexual assault survivors.
- Rapid HIV screening of patients before medical care is provided to them (or of inmates in correctional institutions) would not be justified.
- Generally, the availability of rapid test kits does not remove the requirement for specific, informed consent to HIV testing. Professional codes of conduct, ethical consciousness, and Canadian law require consent to HIV testing. In order to reinforce that testing can only be undertaken with the specific, informed consent of the person being tested, colleges of health-care professionals, and health-care professionals' associations, should adopt (or update) regulations and/or policies to that effect.
- More research in the area of HIV testing must be funded, so that we acquire solid, systematic, and comprehensive data about testing and counseling, as well as about barriers to testing and counseling. This must include careful investigation, evaluation, and monitoring of the experience with rapid HIV screening at the point of care.

Many, although not all, of the concerns raised are related to *who* could potentially administer rapid HIV screening tests at the point of care. There would be little concern if the test was administered by a test provider in a testing clinic, particularly if that provider had received training in how to administer and apply the tests, and in how to provide counseling using such tests; and if the clinic was able to provide support to a person who screened positive, as well as a confirmed test result within two days.

But there would be concern if the test was administered by a physician who had little experience with HIV testing and counseling, no training specifically about rapid screening kits, and no ability to guarantee the support that a person who screens positive may need. As mentioned above, research has shown that many physicians do not provide adequate counseling, although law and ethics require that testing not be undertaken

without it and there are counseling guidelines that have been widely distributed. There is no reason to believe that a label on the kit requiring counseling and explaining the limitations of the rapid screening tests would be sufficient to prevent testing without adequate counseling. These same concerns (or even greater concerns) would arise if rapid testing was being done by health-care professionals who currently do not administer HIV testing.

Therefore, regulating the use of rapid HIV screening tests will be important. Governments must exercise their regulatory authority to ensure that rapid test kits are only available in those settings and under those conditions in which their benefits will be most likely realized and the potential misuses prevented. In particular:

- In every jurisdiction where these devices are introduced, their use should be phased in by providing rapid testing as an option in specific sites only, followed by evaluation of the experience, before proceeding further with their use.
- Governments should establish, by way of regulation and in consultation with community-based organizations, health-care professionals, and current HIV counseling and testing providers, which "health-care professionals" entitled to provide health services in their province or territory shall be permitted to administer a rapid HIV test.
- Governments should use their regulatory powers, and health-care professionals' regulatory bodies should similarly use their powers, to issue regulations, guidelines, or policies to restrict the use of rapid HIV screening tests to point-of-care settings that ensure that a person receiving a positive screening test will have accelerated access to a confirmed result, and to support while waiting for the confirmed result; and that those providing testing have received training in how to provide quality pre- and post-test counseling, including how to do counseling accompanying the use of rapid screening tests.
- Federal and provincial authorities must ensure that the restrictions placed on the use of rapid test kits to ensure maximum benefit and minimum harm are actually enforced, by responding decisively and swiftly to breaches of these conditions.

Conclusions

We need to be open to the challenges posed by the availability of rapid HIV screening and test our deeply held beliefs. However, we must do so without forgetting the lessons learned over the last 20 years and without forgetting that, because HIV/AIDS continues to disproportionately impact on marginalized populations, leading to discrimination against those infected and affected, it remains different from other diseases. In particular, the new treatments constitute a huge step forward, but do not represent a solution to all problems faced by people with HIV or AIDS – problems that stem from the underlying problems of poverty and discrimination that are both a result and a cause of HIV infection. Therefore, while encouraging people to voluntarily test for HIV must indeed be a priority, we must not forget that the testing at issue here is testing for HIV, a disease that continues to have a social and cultural impact far beyond the numbers of people affected.

Overall, the advent of rapid HIV screening tests offers some benefits. However, the concerns and uncertainties about their use must be addressed. Otherwise, there is a real threat that technology will drive what type of testing will be available in Canada and how testing will be done, rather than a careful consideration of risks and benefits, informed by solid scientific research, that balances an individual's human rights and society's need to maintain public health.

Testing, and increasing access to testing, is not good per se. Although the potential benefits of testing have significantly increased over the last decade, many of them will only be realized if *quality* testing and counseling that maximize the benefits of testing while minimizing the potential harms are undertaken. Rather than lead to an abandonment of the requirement that HIV testing should only be undertaken with the informed consent of the person being tested, with pre- and post-test counseling and when confidentiality of test results can be guaranteed, the introduction of rapid testing must become an opportunity to reaffirm those principles, so that the benefits of HIV testing are maximized while the potential harms are minimized. Canada must recommit to *quality* testing and counseling.

– Ralf Jürgens & Richard Elliott

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[1] Elliott R, Jürgens R. *Rapid HIV Screening at the Point of Care: Legal and Ethical Questions*. Montréal: Canadian HIV/AIDS Legal Network, 2000.

CRIMINAL JUSTICE

Criminal Law and HIV/AIDS: Update III

This regular column reviews *new* developments in the area of criminal prosecutions for HIV transmission or exposure, or developments that have come to our attention since the last issue of the *Newsletter*. Canadian developments are the focus. Cases and legislation from other jurisdictions are only included if they represent a significant development in this area of the law or for the jurisdiction in question.

Canada

Newfoundland

In the first case to be decided by a Canadian court following the *Cuerrier*[1] decision by the Supreme Court of Canada, an HIV-positive man was convicted in St John's on 26 April 2000 of aggravated assault and common nuisance for continuing to have unprotected sex with his girlfriend, after learning he was HIV-positive, without disclosing his status to her. He was found not guilty on the charge of criminal negligence causing bodily harm.[2]

The accused, HW, began a relationship with the complainant, JM, in June 1991 that included unprotected sex (she did not take precautions against pregnancy because HW told her he had had a vasectomy). On 15 November 1991, he tested HIV-positive, which he did not disclose to JM. Separately, she also got tested; on 20 November 1991, she tested HIV-negative, which she told HW; she did not get tested again during the relationship. HW did not tell any health-care professional or counselor that he was having any sexual relationship. In 1994, JM tested HIV-positive. She provided police with the names of all her sexual contacts; the police investigation showed that HW had received a positive test result in November 1991 and been counseled to practise safer sex and disclose to his partners. JM's other sexual contacts all tested HIV-negative. Criminal charges were then laid against HW.

Rowe J of the Newfoundland Supreme Court (Trial Division) found that "a single act of unprotected vaginal intercourse carries a significant risk of HIV transmission," and that an HIV-positive man is 17 times more likely to infect a female partner through unprotected sexual intercourse than vice versa. Rowe J also noted that HW's unprotected sex with JM before he learned of his HIV infection can attract no criminal sanction, because there was no "guilty mind." The issue was HW's conduct after learning of his infection.

HW admitted he had infected JM. He also admitted that he continued to have unprotected sex with JM after learning he was HIV-positive, did not tell her he was infected, and did not take any precautions against transmission. However, he could have infected her before he knew of his own HIV infection. A conviction for aggravated assault would require that HW have "endangered the life" of JM. The defence therefore argued that, if JM were already infected by the time HW learned he was HIV-positive, then HW did not endanger her life by having unprotected sex. Therefore, unless the prosecution could prove, beyond reasonable doubt, that JM was still HIV-negative at the point when HW learned he was infected, HW could not be convicted of aggravated assault because it was not proved that he endangered her life.

However, Rowe J rejected this argument, saying that it "would be a perverse interpretation" of the *Criminal Code* definition of aggravated assault to require the prosecution to prove that JM was still HIV-negative by the point HW learned of his infection and then continued to have unprotected sex with her. Citing the *Cuerrier* decision, as well as other jurisprudence and statutory rules about the interpretation of statutes, he ruled that requiring the prosecution to prove this

> would permit an accused who had done something the law seeks to prevent and punish ...

that is, someone who knows he is HIV-positive engaging in unprotected sex with someone whom he could well thereby infect ... to escape criminal liability because of happenstance ... that is, because she previously had unprotected sex with him and she later tested HIV-positive.

As an aside, [HW's] submission seems to have implications that are even more far-reaching. As a practical matter, the prosecution might well have difficulty proving the complainant was not infected (at the relevant time) where a complainant (who later tested HIV-positive) had had sexual relations with someone else, for example, three months before the accused. Might not the source of the infection have been this earlier sexual partner? What if this person refused to be tested?

In any case, if [HW's] submission is correct, where a complainant has had prior sexual activity with the accused and tests HIV-positive after having unprotected sex with the accused, then an accused who has knowingly exposed the complainant to the risk of infection would likely escape criminal liability.

This would lead to the perverse result that criminal liability would only attach to an accused who, knowing he was HIV-positive, had unprotected sex with a complainant, but the complainant did not become infected. In other words, an accused would be found not guilty where the complainant did become infected, but guilty where she did not. This would turn the meaning of "aggravated assault" on its head.

In the *Cuerrier* case, the Supreme Court of Canada ruled that a person's consent to unprotected sexual intercourse is vitiated (ie, legally invalid) when her partner does not disclose his HIV-positive status and there is a "significant risk of serious bodily harm." Based on the same possibility of transmission *before* HW learned of his infection, the defence also argued that it could not be proved that HW placed JM at "significant risk of serious harm" by having unprotected sex with her *after* learning of his status. For the same reasons as before, Rowe J dismissed this argument.

With respect to the criminal negligence charge, the court noted that this charge has been interpreted as applying to an HIV-positive person who transmits the virus through unprotected sex – in the earlier *Mercer*[3] case, which was noted with approval in *Cuerrier*. The court found that HW's conduct did "show wanton disregard" for the life and safety of JM. However, while the offence of aggravated assault requires only a significant *risk* of harm, the offence of criminal negligence causing bodily harm requires the prosecution to prove *actual* harm was caused. In finding HW not guilty of this charge, Rowe J said:

> In my view, this does not mean with respect to a charge under [this section] that ordinarily the prosecution must prove the complainant infection-free at the relevant time, but it does require this where there is an air of reality to the possibility that the complainant was already infected when the accused knowing he was HIV-positive had unprotected sex with her. This is such a case. The prosecution conceded that on the facts as agreed, it is not proven beyond a reasonable doubt that JM was HIV-negative when [HW] had unprotected sex with her after he became aware that he was HIV-positive.

Finally, the offence of common nuisance requires that a person endanger the lives, safety or health of "the public." Again Rowe J rejected the defence argument that, because JM might already have become infected, it could not be proved beyond reasonable doubt that HW "endangered" her. He also considered the interpretation of "the public." After reviewing the conflicting cases on this point (decided before *Cuerrier*), and the Supreme Court's comments in *Cuerrier* regarding the threat to public health from HIV transmission, he concluded that the requirement of endangering "the public" was satisfied:

> Anyone ... male or female ... who engages in unprotected sex, knowing they are HIV-positive (and not disclosing this) endangers not only their sexual partner but every person with whom that partner subsequently has unprotected sex. That constitutes a threat to public health. ... This threat comes within the traditional interpretation of "public,"... and, in my view, answers the otherwise valid point raised by counsel for [HW] that "public" must mean more than the complainant.

On 23 May, the accused was sentenced to 5 1/2 years in prison.[4] (The same accused has also consented to trial without a preliminary inquiry on similar charges related to other complainants.)[5]

In a previous issue, we reported on another case, the *Hollihan* case, in which the Newfoundland Provincial Court, following a preliminary inquiry, had ordered that an HIV-positive man stand trial on a charge of *common nuisance* for engaging in unprotected sex with one woman without disclosing his status.[6] Section 180 of the *Criminal Code* states that the offence of common nuisance, which is punishable with up to two years in prison, is committed when a person does "an unlawful act or fails to discharge a legal duty and thereby endangers the lives, safety, health, property or comfort of the public." At the preliminary inquiry, the court dismissed the defence argument (and the holding in the earlier *Ssenyonga*[7] case in Ontario) that conduct with respect to one person could not endanger the lives and safety of "the public." However, according to the Crown attorney involved, the charge was stayed following that decision; the matter has not, and will not, proceed to trial.[8]

Manitoba

In December 1999, a 30-year-old Alberta man was charged in Winnipeg with four counts of aggravated assault for allegedly having unprotected sex with four women between 1995 and 1999, knowing of his HIV infection. Allegedly as a result of sex with the accused, two women have tested HIV-positive; a third became pregnant and had an abortion. The fourth woman was reported to have tested HIV-negative. The accused's picture was distributed by police as a "safety alert" and printed on the front page of newspapers. The accused was reported as saying that he was using drugs when he was diagnosed, he was not well educated on precautions, and he "didn't plan for them [the complainants] to get sick." His current partner told reporters that he had been "completely honest" with her, disclosing his HIV status to her "long before we got into the relationship." On 19 January 2000, the accused was denied bail, and the court ordered a ban on publishing details of the bail hearing.[9] On 9 May 2000, he pleaded guilty to all four counts of aggravated assault,[10] and on 18 May 2000 he was sentenced to eight years in prison, representing two years on each of the four counts, to be served consecutively.[11]

Saskatchewan

In February 2000, a 29-year-old drug user with hepatitis C pleaded guilty to assault with a weapon (and five other charges, including theft, obstructing a peace officer, and breach of a probation order) after she stabbed a pharmacy clerk with a used needle in the summer of 1999. The woman was confronted by the clerk when she set off a theft alarm upon leaving the store. She took the needle from her purse, told the clerk "to back off" because she had HIV, and ran away. The clerk gave chase, and the woman jabbed her arm with the needle. The woman agreed to give a blood sample and tested HCV-positive; the clerk has tested negative for both HIV and HCV.[12]

Ontario

In October 1999, a man arrested in a suspected drug deal was charged with aggravated assault and assault on police officers after biting two officers and a bar patron and then telling the police that he was HIV-positive.[13]

British Columbia

In November 1999, it was reported that police were investigating allegations that an HIV-positive man in Sechelt, BC, had infected a woman through unprotected sex without disclosing his serostatus. The case arose in the same health unit as the earlier *Cuerrier* case.[14] At the time of the reports, the accused was in custody on unrelated matters. The medical officer of health for the unit was reported as considering issuing an order to him, under the provincial public health statute, to refrain from unprotected sex; breaching such an order could result in his detention.[15]

In March 2000, the BC Supreme Court declared an HIV-positive man a "dangerous offender" and sentenced him to imprisonment for an indeterminate period of time. Mark Antonius pled guilty in 1998 to a charge of sexual assault causing bodily harm for a 1996 incident in Nelson, BC in which he accosted a woman in an alley. He had a lengthy criminal record, including a previous sexual assault nine years earlier. He admitted that he knew, at that time of the assault, "that he may be HIV positive" and that he was "undergoing further HIV related blood testing," and that HIV "could be passed on through unprotected sexual intercourse and through oral sex." The court based its decision to declare him a dangerous offender on a number of factors; one of those was his "substantial level of indifference ... to the reasonably foreseeable consequences to others of his behavior. Mr Antonius was completely indifferent to [the victim's] position given his HIV status."[16]

Alberta

A Calgary man pleaded guilty to robbery in a 17 January 2000 appearance before the Alberta Court of Queen's Bench. He had been accused of holding up a video store employee with a syringe he claimed contained HIV-contaminated blood. This later turned out to be false, based on tests done following his immediate arrest during the attempted robbery.[17]

United States

Kentucky

In September 1999, the Kentucky Supreme Court denied an HIV-positive man's application for a discretionary review of an appellate court decision that had upheld his conviction for second-degree "wanton endangerment." His conviction was based on the allegation that he had engaged in sexual intercourse with a woman without disclosing his HIV status. He testified that he had disclosed; the complainant (who was not infected) denied that he had. In 1998, the Kentucky Court of Appeals stated that his allegation that she consented to sex, knowing he was HIV-positive, had no bearing on the issue of whether it was legally correct that he could be charged with the offence of wanton endangerment.[18] The Supreme Court denied review of this decision.

Maryland

In January 2000, an HIV-positive man was sentenced to five years' imprisonment, with all but 18 months of his sentence suspended, for second-degree assault and reckless endangerment, after biting a security officer during a scuffle. The guard continued to test HIV-negative more than six months after the incident. The state attorney expressed the view that the sentence was not severe enough because of the "potential harm" posed by a bite from an HIV-positive person.[19]

Ohio

On 23 December 1999, the state Governor signed legislation (House Bill 100) making it a felony for a person who knows they are HIV-positive to have sex without obtaining the partner's consent in advance. The law expands the existing offence of "felonious assault" to include vaginal, anal, or oral sex by a person who knows they are HIV-positive and does not disclose this to their sexual partner. The bill also prohibits HIV-positive individuals from having sexual contact with unmarried minors under the age of 18, and with people who lack the mental capacity to understand an HIV diagnosis. A second-degree felony, the offence carries a sentence of two to eight years in prison and a maximum fine of $15,000. Before this bill was enacted, Ohio law regarding criminal exposure to HIV applied only to prostitution cases, a third-degree felony.[20] While Ohio had previously seen convictions on "felonious assault" charges for exposing sexual partners to HIV, prosecutors had been required to prove a "serious physical harm."[21]

Pennsylvania

On 7 December 1999, the state Senate overwhelmingly approved a bill (Senate Bill 847) creating the crime of "criminal transmission of HIV/AIDS" as a third-degree felony, punishable by up to seven years in prison and a maximum fine of $15,000. The bill would criminalize anyone who knows they are HIV-positive and engages in sexual intercourse or shares a needle, without disclosing their infection to their partner. Pennsylvania law defines "sexual intercourse" as including vaginal, anal, and oral sex. The bill was forwarded to the state House of Representatives for approval.[22]

South Dakota

In February 2000, the House voted overwhelmingly to approve a bill already approved by the state Senate (SB 48) to create the offence of "criminal exposure to HIV." Under the bill, this offence is committed when a person who knows they are HIV-positive engages in "intimate physical contact" that presents a "significant risk" of transmission. It also applies to sharing needles; donating blood, body tissue, organs, semen or other body fluid; or throwing blood or semen at another person for the purpose of exposing them to HIV. The offence is a felony punishable by up to 15 years in prison and a $15,000 fine. The bill was forwarded to the state Governor for signature.[23]

Texas

In January 2000, an HIV-positive Texas man was facing possible charges of assault with a deadly weapon for allegedly having unprotected sex with a woman in Texas and five women in Kentucky without disclosing his HIV status. Texas has no specific criminal statute dealing with HIV transmission, as it was repealed in 1994.[24]

Virginia

In March 2000, after significant amendments, the Virginia House of Delegates approved a bill (HB 141) creating the offence of "infected sexual battery." The offence applies to individuals who know they have HIV, syphilis, or hepatitis B, who

have sex or share drug-injection equipment without first disclosing their status to their partner. The prosecution must prove the accused had "the intent to transmit" the disease in question. The felony is punishable by one to five years in prison. The bill was forwarded to the state Governor for approval.[25] A similar bill was approved by the House in 1999, but did not pass the Senate.[26]

Washington

In November 1999, the Washington Court of Appeals upheld a conviction and 10-year sentence imposed on an HIV-positive man charged under the state's "criminal exposure law" with second-degree assault for having unprotected sex with a woman. According to the trial record the accused, Randall Ferguson, a drug user, did not hide his HIV status from his numerous sexual partners, but was inconsistent in his use of condoms and had expressed to several witnesses that he was not particularly concerned if some of his partners became infected. There are two significant aspects to the appellate court's decision.

First, the Court dismissed Ferguson's argument that the state's "criminal exposure" law was unconstitutional because it violated the "equal protection" clause of the US Constitution by singling out people infected with HIV for unequal treatment. The Court ruled that the law applied equally to infected and non-infected defendants, and merely criminalized specific conduct. Appellate courts in several other states have upheld HIV-specific criminal exposure laws as constitutional.[27]

Second, the Court rejected Ferguson's argument that his partner consented to what the Court called "assault with HIV." This decision was based on the facts of this particular case, and the Court said it made this decision "without determining whether consent can sometimes be a defense to an assault with the AIDS virus." The Court suggested, however, that Washington's statute might not recognize a consent defence, even where the evidence showed that a complainant knowingly consented to unsafe sex with an HIV-positive person.[28]

Wisconsin

In January 2000, the Wisconsin state Assembly approved a bill (AB 550) that would make it a criminal offence for any HIV-positive person to have any sexual contact without first disclosing their status. "Sexual contact" is poorly defined, and the bill makes no reference to safer sex or other precautions, meaning that an HIV-positive person can be convicted even if they use protection. The offence would be punishable by up to 25 years' imprisonment, with an additional 15 years of close supervision. The bill was forwarded to the state Senate for approval.[29]

Other Jurisdictions

In October 1999, an *Italian* court sentenced a man to 14 years in jail for murder, upon proof that he had infected his wife with HIV and she subsequently died of AIDS.[30] In *Kazakhstan*, a 21-year-old Russian woman was sentenced in January 2000 to a year in prison for having transmitted HIV to several men, with knowledge of her HIV status. It was reported that she will serve her sentence in "a special detention camp for HIV-positive prisoners."[31] In an update on a case in *New Zealand* reported in the last issue of the *Newsletter*, on 22 October 1999, an HIV-positive gay male prostitute, Christopher Truscott, pleaded guilty in Christchurch District Court to the offence of criminal nuisance for having unprotected sex without disclosing his HIV status, and was remanded for sentencing.[32]

– Richard Elliott

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[2] *R* v *Williams*, [2000] NJ No 138 (SC-TD); Newfoundland: Guilty of transmitting HIV. *National Post*, 28 April 2000: A8.

[3] *R* v *Mercer* (1993), 84 CCC (3d) 41 (Nfld CA).

[4] Man gets 5½ years for spreading HIV. *Globe and Mail*, 24 May 2000: A8.

[5] Communications with R Huntsman, Crown Attorney's Office, Attorney-General of Newfoundland & Labrador, 14 March 2000 & 11 April 2000.

[6] *R* v *Hollihan*, [1998] NJ No 176 (Prov Ct) (QL); Elliott R. Criminal law and HIV/AIDS: new developments. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(2/3): 45-51 at 45.

[7] *R* v *Ssenyonga* (1992), 73 CCC (3d) 216 (Ont Ct Prov Div).

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[11] Personal communication from E Roitenberg, Barrister & Solicitor, 18 May 2000; D Kuxhaus. HIV-positive man gets 8 years for having unprotected sex. *Winnipeg Free Press*, 19 May 2000: A3.

[12] Drug addict who jabbed clerk with needle gets one year in jail. *Canadian Press*, 8 February 2000.

[13] Alleged biter agrees to test. *Canadian Press*, 28 October 1999.

cont'd from previous page

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[17] Hainsworth J. Syringe used as weapon. *Calgary Herald*, 18 January 2000, B2; Martin K. Weapon not AIDS-tainted. *Calgary Sun*, 18 January 2000, 32.

[18] Reported in *Lesbian/Gay Law Notes* November 1999: 179, with reference to: *Hancock* v *Commonwealth of Kentucky*, 998 SW 2d 496 (Ky App, 1998).

[19] 18 months for biting. *AIDS Policy & Law* 2000; 15(1): 12.

[20] Ohio creates new felony for exposing sex partners to HIV. *AIDS Policy & Law* 2000; 15(1): 2.

[21] Three states ready to approve bills on criminal exposure. *AIDS Policy & Law* 1999; 14(21): 5.

[22] Similar bill advances in Pa. *AIDS Policy & Law* 2000; 15(1): 2; Three states ready to approve bills on criminal exposure. *AIDS Policy & Law* 2000; 14(21): 4.

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[24] Kalfrin V. Sex offender accused of spreading HIV. *APB News*, 14 January 2000, at www.apbnews.com

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[26] See *AIDS Policy & Law* 1999; 14(4): 4.

[27] Washington upholds HIV exposure law as constitutional. *AIDS Policy & Law* 1999; 14(22): 5; see, for example: *People* v *Russell*, 630 NE 2d 794 (Illinois), cert denied 513 US 828 (1994); *State* v *Serrano*, 1998 WL 352798 (La Ct App, 17 June 1998); *State* v *Gamberella*, 633 So 2d 595 (La Ct App 1993, writ denied); *State* v *Stark*, 832 P 2d 109 (Wash Ct App, 1992); *State* v *Mahan*, 1998 WL 312752 (Missouri, 16 June 1998).

[28] *Washington* v *Ferguson*, No 21329-0-II (Wash Ct App, 5 November 1999), unreported decision; Washington upholds HIV exposure law as constitutional. *AIDS Policy & Law* 1999; 14(22): 5; Washington Appeals Court upholds 10-year sentence for HIV+ man who had unprotected sex with women. *Lesbian/Gay Law Notes* December 1999; 191-192.

[29] Three states move to adopt criminal exposure statutes. *AIDS Policy & Law* 2000; 15(4): 7; A Leonard. Low blows: nondisclosing HIVers are being sent to the slammer for having sex. *POZ Magazine*, March 2000, 33; Harsher penalties sought for AIDS transmission. *Associated Press*, 26 January 2000.

[30] Reported in *Lesbian/Gay Law Notes* November 1999: 179.

[31] HIV-Positive Woman Jailed for Spreading AIDS Virus. *Agence France-Presse*, 17 January 2000, posted via www.russiatoday.com

[32] Reported in *Lesbian/Gay Law Notes* November 1999: 179.

CARE, TREATMENT, & SUPPORT

Mixed WTO Ruling on Generic Drug Development

On 17 March 2000, the World Trade Organization upheld the provision in Canada's patent laws that allows generic drug manufacturers to develop (but not sell) their cheaper versions of patented medicines before the 20-year patents expire. The decision prevents pharmaceutical companies from enjoying market monopolies beyond their patent terms, avoiding what would otherwise be even lengthier delays in the sale of cheaper, generic drugs in Canada. This decision is of significance not only to Canada, but also to other WTO member countries and to all individuals who use pharmaceutical products. However, the decision is not all positive: the WTO also ruled that Canada is violating international agreements by letting generic manufacturers stockpile their versions of patented drugs before patents expire. This article explains the issues, the arguments, and the decision.

Background

The Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS)[1] is an international trade agreement that requires all WTO member nations to implement the US model of protection for intellectual property rights, including patent rights for pharmaceutical inventions. A country that breaches its obligations under TRIPS faces severe trade sanctions.

In December 1997, the European Communities and their member states (EC) alleged that two provisions in Canada's *Patent Act* violated TRIPS. The EC asked for a ruling requesting Canada to change its domestic legislation. The final WTO Panel Report was issued 17 March 2000,[2] and was adopted by the WTO's Dispute Settlement Body on 7 April 2000.[3] While 11 other countries intervened, only Canada or the EC is entitled to appeal. The 60-day appeal period expired in mid May 2000, and neither party appealed the decision.

The Issues

Under Canada's *Patent Act*, a patent for an invention gives someone, for

the term of their patent, "the exclusive right ... of making, constructing and using the invention and selling it to others,"[4] subject to other provisions in the statute. The Act also contains two provisions that enable a generic drug manufacturer, before a patent expires, to *prepare* to sell its cheaper copy of a patented drug once the patent expires: the "regulatory review" exception and the "stockpiling" exception. In its complaint to the WTO, the EC challenged these two provisions.

"Regulatory review exception": submitting information for market approval

Canada's *Patent Act* states that it is not patent infringement for anyone "to construct, use or sell the patented invention *solely for uses reasonably related to the development and submission of information required under any law* of Canada, a province or a country other than Canada that regulates the manufacture, construction, use or sale of any product."[5] This is referred to as the "regulatory review," "early working," or "experimental use" exception to patent rights, and applies at any time during the term of a patent. (It is also commonly called the "Bolar exemption," after a US court case.)

Without this exception, generic drug manufacturers would be prohibited from even researching and developing generic versions of patented medicines until the 20-year patent term expires, because they need to use the patented drug in research comparing their generic version to the already-approved patented version. They would also be prevented from submitting the necessary research data and application for a licence to eventually sell their drug, and from submitting the information necessary to have their generic drug covered under each Canadian province's public health insurance plan. Given the delays in getting such approvals, this would extend the de facto market monopolies of pharmaceutical patent holders by months to years for every drug.

"Stockpiling exception": manufacturing and storing generic drugs

Canada's *Patent Act* and Regulations[6] also provide that, during the six months before a patent expires, there is no patent infringement if a generic drug company seeking regulatory approval of its own generic drug uses a patented drug in "*the manufacture and storage*" of its own generic product, which it intends to sell once the patent expires.[7] The generic manufacturer is not permitted to sell its copy product until the patent expires. These sections of the Act simply allow it to stockpile its product in anticipation of patent expiry.

The EC's Arguments

The EC alleged that Canada's "regulatory review" exception violated two articles of the TRIPS Agreement, and the "stockpiling" exception also violated a third article.

- First, it argued that both provisions infringe the "exclusive patent rights" that must be conferred by a patent, which are: making, using, offering for sale, or selling a product, or importing a product for these purposes (Article 28).
- Second, it argued that both provisions of Canadian law "discriminate" against pharmaceutical companies by treating them less favourably than inventors in all other fields of technology, whereas TRIPS requires that patents be available, and patent rights enjoyable, "without discrimination as to the field of technology" (Article 27).
- Third, with respect to the "stockpiling" provision only, it also argued that, by allowing stockpiling during the six months preceding patent expiry, the patent was protected for only 19½ years instead of the *minimum 20-year term* required by TRIPS (Article 33).

The EC argued that, without these provisions in Canadian law, generic drug manufacturers would not be able to effectively market their products until at least two years after patent expiry. Brand-name pharmaceutical companies would thus enjoy extra years of market monopoly, worth more than CDN$100 million per year. In effect, the EC sought a de facto extension of patents for its pharmaceutical companies beyond the 20-year period already required under TRIPS. Canada indicated that the process of developing generic drugs and obtaining regulatory approval could actually take even longer, from three to six-and-a-half years.

Canada's Position and the EC's response

Canada made three arguments in defending its *Patent Act* provisions.

Minimum patent term protected

First, Canada argued that its "stockpiling" provision in no way impaired a patent holder's right to exploit its patent for the full 20 years for its private commercial advantage.

A majority of the intervening countries agreed.

Justifiable "limited exception" to exclusive patent rights

Second, Canada invoked TRIPS Article 30, which allows "limited exceptions" to patent rights, provided they "do not unreasonably conflict with a normal exploitation of the patent" and "do not unreasonably prejudice the legitimate interests of the patent owner, taking account of the legitimate interests of third parties."

Canada argued that allowing the sale of generic drugs only *after* patent expiry does not "unreasonably" prejudice the patent owner's *legitimate* interests, and reiterated that patent holders' market monopoly was protected for the full 20 years.

Canada also asserted that allowing free competition after patents expire took into account the "legitimate interests" of generic drug manufacturers, consistent with the TRIPS policy of full competition. The EC disagreed, saying "there could be no legitimate interest of the generic producers to be able to sell on the Canadian market ... on the day the Canadian patent lapsed."[8] Such an argument is patently absurd: how can the patent holder claim that its interest in maintaining market supremacy after patent expiry is legitimate, yet deny the legitimacy of its competitors' interest in the market?

Canada also maintained that it has a legitimate "national interest in measures conducive to social welfare" and that it sought to protect public health (as recognized in Article 8), by

> promoting access to cost-effective generic medicines following patent expiry, taking into account the legitimate interests of individuals, private insurers and public sector entities that financed health care in maintaining access to affordable medicines.[9]

Without any apparent shame, the EC argued that such considerations were

> of little, if any, relevance for the purposes of interpreting the TRIPS Agreement. It was one of the major features of the TRIPS Agreement that its implementation was in principle neutral vis-à-vis societal values.... None of [these] public policy considerations could be invoked to justify measures which were inconsistent with provisions of the TRIPS Agreement.... [P]ublic health, nutrition and other public interests were to be considered subordinate to the protection of the intellectual property rights insofar as the minimum rights guaranteed by the TRIPS Agreement were concerned.[10]

In fact, the EC expressly rejected the idea that "consumers or society at large" could have any "legitimate interests" that could be considered in the context of TRIPS, and nonsensically asserted that "[t]he purchase or consumption of a medicine by a patient was no act which was of any relevance in patent terms. This meant in turn that *there could be no adverse interests between the consumer and the patent holder.*"[11]

The EC's response was brutally honest in privileging trade concerns over health and human rights.

The EC (and the US) also objected that Canada's law allowed a "regulatory review" exception not just for Canadian approval, but for getting a generic drug approved in other countries. Yet according to a 1999 World Health Organization report, more than one-third of the world's population lack regular access to essential drugs, and every year millions of children and adults in developing countries around the world die from diseases that could be readily treated by drug therapies, and more economically treated with generic drugs.[12] In the face of this tremendous need, Canada argued:

> Many countries still lacked the facilities and expertise needed to review the safety, efficacy and quality of drugs destined for their national markets, and remained dependent on reliable foreign authorities to set the necessary standards and on foreign generic companies to do the necessary testing to those standards.... A refusal to allow testing of generic medicines for the purposes of foreign regulatory submissions during the term of patent protection, while permitting it for domestic submissions, would needlessly delay the regulatory review process in many countries. As a result, generic drugs would not be readily available, and many treatable diseases would remain untreated, in the period following patent expiry.[13]

The EC's response was brutally honest in privileging trade concerns

over health and human rights: "Article 30 of the TRIPS Agreement was not a clause aimed at solving the public health problems of the entire world."[14]

No "discrimination" against pharmaceutical industry

Finally, Canada argued that the TRIPS "non-discrimination" clause does not apply to "limited exceptions" allowed under TRIPS. Alternatively, if it did apply, then Canada's laws did not discriminate because they were not expressly related to any particular field of technology. Canada also criticized the EC's attempt to extend market monopolies as itself an attempt to obtain preferential treatment for pharmaceutical companies. The EC argued this was based on the "good reason" that patent holders lost part of their period of market monopoly to the time-consuming regulatory approvals process, and analogized this to giving "the handicapped and the elderly" priority seating on public transportation.[15] Canada's response highlights the venality of this argument:

> there was good reason for the limited exceptions in Section 55.2(1) and 55.2(2) of the Canadian *Patent Act*, because they were clearly aimed at ensuring that necessary medicines were made available at competitive prices to those in need – the sick, the elderly, the physically and mentally disadvantaged – as soon as possible after patent expiry. On the EC's own approach, then, the challenged provisions were not discriminatory.[16]

The juggernaut of global corporate interests poses a direct and dire threat to the health and human rights of people with HIV/AIDS, as it does to the welfare of all the world's citizens and the planet.

The WTO's Decision

The WTO Panel rejected the EC's "discrimination" argument with respect to both the stockpiling exception or the regulatory review exception.[17] Its decision turned on the question of whether these provisions could be defended as "legitimate exceptions" to exclusive patent rights.

Stockpiling exception

The WTO ruled that patent rights include "a right to prevent competitive commercial activity by others" and that manufacturing a drug for commercial sale is "a quintessential competitive commercial activity, whose character is not altered by a mere delay in the commercial reward."[18] According to the Panel, allowing a generic drug company to manufacture and store product for sale once the patent expires, infringes patent rights. Despite the express positions to the contrary taken by Canada and a majority of interveners, the WTO decided that because countries are aware that granting patent rights can result in market monopoly even *after* patents expire, they must be affirming this purpose. In the Panel's view, the stockpiling exception

> constitutes a substantial curtailment of the exclusionary rights required to be granted to patent owners.... [T]he Panel agreed with the EC that six months was a commercially significant period of time, especially since there were no limits at all on the volume of production allowed, or the market destination of such production.[19]

Having characterized the infringement of patent rights as "substantial," the Panel naturally concluded that stockpiling could not be considered a "limited exception" under Article 30. Canada was therefore in violation of Article 28 by not protecting exclusive patent rights. The Panel did not rule directly that stockpiling infringes minimum patent terms (Article 33), although this seems implicit.

Regulatory review exception

However, the WTO Panel did find that Canada's "regulatory review" provision was a "limited exception" to patent rights because it was limited to acts required to comply with the regulatory approvals process, and did not allow commercial uses of the invention. This exception was justified because the "normal exploitation" of a patent does not include using patent rights to prevent others from submitting their own products for regulatory authorization, so as to gain an additional period of market exclusivity.[20] And in any event, this interest of patent owners

> was neither so compelling nor so widely recognized that it could be regarded as a "legitimate interest" within the meaning of Article 30 of the TRIPS Agreement ... [and] is a normative policy issue that is still obviously a matter of unresolved political debate.[21]

Astonishingly, the WTO Panel made absolutely no comment in its decision as to whether considerations of public health and access to affordable medicines would qualify as "legitimate interests" to be taken into account while protecting the intellectual property rights of pharmaceutical companies.

Conclusion

This is one of the first cases to consider the effect of TRIPS on the domestic patent law of WTO member countries. India correctly noted that it raises the "fundamental issue of the appropriate balance between private intellectual property rights and public policy objectives."[22] Given the potential significance of this decision, it should be cause for both relief and concern for those concerned about affordable access to medicines. We should be relieved that the "regulatory review exception" has been upheld; any other result would have meant even greater delays in the marketing of cheaper, generic medicines.

However, there is much cause for concern as well. The EC's appropriation of the language of "discrimination" to argue in favour of extended market monopolies for some of the world's most profitable corporations is grossly offensive. A law that permits only the manufacture and storage of generic drugs, and even then only in the last six months of a 20-year patent term, and which fully preserves the market monopoly of patent owners, has been declared by the WTO to violate international trade rules. It is particularly noxious that the EC, to satisfy the claims of profitable and powerful pharmaceutical corporations, could and would invoke an international trade agreement in pursuit of such extended monopolies, and that such arguments could be given serious consideration by a body with the power to authorize severe trade sanctions. Equally disturbing is the WTO Panel's failure to decide that trade agreements should not be allowed to override people's health by further restricting access to medicines.

It becomes increasingly clear that all those working on HIV/AIDS issues and, generally, those concerned with health and human rights, must develop literacy in international trade issues, and that mobilization must happen now. The juggernaut of global corporate interests poses a direct and dire threat to the health and human rights of people with HIV/AIDS, as it does to the welfare of all the world's citizens and the planet.

– Richard Elliott

Richard Elliott is Director of Policy & Research of the Canadian HIV/AIDS Legal Network (email: relliott@netrover.com). The TRIPS Agreement and a plain-language overview can be retrieved on the WTO website (www.wto.org). The Consumer Project on Technology (www.cptech.org), Health Access International (www.haiweg.org), Medecins Sans Frontières (www.accessmed-msf.org), and the Health Gap Coalition (http://aidsorg/health-gap) provide a wealth of research and policy material on the consequences for health care and access to medicine of corporate globalization. For an excellent primer on the WTO and the numerous international trade agreements it enforces, see: Shrybman S. *A Citizen's Guide to the World Trade Organization.* Ottawa: Canadian Centre for Policy Alternatives & James Lorimer and Co Ltd, 1999 (www.policyalternatives.ca).

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[1] Agreement on Trade Related Aspects of Intellectual Property Rights, being Annex 1C of the Marrakesh Agreement Establishing the World Trade Organization, 15 April 1994, Marrakesh, 1867 UNTS 3.

[2] Canada – Patent Protection of Pharmaceutical Products. Report of the Panel. WT/DS114/R (hereinafter "Panel Report"). Available online via WTO website (www.wto.org).

[3] Canada – Patent Protection of Pharmaceutical Products. Panel Report - Action by Dispute Settlement Body. WT/DS114/9.

[4] *Patent Act*, RSC 1985, c P-4, s 42 as amended by SC 1993, c 15; SC 1993, c 2; SC 1994, c 47.

[5] Ibid, s 55.2(1).

[6] Patented Medicines (Notice of Compliance) Regulations, SOR/93-133, as amended by SOR/98-166.

[7] *Patent Act*, s 55.2(2)-(4).

[8] Panel Report, at 60.

[9] Ibid at 18.

[10] Ibid at 50, 53.

[11] Ibid at 58 [emphasis added].

[12] *The Worldwide Role of Generic Pharmaceuticals*. Presentation to the International Generic Pharmaceuticals Association by Dr Jonathon D Quick, Director of Essential Drugs and Other Medicines, World Health Organization, June 1999.

[13] Panel Report, at 80-81, references omitted.

[14] Ibid at 86.

[15] Ibid at 49 (note 146).

[16] Ibid at 91.

[17] Ibid at 174.

[18] Ibid.

[19] Ibid at 156.

[20] Ibid.

[21] Ibid at 168-169.

[22] Ibid at 119.

Panel Rules against Canada on Patent Terms for Pre-TRIPS Patents

On 5 May 2000, the WTO Panel issued another ruling regarding patents of relevance to pharmaceutical products. Upholding a complaint by the US, the Panel ruled that Canada's *Patent Act* was in breach of the minimum patent terms for inventions required by the *Agreement on Trade-Related Aspects of Intetellectual Property Rights* (the TRIPS Agreement).[1]

Under Canada's *Patent Act*, before October 1989 a patent term was 17 years from the *date a patent was granted*. Following amendments, the Act now says that:

- for any patent applications filed *before* 1 October 1989, the patent term remains 17 years *from the date of patent grant* (ie, the law that was in place when the application was made still applies); but
- for any application filed *on or after* 1 October 1989, the patent term is 20 years *from the date of application*.

Canada became bound by the terms of the TRIPS Agreement on 1 January 1996. The Agreement states that patent terms must be for a minimum of 20 years from the date of filing a patent application (Article 33). It also says that it "gives rise to obligations in respect of all *subject matter* existing at the date of application of this Agreement ... which is protected in [the country in question] on the said date." (Article 70.2)

The US argued that this meant the minimum 20-year patent term required by TRIPS should apply to all inventions that were patented in Canada as of January 1996, including those inventions for which the patent application had been filed before October 1989 (and which had therefore received a term of only 17 years from grant). This would mean, in effect, lengthening the terms of patent protection in the case of any invention for which a patent application had been filed before October 1989 and/or for which a patent was granted less than three years after this application.

In response, Canada argued that patents granted before TRIPS came into effect in Canada are not covered by the treaty's requirements. It pointed to the "non-retroactivity" clause, which says that TRIPS "does not give rise to obligations in respect of *acts* which occurred before the date of the application of the Agreement" for the country in question (Article 70.1).

However, the WTO rejected Canada's argument. It ruled that, while TRIPS may not apply to the administrative *act* of granting a patent before 1 January 1996, TRIPS does apply the *subject matter* that is patented on that date: "Holders of patents valid on the date of the application of the *TRIPS Agreement* are entitled to protection of all of the rights set out in the Agreement for a term consistent with the requirement in Article 33."[2]

As reported elsewhere in this issue of the *Newsletter* (see "Federal Court of Appeal Strikes Claim for Extending Patent Term"), in 1999 the Federal Court of Canada considered the very issue raised in the US complaint to the WTO. In *Pfizer Inc* v *Canada*, the Court's trial division concluded that Canada had not legislated TRIPS Article 33 into domestic law, but expressly said that whether this amounted to a breach of international obligations was a question that fell to be decided through the WTO's dispute resolution procedures. The appellate division upheld this ruling.[3] The WTO has now ruled on the question.

The industry association representing Canadian generic drug manufacturers had previously warned that the US complaint, if successful, would lead to even higher drug costs for Canadians, by delaying the availability of generic versions of brand-name drugs for which patent applications were filed before October 1989.[4] Following the decision, the federal Minister of Health stated that Canada would appeal the ruling.[5]

– Richard Elliott

1. Agreement on Trade-Related Aspects of Intellectual Property Rights, being Annex 1C of the Marrakesh Agreement Establishing the World Trade Organization, 15 April 1994, Marrakesh, 1867 UNTS 3.

2. Panel Report, at 15.

3. *Pfizer Inc* v *Canada*, [1999] FCJ No 1598 (CA), aff'g [1999] 4 FC 441, [1999] FCJ 1122 (TD).

4. Canadian Drug Manufacturers Association. Press release: US threatens Canada at WTO for increased patent protection for brand name drugs. 10 June 1999.

5. Scoffield H. WTO rules against Canada on patents. *Globe and Mail*, 6 May 2000.

INSURANCE

US Supreme Court Allows Limits on AIDS-Related Insurance Benefits

In a ruling issued on 10 January 2000 with respect to *Doe* v *Mutual of Omaha Insurance*,[1] the US Supreme Court refused to review a lower-court decision allowing an insurance company to limit health-care benefits for AIDS-related claims to less than one-tenth of what it pays under the same policies for expenses related to other illnesses. The lower court had ruled that anti-discrimination legislation does not apply to insurance policies.

Two HIV-positive men, "John Doe" and "Richard Smith," had sued Mutual of Omaha Insurance Company in 1997 because the company's insurance policies capped payment of health benefits at $25,000 and $100,000 respectively for AIDS or HIV/AIDS-related illnesses. Both policies had a lifetime limit of $1 million for all other illnesses. Represented by lawyers from Lambda Legal Defense and Education Fund, Doe and Smith argued this violated the *Americans with Disabilities Act* (ADA), which states that "no individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation."[2] The US Supreme Court has ruled that HIV infection is a disabling condition from the onset of infection.[3]

The trial court judge agreed with Doe and Smith, finding that the policies violated the ADA. The insurance company appealed. A number of organizations intervened in support of the two men, including the Infectious Diseases Society of America, the HIV Managed Care Network, the American Public Health Association, the AIDS Foundation of Chicago, the American Civil Liberties Union, the Disability Rights Education and Defense Fund, the AIDS Action Council, and the US Department of Justice (Civil Rights Division). However, the US Court of Appeals (7th Circuit) reversed the trial judge's decision. Without any comment or dissent, the US Supreme Court denied leave to appeal this decision.

The insurance company admitted that "it has not shown and cannot show that its AIDS caps are or ever have been consistent with sound actuarial principles, actual or reasonably anticipated experience, bona fide risk classification, or state law." It also conceded that AIDS is a disabling condition within the meaning of the ADA.[4]

As the plaintiffs pointed out, the very same illness (eg, pneumonia) may be AIDS-related or it may not be, and that, in such cases, coverage under Mutual of Omaha's policies would depend solely on whether the patient has AIDS. In the dissenting view of Judge Evans, "that is more than enough to trigger an ADA violation." Yet Chief Judge Posner, writing for the majority, concluded that the insurance company was not discriminating, because of the nature of HIV disease:

> The essential point to understand is that HIV doesn't cause illness directly. What it does is weaken and eventually destroy the body's immune system.... An AIDS cap would be meaningless if it excluded the opportunistic diseases that are the most harmful consequences of being infected by the AIDS virus.... It is these distinctive diseases that are the target (along with the costs of directly treating infection by HIV) of the AIDS caps. It is true that as the immune system collapses because of infection by HIV, the patient becomes subject to opportunistic infection not only by the distinctive AIDS-defining diseases but also by a host of diseases to which people not infected with HIV are subject. Even when they are the same disease, however, they are far more lethal when they hit a person who does not have an immune system to fight back with. Which means they are not really the same disease.[5]

Judge Posner expressly stated that it would be a prima facie violation of the ADA for an insurance company to refuse to sell health insurance to people with HIV/AIDS (unless it could justify this decision on sound actuarial principles). However, he took the view that "the *content* of the goods or services offered" (ie, the content of insurance policies) is not regulated by the ADA:

> There is a ... difference between refusing to sell a health-insurance

policy at all to a person with AIDS, or charging him a higher price for such a policy, or attaching a condition obviously designed to deter people with AIDS from buying the policy (such as refusing to cover such a person for a broken leg), on the one hand, and, on the other, offering insurance policies that contain caps for various diseases some of which may also be disabilities within the meaning of the Americans with Disabilities Act.[6]

Judge Posner felt that to require the insurance company to provide the same coverage for HIV/AIDS-related illnesses as it does for other illnesses would be akin to requiring a camera store to stock cameras specially designed for disabled persons. In dissent, Judge Evans said that this analogy missed the mark: "The better analogy would be that of a store which lets disabled customers in the door, but then refuses to sell them anything but inferior cameras."[7]

Surprisingly, in April 2000, Mutual of Omaha announced that it would voluntarily lift its cap on coverage for HIV/AIDS-related claims. A company spokesman said that "increased medical knowledge regarding HIV/AIDS allows insurers today to better understand and manage the financial risk associated with AIDS-related claims."[8]

– Richard Elliott

[1] *Doe v Mutual of Omaha Insurance Company*, 179 F 3d 557 (7th Cir 1999), cert denied 10 January 2000 (US Supreme Court, No 99-772).

[2] *Americans with Disabilities Act of 1990*, § 302(a), 42 USC § 12182(a).

[3] *Bragdon v Abbott*, 524 US 624, 118 S Ct 2196, 141 LEd.2d 410 (1998).

[4] *Doe v Mutual of Omaha Insurance*, supra, note 1 at 558.

[5] Ibid at 560-561.

[6] Ibid at 563.

[7] Ibid at 565.

[8] Fargen J. Mutual of Omaha lifts AIDS cap. *Associated Press*, 13 April 2000.

LEGAL CLINICS

The BC Persons with AIDS Society Advocacy Department

This is the fourth in a series of articles about specialized legal and advocacy services for people with HIV/AIDS. In previous issues of the *Newsletter*, Ruth Carey provided an overview of the work of the HIV & AIDS Legal Clinic, Ontario (HALCO),[1] Johanne Leroux described the work of the legal clinic of the Québec Committee for people with HIV in Montréal,[2] and Jennifer Duff described the work of the HIV Legal Services division of the Ottawa Clinic.[3] In this article, Tarel Quandt, Director of Individual Advocacy, describes the work of the Advocacy Department of the British Columbia Persons with AIDS Society (BCPWA).

BCPWA

BCPWA promotes self-help and self-care by providing support, treatment, and advocacy services to people with HIV/AIDS. The Society is directed by and for people with HIV.

The Advocacy Department

The Advocacy Department consists of two lay advocates, a prison coordinator, one lawyer, a handful of dedicated volunteers, a bi-monthly student law clinic, and a few volunteer lawyers. It provides advocacy services for approximately 100 new files every month and has over 300 additional contacts with individuals each month on ongoing files. In addition, the Prison Outreach Program (POP) receives approximately 50 contacts every month on its prison hotline.

Poverty law issues are the primary focus of the Department's work: appeals for Canada Pension Plan disability and welfare disability; securing health benefits and other needs; debt forgiveness; wills and powers of attorney; and residential tenancy issues. Other issues include long-term disability, trusts, human rights, employment, and immigration.

Because of overwhelming workloads, legal issues that require ongoing legal attention are referred to our volunteer lawyers in the community. It is unfortunate and wholly inadequate that legal issues faced by HIV-positive individuals are often not covered by Legal Aid and that we must rely on the goodwill of lawyers to donate their time.

Highlights

Health benefits

In 1999, the Advocacy Department put over $1 million into the hands of almost 300 people with HIV/AIDS to help them meet their life-threatening health needs. By applying for particular health-care goods to slow the pro-

gression of HIV to AIDS, the Department secured ongoing monthly health allowances averaging $370 for persons receiving income assistance from the province.

A section of BC's welfare legislation allows for an application for health-care goods if a person is facing a life-threatening health need, and no other sources of funding are available to the person.[4] With the endorsement of the person's physician, a nutrition expert, and medical and scientific evidence, we establish that vitamins, nutritional supplements, food, and bottled water constitute health-care goods in the context of HIV disease – they help strengthen an individual's immune function and prevent disease progression. And we argue that the income assistance received by disabled persons is inadequate. Individuals who live on income assistance cannot afford to eat properly, take the necessary vitamins and mineral supplements, or drink purified water when their health condition requires them to do so. Furthermore, there are no community resources available that provide these health-care goods on an ongoing and adequate basis.

But this success has not been easy. Initially, in 1996, we lost all our applications. After a year of refining our arguments we began succeeding. Currently, our advocates wade through a cumbersome and time-consuming appeal process – from the original denial at the welfare office, to tribunal, to the appeal board. In almost all 300 cases we have won at the tribunal level only to have the government appeal to the appeal board. To date, we have won every case at the appeal board.

The entire process usually takes six to eight months and the Department has a waiting list of almost 400 people. Currently, a person will probably wait over two years before the Department begins their application. Because of the onerous nature of the application process, very few community groups have taken on this project. Almost all people with HIV in the Vancouver and outlying areas are referred to our Department. For the few groups in other parts of British Columbia that undertake these applications, we provide support and advice.

We have learned that building strong relationships with health-care professionals is key to much of our advocacy work. Often the endorsement of a health-care professional is pivotal to a successful application. Streamlining the paperwork required from the health professional has been essential in enabling these professionals to participate in the applications because of their own large workloads.

BC's new adult guardianship laws

In February 2000, four new acts governing adult guardianship in BC became law.[5] The Department is endeavouring to help HIV-positive individuals benefit from the new laws. The new legislation is not without controversy, but much of it can potentially promote the self-determination of HIV-positive persons.

Under the new legislation, an adult can write an agreement that gives a chosen representative many decision-making powers. These agreements give adults in BC a new legal right – the right to determine their future personal and health care. Should the adult become mentally incapable, the representative can make not only financial decisions, but personal or health-care decisions for the adult following the instructions in the agreement. This is new law for British Columbians. In the past, the only legal instrument available for future decision-making was the enduring power of attorney. However, this power of attorney only allowed for the management of a person's financial affairs if they became incompetent. While living wills and health directives were used in BC by HIV-positive persons, these documents did not have legal authority and did not adequately meet individuals' needs for future health-care planning.

The new legislation also gives spouses the primary right (over all family members and the government) to consent to health-care treatment for their spouse if that adult has become mentally incompetent. The definition of "spouse" includes persons in same-sex "marriage-like relationships."

Prison work

The Prison Outreach Program (POP) provides a telephone hotline for inmates to call collect from the institutions for advocacy services. The hotline is staffed by volunteers five evenings a week. Issues most often raised include:

Access to specialists

Inmates often report that passes from institutions to see specialists are not given the weight and importance they deserve. Specifically, the physical distance between many institutions and specialists in hospitals requires a considerable time investment by the escorting staff. Added to this are security issues – some inmates have to be escorted by two staff. If an institution feels that it

cannot spare the escorting staff, it will cancel the pass rather than seek alternative solutions. Furthermore, POP volunteers have noted different standards of care in accessing specialists for HIV-positive inmates even in the same institution.

Adequate access to medications

Inmates report returning from medical-specialist appointments with prescriptions, only to be told that they will not be receiving the prescribed medication. At other times, inmates report that health-care staff have canceled medications ordered by licensed physicians.

Adequate nutrition

Inmates are required to eat at predetermined mealtimes and they are not generally provided with additional food or permitted to remove food from the institutional dining rooms. There have been several instances where inmates have been disciplined for doing so.

Many medications need to be taken on a strict schedule related to food intake, often at unusual times between normal meal hours. Certain medications work better with certain types of diets. Institutional menus typically contain high levels of unhealthy fats and are low in protein and vitamins and other essential nutrients. Many HIV-positive inmates, together with POP volunteers, have tried requesting extra nutritional food to assist inmates with their drug regime and their health promotion. Except in a very few cases, the requests have been refused.

Besides individual advocacy services provided to inmates, POP volunteers and staff attend information fairs at institutions and provide information about HIV/AIDS to inmates and staff, meet with inmates at pre-trial stage, or arrange special visits with inmates in institutions in order to provide information and support. Last year, the Department hired a Prison Outreach Coordinator to provide support to the prison program.

Advocacy training

In keeping with the Society's mandate to promote personal empowerment, the Department provides advocacy skills-building training to individuals and community groups. We also make all our advocacy materials available to the public. While we receive many requests for our training, we are able to respond to only a few each year because of our individual advocacy caseload.

To further our community work, in 1999 we published *Positive Change: Advocacy for People with HIV Disease and AIDS*, with funding from the Law Foundation of British Columbia. The manual provides advocacy information on BC welfare rights, Canada Pension Plan benefits, Employment Insurance benefits, debt forgiveness, human rights, wills, and confidentiality.[6]

Law reform

Our advocates identify and inform our collective advocacy efforts on common recurring problems faced by individuals. In the last year, in partnership with a few community groups we have successfully lobbied the BC government

- to provide infant formula to all infants with HIV-positive mothers who receive income assistance (this had far-reaching effects because government extended the benefit to all infants whose mothers on income assistance were incapable of breastfeeding)
- to stop clawing back tax on Canada Pension Plan earnings for individuals receiving income assistance;
- to standardize the procedure for provision of diet allowances;
- to provide condoms to income assistance recipients; and
- to provide pre-release welfare assistance to inmates so that upon release from prison an individual can immediately begin receiving welfare. So far, the government has introduced a pre-release program for the women's prison.

Furthermore, we continue to press the government to streamline the appeal process for the health-care benefits we have secured over the last the four years. We have been in discussion with government for over a year to find ways to provide all income recipients with HIV a special monthly health allowance.

– Tarel Quandt

Tarel Quandt is Director of Individual Advocacy, British Columbia Persons with AIDS Society. She can be reached at <tarelq@parc.org>. For more information on problems in BC prisons, visit BCPWA's website (www.bcpwa.org/living/lvg2/prison.htm).

The Advocacy Department receives funding from a number of sources. The AIDS Community Action Program (Health Canada) and the BC provincial government provide core funding. Funding for special projects is obtained from the BC legal community. Unfortunately, the Society has been unsuccessful in securing annual funding for its prison program. The Society has dedicated money it has yet to raise to financially support this program.

[1] Carey R. Provision of legal services to persons with HIV or AIDS: barriers and trends. *Canadian HIV/AIDS Policy & Law Newsletter* 1997/98; 3(4)/4(1): 9-11.

[2] Leroux J. The Montréal legal clinic for people with HIV/AIDS. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(2/3): 15-17.

[3] Duff J. The University of Ottawa Community Legal Clinic. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 5(1): 41-43.

[4] *Disability Benefits Program Act, Schedule C* 2(1)(l), RSBC 1996, c 97.

[5] *Representative Agreement Act*, RSBC 1996, c 405; *Public Guardian and Trustee Act*, RSBC 1996, c 383; *Health Care (Consent) and Care Facility (Admission) Act*, RSBC, c 181; *Adult Guardianship Act*, RSBC 1996, c 25.

[6] For more details, see *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(4): 78.

DISCRIMINATION & HUMAN RIGHTS

HIV/AIDS, Human Rights, and Development

In just two decades, AIDS has become the leading cause of death in Africa, and now kills more people worldwide than any other infectious disease. Although current treatments are expensive, and an affordable vaccine in the developing world is many years away, HIV/AIDS prevention programs and activities often remain narrow in their scope, applicability, and impact.

A human rights approach to the HIV/AIDS epidemic moves beyond a focus on the individual to address social, economic, and political factors that drive the epidemic, such as gender-based inequalities, poverty, corruption, and government inaction. A rights-based approach empowers affected individuals and communities, and challenges governments to justify their actions (or inaction) to the people they represent and, ultimately, to the global community.

We reproduce a fact sheet written by David Patterson for the Interagency Coalition on AIDS and Development (ICAD). It sets out a rights-based approach to development, examines the human rights dimensions of the HIV/AIDS pandemic, and gives examples of rights-based programming in the context of the developing world. It concludes with sources of further information, both in hard copy and on the web.

A Rights-Based Approach to Development

In 1998, the United Nations Secretary-General launched a broad rights-based approach to development, intended to help governments and development agencies redirect their development thinking:

> A rights-based approach to development describes situations not simply in terms of human needs, or of developmental requirements, but in terms of society's obligations to respond to the inalienable rights of individuals. It empowers people to demand justice as a right, not as charity, and gives communities a moral basis from which to claim international assistance where needed.
>
> *– Report of the Secretary-General on the Work of the Organization, 1998, United Nations, A/53/1, paras 173-174.*

The primary legal responsibility for national development rests with national governments. The international community can help with financial and technical assistance to governments and NGOs while also supporting the development of civil society, which is necessary to enable communities to demand the efficient, effective, and equitable use of these resources as a right. Civil and political rights (including freedom of speech and association, due process of law, an independent judiciary, and genuine periodic elections) are thus inseparable elements of development and development assistance.

HIV/AIDS and Human Rights

The human rights dimensions of the HIV/AIDS epidemic span the full range of civil, political, economic, social, and cultural rights:

- direct discrimination against people with HIV infection or thought to be infected (eg, denial of employment or basic medical treatment);
- factors that increase the vulnerability to HIV infection, or the impact it has if infection occurs (eg, poverty, illiteracy, poor nutrition, lack of treatment of sexually transmitted diseases, gender-based discrimination, lack of easy access to water);
- factors limiting the civil society

response to the HIV epidemic (eg, lack of freedom of speech and association for affected groups to discuss and organize their response, police or other harassment of people doing HIV prevention education).

Because it leads to fear, denial, apathy, and isolation, discrimination is one of the biggest challenges. By hindering the participation of people who are infected and affected, discrimination impedes public health prevention and care efforts. Recognizing that people with HIV/AIDS are part of the solution, not the problem, the 1994 Paris Declaration commits governments to the principle of the greater involvement of people living with HIV/AIDS – the "GIPA" principle.

The state is responsible for enacting and enforcing appropriate laws, and also for reducing fear, ignorance, and discrimination by funding public education campaigns, and by other means such as peer-based education. As discrimination and other abuses often occur at the most intimate interpersonal level (eg, family rejection of a person with HIV), education and sensitization are as important as law reform.

Rights-Based Programs, Projects and Activities

The following two case studies and other examples provide models for rights-based HIV/AIDS programming, projects, and activities that can be adapted to different national contexts.

Case study: The AIDS Law Project, South Africa

www.hri.ca/partners/alp/

The AIDS Law Project was founded in 1993 and is based at the Centre for Applied Legal Studies, University of Witwatersrand. The Project:

- carries out litigation to counter wrongs that have occurred and, where possible, to establish legal precedents that prevent them from recurring;
- offers free legal advice that will empower people living with HIV and AIDS to seek legal remedies in response to acts of unfair discrimination;
- carries out research to support policy formulation and bring about practices that prevent discrimination; and
- produces media that create an awareness of rights in government and civil society and promote effective lobbying and advocacy.

HIV/AIDS-related legal issues addressed by the AIDS Law Project have included:

- the lawfulness of HIV testing in the workplace;
- rights concerning access to treatments;
- willful transmission and HIV infection in marriage;
- rights of domestic workers;
- confidentiality of children in pre-school, school, and hospital settings;
- treatment for sexually abused women and rape survivors;
- protocols concerning needlestick injuries;
- liability for infection through blood transfusions;
- adoption; and
- rights to cover HIV infection by means of medical aid schemes.

AIDS Law Project researchers, attorneys, and paralegal officers speak at over 250 meetings a year on a range of topics about AIDS, development, employment, human rights, and the law. In 1999, the Project adopted a partnership agreement with the Canadian HIV/AIDS Legal Network to undertake joint projects and to promote the transfer of skills and experience between the two countries. International funders in 1998-1999 included the European Union, the Southern African AIDS Training Programme (Canadian International Development Agency / Canadian Public Health Association), and the Ford Foundation.

Case study: The Southern African AIDS Training Programme (SAT)

www.cpha.ca/cpha.docs/SAT_web/SAT.html

The Southern African AIDS Training (SAT) Programme is based in Harare, Zimbabwe. Begun in 1991, it now promotes and financially assists community-based prevention and support responses to the HIV/AIDS pandemic in eleven southern African countries. SAT partners include:

- community-based AIDS service organizations;
- church-related organizations and mission hospitals;
- women's health and advocacy organizations;
- women's shelters and neighbourhood associations;
- men's gender and advocacy organizations;
- legal reform and human rights organizations;
- self-help groups for people with HIV/AIDS;
- trade unions and counseling groups;
- youth groups and programs for street kids;
- gay and lesbian groups;
- advocacy and policy organizations; and
- national and regional AIDS NGO networks.

Early discussions with SAT partners revealed that they had difficulty in responding to HIV/AIDS-related human rights abuses in their work. Several partners requested assistance to build their skills and capacity in this area, and in response SAT developed a series of workshops which demonstrated the linkage between HIV, gender, human rights, and child rights issues in practical terms. The workshops identify the laws, both national and customary, that can be applied to enhance the lives of people with HIV/AIDS. Furthermore, SAT partners are equipped with advocacy skills to enable them to lobby for law reform.

A number of partners have since been involved in highly visible landmark cases and initiatives. These include the introduction of the Sexual Offences Act in Tanzania, which was passed to safeguard the rights of women and children against sexual abuse. SAT partners have also played a prominent role in lobbying for land rights for women in Zimbabwe, Tanzania, and Zambia. SAT is funded by the Bilateral Division of the Canadian International Development Agency (CIDA).

Other examples of rights-based projects and activities

Law reform

- Nicaragua: In 1996, the UNDP hosted a parliamentary seminar on HIV/AIDS. A law to protect rights in the context of AIDS was subsequently enacted. A communications strategy that used a video to illustrate the ethical and human rights aspects of the law was developed.

Legal advice and litigation

- India: The Lawyers Collective, HIV/AIDS Unit, responds specifically to the legal needs of people with HIV/AIDS. The Unit provides legal aid and advice, promotes awareness of HIV-related legal issues in the general community and among the legal profession, and advocates for law reform.
- Costa Rica: As a result of legal action by the Coalition of Costa Ricans with HIV/AIDS, the Supreme Court ruled that the national health-care system should provide certain medications for people with HIV infection.

Legal education

- Russia: In 1998, UNAIDS hosted a workshop on HIV/AIDS and legal issues for some 30 legal academics and professionals and government policymakers.
- South Africa: The AIDS Law Project and Lawyers for Human Rights have published a resource manual in plain English for people with HIV/AIDS and the general community.

Monitoring and documentation

- Burma & Thailand: Human Rights Watch investigated the trafficking of girls and their vulnerability to HIV infection. The report re conceptualized the issue as a "human rights violation" rather than a "social problem."
- Romania: The Bucharest Acceptance Group was funded by UNAIDS to report on the impact of the criminal law on HIV/AIDS prevention among men who have sex with men. The United Nations Human Rights Committee considered the report and other evidence, and recommended that Romania reform its laws on homosexual relations between consenting adults.

Women's rights

- India: The Lawyers Collective applied a gender analysis and identified a number of laws whose impact increased the vulnerability of women to HIV and AIDS. Advocacy for appropriate law reform has resulted.
- Zimbabwe: Groups such as the Women and AIDS Support Network applied a gender analysis to a proposal to increase criminal penalties for HIV transmission and realized that, for complex social reasons, women would be differentially affected. These groups then lobbied for a different approach based on a gender and rights analysis.

Children's rights

- Malawi: To address the issue of children orphaned by HIV/AIDS within the framework of the Convention on the Rights of the Child, community based organizations are using a training manual developed by the Unit for Research and Education on the Convention on the Rights of the Child, University of Victoria, Canada.
- Zimbabwe: The Victim Friendly Court System is a multidisciplinary initiative in which the legal courts in Zimbabwe that deal with cases of child sexual abuse rely on evidence provided by a team of experts –doctors, psychologists, and social workers – that attends to the victims of child sexual abuse. The children's hearings take place in camera and they do not have to face the perpetrators. The Family Support Trust coordinates treatment, counseling, and support for the children who have been abused.

Partnerships and networks

- Regional networks on human rights and HIV/AIDS have been established in Asia, sub-Saharan Africa, and Latin America and the Caribbean.

- In 1999, the AIDS Law Project (South Africa) and the Canadian HIV/AIDS Legal Network formally adopted a partnership agreement to provide mutual support in achieving their missions and goals.

Strengthening national institutions

- In 1998, UNAIDS and the Office of the High Commissioner for Human Rights agreed on a pilot project to place two national human rights advisers with HIV/AIDS-related expertise in national human rights commissions in India and Uganda.

Key Documents

The following publications provide further information on aspects of HIV/AIDS, human rights, and development:

- From *Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)*. Geneva: UNAIDS, 1999. Contains the Paris Declaration of 1 December 1994. At www.unaids.org
- *Handbook for Legislators on HIV/AIDS, Law and Human Rights*. Geneva: UNAIDS and the Inter-Parliamentary Union, 1999. Gives examples of positive law and policy reform in both developed and developing countries.
- *HIV/AIDS & Human Development: South Africa*. United Nations Development Programme, 1998. This National Human Development Report focuses on HIV/AIDS and its impact in South Africa.
- *Human Rights and HIV/AIDS: Effective Community Responses*. Ottawa: Human Rights Internet, 1998. Examples of initiatives from different regions.
- *HIV/AIDS and Human Rights: International Guidelines*. Geneva: UNAIDS and Office of the High Commissioner for Human Rights, 1998. HR/PUB/98/1. Includes the Guidelines as well as explanatory and historical material. At www.unaids.org
- *Human Development and Human Rights: Report on the Oslo Symposium*. New York: UNDP, 1998. Provides an overview of the issues and useful recommendations for action. At www.undp.org/hdro/Oslorep1.html
- *Stories from the Frontline*. Ottawa: ICASO, 1999. Examples of initiatives in different regions. At www.icaso.org
- *The UNAIDS Report*. Geneva: UNAIDS, 1999. Provides an overview of the impact of HIV/AIDS in developing countries as well as the expanded UN response. At www.unaids.org
- Legal, Ethical, and Human Rights Issues at Geneva98. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(2/3). Includes eight conference papers, and abstracts on related issues. At www.aidslaw.ca
- Decosas J. AIDS and Development – What is the Link? In: *Development Express* No. 7, Ottawa: International Development Information Centre, 1996. Discusses the interaction of HIV/AIDS and development and identifies biological, cultural, and structural cofactors in developing countries. At www.acdi-cida.gc.ca/xpress/dex/dex9607.htm
- Heywood M. Human Rights Violations of People with HIV/AIDS: The Implications for Equitable Development in South Africa. Examines the issues in the context of a developing country. At www.hri.ca/partners/alp/resource/undp.shtml
- Mann J. Human Rights and AIDS: The Future of the Pandemic. In: Mann et al (eds). *Health and Human Rights: A Reader*. New York: Routledge, 1999, at 216. Provides a historical overview, identifies the inherent limitations of traditional approaches, and proposes an approach that focuses on human rights.

Websites

The following websites provide further information on aspects of HIV/AIDS, human rights, and development.

AIDS Law Project, South Africa: www.hri.ca/partners/alp/

Canadian HIV/AIDS Legal Network: www.aidslaw.ca

François-Xavier Bagnoud Center, Harvard University: www.hri.ca/partners/fxbcenter/

Human Rights Internet, Canada: www.hri.ca

International Council of AIDS Service Organizations, Canada: www.icaso.org

Interagency Coalition on AIDS and Development, Canada: www.icad-cisd.com

Joint United Nations Programme on HIV/AIDS (UNAIDS): www.unaids.org

United Nations Development Programme, HIV and Development Programme: www.undp.org/hiv/

– David Patterson

David Patterson is a human rights consultant based in Geneva. He can be reached at david.patterson@attglobal.net.

For more information, contact the Interagency Coalition on AIDS and Development (ICAD) at 613 788 5107 or info@icad-cisd.com or consult their website at www.icad-cisd.com

PUBLICATIONS REVIEWED

HIV-Related Discrimination in New Brunswick Increasing

In February 2000, AIDS New Brunswick, AIDS Saint John, and SIDA AIDS Moncton released findings of a study on the needs of people with HIV/AIDS in New Brunswick.

Of the 50 participants in the study, 86 percent indicated *a fear of* discrimination because of their HIV status, and 66 percent reported *experiencing* incidents of HIV-related discrimination. A comparable study conducted in New Brunswick in 1992 found a similar level of fear of HIV-related discrimination (87 percent). However, since 1992 there has been an increase in incidents of HIV-related discrimination reported by survey participants (from less than 33 percent in 1992 to 66 percent).

Fewer participants in the new study reported fear of being rejected by family or friends than in 1992 (42 percent versus 68 percent in 1992). Participants also reported being rejected by family and friends less frequently than they experienced overall HIV-related discrimination (34 percent versus 66 percent). Many experiences of discrimination are thus occurring in public settings (eg, workplaces and public services), pointing to the need for continued efforts to create supportive environments for people with HIV/AIDS through public education and public/workplace policies.

– Claude Olivier

Claude Olivier is Executive Director of AIDS New Brunswick. A copy of the study can be obtained through AIDS New Brunswick (email: sidaids@nbnet.nb.ca).

Blood Feuds: AIDS, Blood and the Politics of Medical Disaster[1]

In 1997 the Commission of Inquiry on the Blood System in Canada, chaired by Mr Justice Horace Krever, produced its final report[2] on Canada's tainted-blood scandal. The contamination of Canada's blood supply by the AIDS virus produced, in Justice Krever's words, "a public health disaster that was unprecedented in Canada." The Commission's final report made a number of recommendations intended to prevent future problems with the country's blood supply. It also produced a narrative detailing how politics, poor judgment, bureaucratic inertia, and the emerging HIV threat combined to destroy a blood supply and regulatory system that Canadians trusted implicitly.

But of course the HIV-contaminated blood tragedy was not confined to Canada. Similar disasters unfolded in every nation with an organized system for the collection and therapeutic use of blood and blood products. *Blood Feuds* is an important book that provides an authoritative account of the experience of a number of culturally distinct industrialized countries.

Blood Feuds explores how different political and cultural contexts resulted in quite different national responses to what was at root essentially the same issue. It endeavours to determine what made the existing blood systems so vulnerable and what, if any, global lessons emerge that might prevent future problems.

A major contribution of *Blood Feuds* is that its comparative analysis of national experiences should puncture any complacency that may exist about the absolute safety of Canada's blood supply, or about the likelihood that our public health and political systems will respond more effectively to future health threats. As maladaptive political and cultural values created the initial vulnerability, these same values shaped the institutional response. *Blood Feuds* should raise serious questions about the appropriateness of the resulting changes that have been made in many national blood systems.

Blood Feuds establishes a framework for analysis in the first chapter, and then details national experience in chapters covering the United States,

Japan, France, Canada, Denmark, Germany, Italy, and Australia. Each chapter is prepared by an author or authors familiar with that nation's experience. Each outlines the institutional and cultural background of the blood tragedy, the extent of the problems that resulted, the nature and focus of the scandal that inevitably followed, and the changes made in order to prevent future problems. Additional chapters discuss the cultural issues involved, the politics of blood and the role activists played in the AIDS crisis, and what might be called the politics of information – who has it, who needs it, what it means, and how politics and culture mediate transfer and understanding.

In Canada, most public discussion of Justice Krever's final report concentrated on the recommendations. However, the narrative subtext – the detailed outline of the people, conflicts, decisions, and events surrounding the blood crisis – was largely ignored, thus suggesting that the broader lessons of the blood tragedy were being lost.

Blood Feuds is a disturbing book because it suggests that, as in Canada, the fundamental lessons are being lost in most of the countries analyzed. Each country included in the analysis had its own way of making essentially the same mistake, despite substantive differences in their blood systems. This should suggest that the unique political and cultural context of each country was more important than the particular institutional structures that made up the blood system. However, in each country the response to the tragedy emphasized reorganization and greater centralization of authority.

The tendency to focus on the mechanics of organizational structure and reporting mechanisms, rather than on the values that underlie how people behave within these structures, should reinforce in readers a sense of the vulnerability of public health systems to future threats. Most of the countries considered seem to imply by their actions that professional and managerial inadequacies can be remedied by simple structural changes or refinement of lines of authority.

Despite *Blood Feuds'* conclusion regarding a scarcity of common lessons, issues do emerge from the analysis that need further examination, for example: the continuing confusion between health or therapeutic goals with political and ideological issues; the relative futility of organizational restructuring as a means of dealing with problems rooted in cultural and political factors; and the apparent inability of those with a clinical orientation to deal with data at a population level.

Blood Feuds' most important contribution may be the recognition that national responses to the blood tragedy, including the extent and severity of the ensuing scandal, directly reflected the dominant political and cultural values of the nation rather than the precise nature and extent of the tragedy itself.

Australia, for example, reacted much more effectively than others to early warning signs of a problem, and acted quickly and pragmatically, if not with complete success. The United States had an energetic public debate on the issues almost as soon as the first signs of trouble emerged and, despite the acrimony of that debate, proved more effective in their resulting actions than some others. Canada was relatively slow to respond, and the effort to keep the debate internal, not to upset activist groups, and to be absolutely certain before acting, arguably made the health consequences and ensuing scandal worse.

Attempts to assign responsibility also showed major differences between nations. Japan laid responsibility largely on a few individuals. Canada's attempt to determine responsibility resulted in finger pointing and denial of responsibility. Only France pursued the issue of responsibility to its conclusion, deciding that both institutions and individuals were culpable.

In terms of reforms, again only France instituted wide and sweeping reforms in its public health system. In most if not all other countries, organizational changes were fairly superficial, and were made without really coming to grips with the underlying personal, professional, and institutional inadequacies that had led to the crisis.

I would have liked *Blood Feuds* to deal much more directly with how health policy and program decisions are actually made. It is likely that the cultural and political values identified as key variables manifest themselves in the mechanics of how each country's decision-makers addressed the early signs of impending crisis.

There is a vast literature on formalized decision-making and on systems that attempt to introduce greater rigour into critical decisions involving complex factors, each with its own relative importance and potential to create future problems. Health institutions, in Canada at least, are increasingly likely to be headed by professional managers untrained in the specific health disciplines they oversee. How decisions are made in this context becomes critical. If committees are struck to advise, who decides the makeup of the committees? What is the balance, for example, between clinical expertise and population-level expertise? Do committees just advise, or do they in fact make the decisions? If so, what is the role of the putative "decision-maker"? How does this person decide

that the decisions "recommended" by professional committees are sound? And so on.

If committees of health professionals are to have a dominant role, then we run the risk of critical information being ignored, as *Blood Feuds* outlines when the US Centers for Disease Control, dominated by epidemiologists expert in population data, were largely ignored by the blood banks, dominated by clinical specialists.

If professional managers are to be dominant, and if the methods chosen to advise them are suspect, or lead to fractiousness, decisions are likely to be dominated by political values. For example, who will react in what way to the decision, rather than whether or not the decision leads in the direction of better health or health protection?

Blood Feuds' conclusions about the extent to which political and cultural values shape institutional responses to risk and tragedy is disturbing in a country like Canada, where so many health issues have become profoundly political. A better balance between the politics of an issue, and the technical and scientific perspective, must be found. Pathogens are not political, and our responses to them cannot afford to be.

– reviewed by Jan Skirrow

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[1] Feldman EA, Bayer R (eds). *Blood Feuds: AIDS, Blood and the Politics of Medical Disaster*. New York and Oxford: Oxford University Press, 1999, 375 pages, ISBN 0 19513 1606 (paperback).

[2] Government of Canada. *Commission of Inquiry on the Blood System in Canada: Final Report*. Ottawa: Minister of Public Works and Government Services Canada, 1997.

The Gender Politics of HIV/AIDS in Women: Perspectives on the Pandemic in the United States[1]

"This volume is founded on a dual premise: first, that HIV and AIDS are best understood as socially, culturally, and ideologically – as well as biologically – determined phenomena; and secondly, that gender, especially as it intersects with race, class, and sexuality, plays a significant role in the way in which women have been infected and affected."[2]

The volume was edited by two women's studies professors from the United States: Nancy Goldstein from Harvard University, and Jennifer Manlowe from Long Island University. Their introduction is strongly reminiscent of other feminist academic endeavours. If you have never heard the words "epistemology," "paradigm," and "phallologocentrism," their introduction may be hard slogging. That said, the collection offers a wide variety of writing styles and addresses a large number of the issues concerning how women are particularly impacted by HIV/AIDS. Anyone interested in these issues in North America will find something useful in this collection. The volume's primary weakness is in its North American focus, where the epidemic's history of homophobia created a milieu in which women were largely perceived as not being at risk for HIV/AIDS. That history lives on in North America and is evident in many of the issues that women with HIV/AIDS still face today.

The volume is divided into four sections. The first, "Critiques of Biomedical Discourse," examines some of the more obvious issues concerning the medical profession and research, such as women's and adolescents' exclusion from clinical trials, and the way that lesbian identity is rendered invisible in the context of HIV/AIDS.

The second section, "Institutional(ized) Myopia," contains essays about issues confronting specific populations, such as African-American women with HIV/AIDS, Latina women in Los Angeles who have sex with women, women in midlife, Asian and Pacific Islander women living in San Francisco, commercial street-sex workers, safe-sex counseling for heterosexual women, and violence and sexual abuse and women living with HIV/AIDS. The most moving essay in the collection is in this section. "Put Her in a Cage: Childhood Sexual Abuse, Incarceration, and HIV Infection" by Debi Cuccinelli and Anne De Groot explores the connection between childhood sexual abuse, loss of self-esteem, incarceration, and increased vulnerability to HIV infection, and does so through the distinct voices of an incarcerated woman living with HIV/AIDS, Debi, and her physician, Anne. For those who work with women prisoners with HIV/AIDS, this essay will certainly ring true.

The third section, "Working (through) Solutions," explores success stories and positive ideas about helping women with HIV/AIDS and about how to better prevent infection.

Essays address topics such as: how churches and other religions can help African-American women affected by HIV/AIDS; teen peer programs; being sexually active – initiatives of the National Native American AIDS Prevention Centre; and how needle exchanges can better serve their female clientele. There is even an essay that explores socialized medicine in Cuba and asks what lessons the United States might learn from the Cuban example.

The last section of the book is the best. It is a compilation of the voices of women living with or affected by HIV/AIDS. It has long been a belief of the feminist academic community that personal voices and experiences must be validated and heard. This volume succeeds admirably in being true to that tradition.

The Gender Politics of HIV/AIDS in Women reminded me strongly of the publishing debut of the ACT UP/ NY Women & Aids Book Group, *Women AIDS & Activism*, in 1990.[3] When that book was published it was not easy to get a copy of it, and it was the only substantial feminist work I had ever seen on the topic of women and HIV/AIDS. I had to special-order it from the publisher. It never occurred to me ten years ago that we would be talking about the same issues and the same problems a decade later.

– reviewed by Ruth Carey

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[1] Goldstein N, Manlowe J (eds). *The Gender Politics of HIV/AIDS in Women: Perspectives on the Pandemic in the United States*. New York: New York University Press, 1997.

[2] Ibid at 4.

[3] The ACT UP/ NY Women & AIDS Book Group, *Women AIDS & Activism*. Boston: South End Press, 1990.

Female and Male Prostitution

Two books on prostitution in Canada have recently been published. The first, *Making Work, Making Trouble: Prostitution as a Social Problem*,[1] deals with female prostitution. The author, a sociologist, develops a theoretical framework for better understanding the legal issues involved. There is little discussion of the association between prostitutes and HIV transmission, the issue being relegated to a three-page appendix. The second book deals directly with the HIV/AIDS epidemic in connection with male sex work. Dan Allman's *M is for Mutual, A is for Acts: Male Sex Work and AIDS in Canada*,[2] a French translation of which is expected to appear shortly, is the first book to review Canadian studies on male sex work in the context of HIV/AIDS.

Prostitution is not illegal in Canada, but almost all the activities connected with it are. The two publications discuss decriminalization using the following examples:

- the vagrancy provision in the *Criminal Code*, in force until 1972, which excluded male prostitutes and clients;
- the closing of massage parlours on Yonge Street in Toronto in the 1970s, which acted as a catalyst for street prostitution rather than eliminating it;
- the report of the Committee on Sexual Offences against Children and Youth, which pointed out the existence of sexual exploitation in the sex-work industry (the Badgley Report);[3]
- the report of the Special Committee on Pornography and Prostitution, which held public hearings across the country (the Fraser Committee, 1985);[4]
- the provisions of the *Criminal Code* that make it a criminal offence to stop or attempt to stop any person or to communicate or attempt to communicate with any person in a public place for the purpose of engaging in prostitution (Bill C-49, now section 213).

Brock's book is highly theoretical. The author attempts to understand why female prostitution is considered to be a social problem that requires legal control and, first and foremost, for whom this form of prostitution is a problem. "Rather than beginning with the assumption that social problems exist as social facts, as objectively discoverable conditions in a society, I explore them as the creation of a complex interplay of economic and social forces at particular historical moments in specific locations.... My focus ... is on how particular forms of the business of prostitution were *produced* as visible and regulatable social problems from the 1970s through the 1990s" (pp 3-4). She calls into question the dissuasive power of the law and argues that prostitution should be studied not as deviant behaviour but rather as work. The notion of prostitution as work shaped by capitalism, by the social relations of sex and class, enables the author to develop a new theoretical conception of the power of the law. According to her, we must stop thinking that power is an

attribute of legal authorities that persist in operating through ineffective methods (criminalization, stigmatization). There is no single locus of power, since the power to configure the problem of prostitution is shared among many social actors: lawmakers, police, government commissions, feminists, information media, public opinion, and prostitutes.

The state and the client both represent the patriarchy. But patriarchal law, according to Brock, has a dual function: a control function that punishes deviance and a symbolic function that generates multiple interpretations of prostitution and of the identity of those involved in the trade. The identity of the prostitute is forged in the public arena, where various discourses converge to create a stereotype. Prostitutes are exploited, degraded, victims – all labels that mark them with an intrinsic deviance.

Brock establishes interesting links between women who work as prostitutes and the experience of women on the job market in general. "I can, through this study, demonstrate the organization of prostitution as a work relation not so different from other kinds of jobs that women, particularly working-class women, take up" (p 12). Then, after summarizing two interviews carried out during the 1980s with women engaged in prostitution, she describes the legal battles around soliciting in Canada. She demonstrates that prostitution became a social problem because of the explosive combination of various factors – public intolerance, police repression, the role of the media, the formation of social classes in Canadian society, economic recession, and the demands of prostitutes.

Prostitutes cannot count either on the police for protection, since their work is criminalized, or on public understanding, since they are the victims of stigmatization.

The real problem, according to Brock, is that the law accentuates this problematization. "What the law really accomplishes, then, is symbolic, in establishing society's moral code, and is punitive (and professedly 'rehabilitative'), towards those who transgress it" (p 116). Thus, prostitutes cannot count either on the police for protection, since their work is criminalized, or on public understanding, since they are the victims of stigmatization. To work in safety and with dignity is therefore never a sure thing, according to the interviewees. "You have to command respect, or they'll screw you and tattoo you. Like, they don't feel that they should be paying for this anyway, and you're just a slut" (pp 19-20). Prostitutes have a "practical consciousness" about their work and, hence, of how their lives are organized. Once organized, they challenge the coercive aspects of the state, which disrupt and reorganize their "work relations."

And on it goes..., concludes Brock. Because alarmist media coverage perpetuates stereotypical representations of the prostitute and feeds moral panic in the public mind. In short, for Brock the legal response to prostitution must include prostitutes' point of view and stop criminalizing them. "Criminalization cannot eliminate or necessarily decrease the sex trade, because women (and men) have to work, and will continue to find new ways to do so. It cannot adequately address the 'crisis' of youth prostitution, because prostitution is not the source of young people's problems. It does not 'protect' women and young people from violence and coercion, but instead mandates regulatory strategies that may increase their vulnerability. Criminalization does more than make their profession difficult for these sex-trade workers.... [I]t profoundly affects their everyday lives; for example, through the silencing of prostitutes in relation to the regulation of their work, in interactions with family members, in opening a bank account, or in renting an apartment. Although the criminal label is not the only force at work in the creation of 'the prostitute' as a deviant identity and an outcast status, the most difficult part of the prostitute identity may be, not the use of one's body for sexual commerce but the stigma of the occupation, which criminal sanctions reinforce" (p 139).

Dan Allman's book is much more accessible. In both content and presentation, *M is for Mutual, A is for Acts* is a very impressive survey of the research that has been done in the last 25 years on male sex work in Canada. The author worked in cooperation with Health Canada, AIDS Vancouver, the Sex Workers Alliance of Vancouver, and the HIV Social, Behavioural and Epidemiological Studies Unit of the University of Toronto. He does not attempt to theorize about the power of the law to control male sex work; rather, he presents an account of scientific and community research on the subject. "The objective is to make a resource document available to focus health

discussions about male sex work in relation to HIV and AIDS. One goal is to help the reader better understand some of the current realities of sex work in Canada. Another is to inform the very pressing legal, ethical and policy debates on the roles and rights of sex workers in Canadian society" (p 8). There is good reason to do so, as "[m]ost Canadian research and attention have focused on female sex workers, as they are involved in an estimated 80% of interactions where money is exchanged for sex" (p 9).

The history of male sex work highlights the invisibility of this form of prostitution. "One of the problems in trying to sort through the data on male sex work and HIV and AIDS is that much of the information is based on samples of street youth and injection drug users, two populations identified early on as being at risk for HIV infection. Very few studies exist which include male sex workers from a broader range of lifestyles" (p 23). Allman draws a demographic profile of male sex workers and their clients, taking into account the diversity of experiences, including those of escorts, masseurs, bisexual men, Aboriginal people, and incarcerated sex workers. This portrait leads to important considerations for the prevention of HIV/AIDS among sex workers. "Many Canadian researchers have concluded that conventional HIV and AIDS prevention programs may not reach male sex workers. One reason is that provincial and national initiatives fail to focus on the potential differences between male and female sex workers. Another reason is that many male sex workers do not self-identify as gay, so special efforts should be made to address potential barriers to safer sex, including social, cultural, economic and sexual realities" (p 59).

In describing the theoretical approaches used in Canadian research, Allman concurs with Brock. "In order to fully understand male sex work in Canada, we have to consider not only what in some cases might 'push' men away from their homes and 'pull' them into sex work. We also have to consider the human and legal rights of these individuals, as well as looking at how it is that male sex work and the buying and selling of sex are seen as social problems" (p 68). But in terms of understanding why male sex work is considered to be a social problem that calls for legal controls, and above all for whom this kind of work poses a problem, Allman provides no answers.

The book ends with a list of recommendations that should direct future research initiatives dealing with male sex work. The recommendations are taken from the book *Men Who Sell Sex: International Perspectives on Male Prostitution and HIV/AIDS* (1999), edited by Allman himself and Ted Myers. Under this heading, Allman proposes reconceptualizing sex work in more objective terms, and invites researchers to develop more methodologically sound practices and to abandon moral values that skew research results. "The achievement of a truer understanding of male sex work and HIV and AIDS in Canada, free of ignorance, stigma and discrimination, will entail a continuing reconsideration of how research approaches modern male prostitution" (p 79). Finally, a major contribution of the book lies in a fairly exhaustive bibliography of works on prostitution, HIV/AIDS in general, and the place of men who engage in sex work in particular.

– reviewed by Maria Nengeh Mensah

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[1] Deborah R Brock. *Making Work, Making Trouble: Prostitution as a Social Problem.* Toronto, University of Toronto Press, 1998. 206 pp, ISBN 0-8020-7035-0.

[2] Dan Allman. *M is for Mutual, A is for Acts: Male Sex Work and AIDS in Canada*. Ottawa: Health Canada/AIDS Vancouver/Sex Workers Alliance of Vancouver/HIV Social, Behavioural and Epidemiological Studies, University of Toronto, 1999. 100 pp, ISBN 1-895922-12-7, free from the Canadian HIV/AIDS Clearinghouse.

[3] Badgley Committee (Committee on Sexual Offences against Children and Youth). *Sexual Offences against Children*. Ottawa: Department of Supply and Services, 1984.

[4] Fraser Committee (Special Committee on Pornography and Prostitution). *Pornography and Prostitution in Canada*. Ottawa: Department of Supply and Services, 1985.

NEW PUBLICATIONS

Handbook for More than Legislators on HIV/AIDS, Law and Human Rights

In December 1999, UNAIDS and the Inter-Parliamentary Union (IPU)[1] launched the Handbook for Legislators on HIV/AIDS, Law and Human Rights.[2] This publication will have a wide appeal to everyone working in the area of HIV/AIDS law and policy reform because it contains not only the principles that should underpin law reform but positive examples of initiatives from many countries and regions.

The publication uses as its framework the International Guidelines on HIV/AIDS and Human Rights.[3] The Guidelines were drafted in 1996 but their impact has not reflected their importance, perhaps because of limited dissemination and ignorance of, or discomfort with, the human rights principles on which they are based.[4] The Handbook will address these limitations because it will be disseminated not only by UNAIDS but through the IPU network of 139 national parliaments and five international parliamentary assemblies. The many practical examples of national initiatives will also reassure nervous politicians that HIV/AIDS policies that respect human rights are being implemented successfully around the globe.

The commentary accompanying the examples distils best practice and accumulated global wisdom in law and policy reform, in areas such as public health, criminal law, anti-discrimination laws, legal support services, women, children and other vulnerable groups, etc. A particularly useful feature is the provision of summary checklists against which current policies or proposed initiatives can be assessed.

The Handbook is available from UNAIDS in English and French, and will soon be available also in Portuguese and Russian. Copies can be retrieved from the UNAIDS website (http://www.unaids.org) or by contacting UNAIDS at 20 avenue Appia, 1211 Geneva 27, Switzerland (tel: 41 22 791 46 51; email: unaids@unaids.org).

[1] The involvement of the IPU follows the unanimous adoption of a broad resolution on HIV/AIDS at the 99th IPU Conference in Windhoek, Namibia, in April 1998.

[2] UNAIDS and Inter-Parliamentary Union. *Handbook for Legislators on HIV/AIDS, Law and Human Rights: Action to Combat HIV/AIDS in View of its Devastating Human, Economic and Social Impact*. Geneva: UNAIDS/IPU, 1999 (UNAIDS/99.48E).

[3] The principal author of the Handbook, Helen Watchirs, also drafted the original Guidelines.

[4] Patterson D. International Guidelines on HIV/AIDS and Human Rights – three years on. *Canadian HIV/AIDS Policy and Law Newsletter* 1999; 5(1): 30-31.

Background Paper on Legal and Ethical Issues Related to HIV/AIDS Care, Treatment, and Support

The Canadian HIV/AIDS Legal Network has begun a multi-year project analyzing legal, ethical, and policy issues related to HIV/AIDS care, treatment, and support.

National consultations held in 1998 identified these issues as high priority. In early 2001, the Network will complete a paper on "Complementary Therapies and HIV/AIDS: Legal and Ethical Issues." At the same time, the Network will begin work on a detailed legal and ethical analysis of a second care, treatment, and support issue. The Network has established a national advisory committee to ensure consultation with, and input from, people with HIV/AIDS, a number of key partner organizations, and individuals from a variety of backgrounds with expertise in different aspects of HIV/AIDS care and treatment.

In March 2000, the committee members and selected other experts discussed a draft of a short paper entitled

"An Assessment of Options for Future Work on Legal and Ethical Issues Related to HIV/AIDS Care, Treatment and Support." The paper provides an overview of work already done or currently underway, and identifies possible issues where an analysis of legal and ethical questions would be of benefit in shaping law, policy, and practice to protect the rights of people with HIV/AIDS, and facilitate access to care, treatment, and support. The issues include:

- clinical research: legal and ethical issues (developing countries; informed consent);
- drug safety issues (faster drug-approval process; public involvement in drug-review process; direct-to-consumer advertising; "off-label use" of approved drugs; post-approval surveillance);
- drug pricing and intellectual property issues (domestic drug pricing; compulsory licensing and parallel importing);
- disability and income maintenance: social assistance and private insurance benefits;
- insurance issues and HIV/AIDS (human rights law and discrimination; "living benefits" and viatical settlements; systemic biases against people with HIV/AIDS in insurance law and practice);
- pharmacare;
- medical marijuana;
- organ transplantation and HIV infection;
- prisons and HIV/AIDS treatment issues (transgendered prisoners; access to needle exchanges and methadone maintenance); and
- privacy and confidentiality of personal health (and other) information.

After the meeting, the short paper was finalized. It can now be obtained on the Network's website at www.aidslaw.ca or by contacting Éric Nolet at enolet@aidslaw.ca or tel: 514 397-6828 ext 227.

DRUG POLICY

Canadian Senate Committee to Review Drug Laws and Policies

Canada's Senate voted on 11 April 2000 to establish a Special Committee to conduct a comprehensive review of Canadian drug laws and policies.

The following is the transcript of the motion adopted by the Senate.[1]

Motion

That a Special Committee of the Senate be appointed to reassess Canada's anti-drug legislation and policies, to carry out a broad consultation of the Canadian public to determine the specific needs of various regions of the country, where social problems associated with the trafficking and use of illegal drugs are more in evidence, to develop proposals to disseminate information about Canada's anti-drug policy and, finally, to make recommendations for an anti-drug strategy developed by and for Canadians under which all levels of government work closely together to reduce the harm associated with the use of illegal drugs;

That, without being limited in its mandate by the following, the Committee be authorized to:

- review the federal government's policy on illegal drugs in Canada, its effectiveness, and the extent to which it is fairly enforced;
- develop a national harm reduction policy in order to lessen the negative impact of illegal drugs in Canada, and make recommendations regarding the enforcement of this policy, specifically the possibility of focusing on use and abuse of drugs as a social and health problem;
- study harm reduction models adopted by other countries and determine if there is a need to implement them wholly or partially in Canada;
- examine Canada's international role and obligations under United Nations conventions on narcotics and the Universal Declaration of Human Rights and other related treaties in order to determine whether these treaties authorize it to take action other than laying criminal charges and imposing sentences at the international level;
- explore the effects of cannabis on health and examine whether alternative policy on cannabis would lead to increased harm in the short and long term;
- examine the possibility of the government using its regulatory power under the Contraventions Act as an additional means of implementing a harm reduction policy, as is done in other jurisdictions;
- examine any other issue respecting Canada's anti-drug policy that the Committee considers appropriate to the completion of its mandate.

That the Special Committee be composed of five Senators and that three members constitute a quorum;

That the Committee have the power to send for persons, papers and records, to examine witnesses, to report from time to time and to print such papers, briefs and evidence from day to day as may be ordered by the Committee;

That the briefs received and testimony heard during consideration of Bill C-8, An Act respecting the control of certain drugs, their precursors and other substances, by the Standing Senate Committee on Legal and Constitutional Affairs during the Second Session of the Thirty-fifth Parliament be referred to the Committee;

That the Committee have the power to authorize television, radio and electronic broadcasting, as it deems appropriate, of any or all of its proceedings;

That the Committee be granted leave to sit when the Senate has been adjourned pursuant to subsection 95 (2) of the Senate Rules; and

That the Committee submit its final report not later than three years from the date of its being constituted.

Further Information

Establishment of this committee was initially proposed on 14 June 1999 by Senator Pierre Claude Nolin. The proposed committee's *original* terms of reference, Senator Nolin's speech in the Senate on 14 June 1999, the extensive drug policy background paper prepared for Senator Nolin by Diane Riley, and the statement issued by the Canadian Foundation for Drug Policy in support of the call for the committee, can all be found on the website of the Canadian Foundation for Drug Policy (www.cfdp.ca).

[1] Debates of the Senate (Hansard), Tuesday, 11 April 2000 (2nd Session, 36th Parliament, Volume 138, Issue 47 (available at www.cfdp.ca).

HIV/AIDS IN PRISONS

Evaluation of Needle Exchange Pilot Projects Shows Positive Results

We first reported on a needle-distribution pilot project undertaken in two prisons in Lower Saxony, a state in Northern Germany, in 1997.[1] Scientific evaluation of the project has now shown what scientific evaluation of such projects in Switzerland[2] had also shown – that needle exchange programs can be successfully implemented in prisons.

Background

In the fall of 1995, the Minister of Justice of Lower Saxony gave the green light to the implementation of a two-year pilot project for the distribution of sterile injection equipment and provision of other methods of prevention to inmates dependent on drugs in a 170-inmate women's prison in Vechta and a 230-inmate men's prison in Lingen.

The positive experiences in Swiss prisons,[3] and supporting recommendations of a panel of experts were the basis for this decision. In addition, the spread of infectious diseases (HIV and hepatitis B and C) among the 80,000 inmates in German prisons was of concern to the prison authorities. It is estimated that approximately one percent of male and five percent of female inmates are HIV-positive, while many more are HCV-positive. Indeed, hepatitis C is very widespread among drug users both inside and outside prison in Germany: according to several studies, 60 to 90 percent of all drug users are HCV-positive. Drug users form the biggest single group in prisons, and are estimated to make up about 30 percent of the prison population.

The Pilot and Its Evaluation

The pilot project in Vechta started on 15 April 1996, using five dispensing machines, which allow for easy, anonymous access to needles. The project in Lingen, the men's prison, started on 15 July 1996. Here, staff of the drug counseling service and of the health-care unit hand out sterile syringes to inmates.

The scientific evaluation was carried out at the Carl von Ossietzky University in Oldenburg, and has

focused on assessing the feasability, usefulness, and efficacy of the harm-reduction measures that were implemented. Of special interest has been whether and, if yes, how changes have occurred:

- in the prison system itself (acceptance of the measures by staff, medical services, and management; changes in the perception by staff of prisoners dependent on drugs; issues related to security, etc); and
- in the drug user's behaviour (needle sharing), knowledge (risks of intravenous drug use, "safer use" and "safer sex"), and assessment of the pilot project.

The impact on the health status of the prisoners has been examined as part of the medical evaluation.

Table 1 presents an overview of the pilot project.

The following paragraphs present some results of the scientific evaluation in more detail.

Needles Not Used As Weapons

There were no attacks on staff or fellow inmates by drug users using needles as a weapon. The project was non-threatening to staff members and other inmates: as in the Swiss prisons in which needles have been available for many years now, there has not been a single threatening scenario, although thousands of needles have been handed out to inmates.

Generally, observance of the regulations agreed upon prior to the start of the project was high, and it was not necessary to exclude participants from the needle exchange project. In both prisons the number of used needles returned was high; the fear that drug users might not handle injection equipment appropriately was not confirmed.

The only violations of regulations that did occur were that

- some syringes were not stored in the places that had been agreed upon (at the beginning of the project the participants were informed that the syringes must be stored at a clearly specified site – on the washbain console or in a lockable closet. This provision was not made to control prisoners but to avoid the possibility that prison staff searching the cells might come into contact with used needles); and
- some prisoners participating in methadone programs were found to have syringes in their possession. In both prisons the exclusion from the needle exchange project of detainees in methadone programs is practically impossible, because they are not and should not be isolated. There are some indications that injection drug use may occur in these instances. It doesn't seem to be a problem for those in methadone programs to get clean needles from participants in the needle exchange projects.

No Increase in Drug Use

During the project, the number of drug finds did not increase, confirming that the level of drug use is independent of the availability of sterile injection equipment and countering the fear that the availability of clean needles would result in increased drug use.

In addition, the implementation of the needle exchange program as part of the general health service for prisoners dependent on drugs did not have a negative effect on the referral of drug users for treatment. On the contrary, since the project started the number of drug users undergoing treatment has increased.

Acceptance of the Needle Exchange Program

For staff the needle exchange programs quickly became part of everyday life; the extraordinary character of the pilot project has vanished, and a process of normalization has occurred.

With regard to inmates' acceptance, the needle exchange program was much better accepted in the women's prison than in Lingen, as shown by the frequent use of the dispensing machines in Vechta and the positive statements made by project participants in Vechta, In contrast, in the men's prison – perhaps owing to the different mode of distribution – the drug users took a much more reserved attitude toward the project. Many drug users were very reluctant to formally declare their participation in the project and some tried to participate in the project secretly by asking others to supply them with sterile needles. They feared negative consequences from becoming known and registered as drug users. Although the staff of the internal drug counseling service had been bound to medical confidentiality, and participation in the project is not recorded in the personal or health file, prisoners were still afraid that other staff could find out – staff who decide about home leave, cell controls, and drug testing.

Absolute anonymity is not possible in prison. However, the main advantage of using dispensing machines rather than handing out injection equipment on request is greater anonymity for the inmates. In the men's prison, it will take longer to reduce mistrust of the needle exchange facility.

Table 1 presents an overview of the pilot project.

	WOMEN'S PRISON VECHTA	MEN'S PRISON LINGEN
Average number of inmates	183	267
Forms of sentences	All forms of sentences: juvenile/ adult delinquency/ custody/ remand pending, deportation	Only adult sentences
Percentage of (former) drug users	About 50 percent	About 50 percent
Start of pilot project:	15.04.96	15.07.96
End:	14.04.98 continued	14.07.98 continued
Mode of distribution of sterile syringes and needles	5 dispensing machines located in different wards	Hand-to-hand distribution by the internal drug counseling service
Goals	• Prevention of the spread of infectious diseases • Health promotion • Easy, anonymous accessibility in order to abolish the status of syringes as contraband • Protection of personnel	• Prevention of the spread of infectious diseases • Health promotion • Easy, anonymous accessibility in order to abolish the status of syringes as contraband • To establish contact with more unknown drug users • Protection of personnel
Access to the program	By declaration of drug addiction to the doctor/given out a dummy Registration once	By declaration of drug addiction to the doctor/drug counseling service/given out a syringe
Exclusions	Drug users in methadone treatment program (about 40), prisoners in the entrance department	Drug users in methadone treatment program (about 20)
Practice	Access to one or more of the 5 dispensing machines	• Access to rooms of drug counseling service and contact café • Registration of needle exchange and frequency of exchange
Storage of the syringe/needle	Visible in a plastic container on the washbasin console	In the cupboard in a special holder
Number of participants in the pilot project ever	169	83
Number of exchanged needles	16,390	4,517
Daily	23	
Percentage of returned syringes	98.9 percent 167* missing *(16.08.96-14.04.98)	98.3 percent 76 missing
Additional preventive information/education units	by JES (Junkies, Ex-Users, Substitutees) and local AIDS self-help group for inmates	• by local AIDS self-help group • by project staff to colleagues

Positive Health Impacts

The medical evaluation showed that the number of abscesses decreased dramatically and that there was no seroconversion during the two-year pilot phase for those participants who were permanently in the exchange scheme.

Recommendations

The scientific evaluation recommended not only to continue these two pilot projects but to expand them to all the prisons in Lower Saxony. The Ministry of Justice of Lower Saxony supports such an expansion, but not as a top-down decision against the resistance of staff in these

Table 2: Needle Exchange Schemes in European Prisons

PRISON	SITE	SIZE	CHARACTER	SENTENCED	NEEDLE EXCHANGE SINCE:	PROVISON OF STERILE SYRINGES THROUGH:	FIRST SYRINGES FROM	EXCLUSION	PREVENTIVE MEASURES
Men's prison Oberschöngrün	Solothurn, Switz.	75	Half open	Adults	1992	Doctor/medical department	Doctor	Non-DU	✓
Women's prison Hindelban	Bern, Switz.	110	Half open	Adults	1994	Slot machines (1:1 exchange)	Internal prevention team	No	✓
Men's and Women's prison Champ Dollon	Geneva, Switz.	No details	Remand prison	No details	1996	Doctor	Doctor	No	✓
	Vechta, Ger.	169	Closed & remand Dep.	Adults/ juveniles	1996	Slot machines (1:1 exchange)	Doctor	Women in methadone program, reception dep., Non-DU	✓
Men's prison Lingen I Abt. Groß Hesepe	Groß Hesepe, Ger.	228	Closed	Adults	1996	Hand-to-hand drug counseling service	Doctor	Men in methadone program, Non-DU	✓
Men's prison Vierlande	Hamburg, Ger.	298	Open	Adults	1996	Slot machines (1:1 exchange)	External drug counseling service	No	✓
Men's prison Realta/Cazis	Graubünden, Switz.	100	Half open	Adults	1997	Slot machines (1:1 exchange)	Internal prevention team	No	✓
Women's prison Lichtenberg Berlin	Berlin, Ger.	Ca. 40-50	Closed	Adults/ juveniles	1998	Slot machines (1:1 exchange)	External. AIDS help group	No	✓
Men's prison Lehrter Str., Berlin	Berlin, Ger.	Ca. 100	Closed	Adults/ juveniles	1998	Slot machines (1:1 exchange)	External. AIDS help group	No	✓
Men's prison Fuhlsbüttel	Hamburg, Ger.	600	Closed	Adults	March 2000	Hand-to-hand	Internal drug service	No details	✓

Abbreviation.: Non-DU= Non-Drug Users

prisons. The two pilot projects are both continuing.

Meanwhile, in Berlin (two prisons) and Hamburg (two prisons) needle exchange schemes have been successfully introduced (table 2 shows where needle exchange programs have been introduced, and how). Other states are discussing implementing them in prisons. Despite the success of the pilot projects, they are being introduced relatively slowly due to resistance of staff, trade unions, and their political lobby. Syringe exchange programs in prison remain a big political issue because they seem to symbolize the failure of keeping prisons free of drugs . But more and more, harm-reduction measures are being introduced into prison health care in order to prevent drug-related harms.

Finally, it may be concluded that there is no general recipe for prison needle exchange programs: every prison system has to find its own method of distribution.

– Heino Stöver

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[1] See Jacob J, Stöver H. Germany – needle exchange in prisons in Lower Saxony: a preliminary review. *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 30-31.

[2] See, eg, Nelles H et al. Reduction of drug and HIV related harm in prison: breaking taboos and applying public health principles. In: Shewan D, Davies JB (eds). *Drug Use and Prisons. An International Perspective*. Amsterdam: Harwood Academic Publishers, 2000, 27-43.

[3] See, eg, Zeegers Paget D. Needle distribution in the Swiss prison setting: a breakthrough? *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(2/3): 60-61.

HIV/AIDS in Prisons: More New Developments

Since our last review,[1] there have been new developments in several jurisdictions in the area of HIV/AIDS and prisons. This column reviews some important developments in Canada and in the US: the results of the evaluation of HIV/AIDS harm-reduction measures in the Canadian federal prison system; another Canadian inmate's fight for methadone maintenance treatment in prison; an important article on health care in Canadian prisons which states that there is little evidence that the federal prison system "is making any serious effort to provide treatment to any drug users"; the US Supreme Court's refusal to review a lower court's ruling permitting Alabama prisons to segregate HIV-positive inmates; an important ruling stating that inmates are entitled to receive medications in jail without interruption; and research showing that women inmates in the US are 23 times more likely to have AIDS than women in the general population.

Canada

Evaluation of harm reduction measures in the federal prison system

In 1999, the Correctional Service of Canada (CSC) released the results of an extensive evaluation of its HIV/AIDS harm reduction measures.[2] The evaluation was initiated for two reasons: to inform CSC's Health Services as to the implementation status of the bleach kit and condom distribution programs in federal prisons; and to comply with a requirement of the 1994 final report on HIV/AIDS in prisons of the Expert Committee on AIDS and Prisons.[3] The evaluation team visited 18 institutions, as well as the regional and national headquarters of CSC, interviewed more than 210 staff members and 110 inmates, conducted a review of the literature on bleach distribution programs, and examined a database of 9751 incident records to determine the number and nature of incidents involving the seizure of injection equipment and the extent to which bleach had ever been used as a weapon.

Six significant findings emerged during the course of the evaluation.

Distribution of bleach not sufficient

The evaluation team concludes that it had "no confidence that the distribution of bleach alone will effectively reduce transmission of infection from Hepatitis or HIV."[4] It says:

> Because of the clandestine and furtive nature under which injection drug users operate in prison settings; of the primitive and make shift equipment used to inject drugs; and, of the tendency of injection drug users to 'cut corners' when their cravings overcome their judgment, there is no guarantee that the use of bleach alone will effectively reduce transmission of infection from HIV or Hepatitis C.[5]

The team stresses that outbreaks of HIV infection can occur "in any location, at any time,"[6] referring to three incidents in federal prisons that have highlighted the prevalence of

bloodborne infectious diseases and high-risk activities in prisons:

> The threat of HIV transmission was judged to be particularly high in one institution. Here an inmate diagnosed with AIDS engaged in high risk behaviour, disclosing that he shared needles. He identified 20 contacts. Following an education and awareness campaign by staff and the Inmate Committee, an additional 80 inmates came forward for testing. In a second incident, an offender, known to be positive for HIV and Hepatitis C was sharing a needle, and twenty inmates cam forward for testing. Test results indicated that some tested positive for HIV and for Hepatitis C. At the time of this evaluation, a third outbreak was under investigation. These results are likely representative.[7]

It concludes by examining two measures that would "enhance" CSC's harm-reduction approach: methadone maintenance treatment (MMT), and needle exchange. While it makes no explicit recommendations on the subject, the team highlights that inmates interviewed during the evaluation were generally supportive of both MMT and needle exchange programs. One inmate commented:

> I think it is hypocritical just to have a bleach program. It is smoke and mirrors. If you really want to do something, you get a needle exchange program. The bleach program is good because it is a foot in the door.[8]

The team also highlights the positive experience of prison systems in which MMT and needle exchange programs have been implemented, commenting that "[o]ne significant advantage of a needle and syringe exchange program in a prison setting is that old, damaged and home made syringes that have the potential to harbor pathogens will be removed from circulation."[9]

Tattooing continues to represent a risk

The evaluation team notes that both staff and inmates report that tattooing is a "fact of life." One group of inmates observed that the "probability of a guy coming in without a tattoo and leaving with one is 90%."[10] While the evaluation confirmed that inmates are "likely using" bleach to disinfect tattooing needles, the safety of the ink may be in question. In addition, at all sites visited, staff and inmates remarked that when inmate tattoo "experts" are disciplined and their equipment confiscated, amateurs begin practising, increasing the risk for transmission of infection. The team concludes:

> Because of the risks presented by amateur tattoo and piercing procedures, there appears to be considerable support, particularly among health services, case management, programs and psychology staff, to confront the reality of tattooing and provide some form of institutionalized access to expert tattooing services, either run by an external contracted resource or run by trained inmates.[11]

Access to bleach is generally not a problem

According to the evaluation team, at all institutions visited, bleach was available to inmates. At 15 of the 18 institutions, the placement of bleach was deemed discreet by the team. Importantly, both inmates and staff reported that bleach had become a "fact of life" in the institutions.

Access to condoms should be improved in Private Family Visit Units

Condoms were also available at all 18 institutions visited by the evaluation team, and in the vast majority of cases, they were discreetly accessible. Inmates said that they never had to ask a staff member for condoms or lubricant. However, only in 10 of the Private Family Visit Units were condoms found, and sometimes the type of condoms available was not appropriate.

Security staff continue to express concerns about making bleach available

Some security staff interviewed expressed concern that making bleach available could be interpreted as condoning injection drug use, leading the evaluation team to recommend that the Correctional Training Program module on infectious diseases be revised "to stress and reinforce the linkages between safe, secure institutions, harm reduction concepts and infectious disease transmission."[12]

Bleach or condoms have not been used as weapons

At all 18 sites visited, staff could not recall any incident where either bleach or condoms had been used as weapons. In addition, interviews with staff across the country indicated that, with a few exceptions, staff concerns in terms of safety have abated.

Recommendations

The evaluation team concludes by making a series of recommendations directed at further improving harm reduction measures in federal correctional institutions. While the recom-

mendations focus on how bleach and condom accessibility can be improved, the report is clear about the fact that making condoms and bleach available is not enough, and that more needs to be done: in particular, staff need to receive better education about harm reduction measures and about why they are necessary, MMT programs need to be expanded to allow prisoners to start such treatment in prison (currently, only prisoners who were receiving such treatment prior to incarceration are allowed to continue the treatment in prison –, see infra), and needle exchange programs need to be piloted.

Prisoner fights for methadone maintenance treatment

Once again, an inmate in a federal correctional institution (Stony Mountain, Manitoba) started legal proceedings in the Federal Court of Canada, alleging that CSC's refusal of permit him to initiate MMT while in prison infringed the *Canadian Charter of Rights and Freedoms* by violating his rights under sections 7, 12, and 15.[13] And once again, as in all previous cases, CSC granted the inmate access to MMT after legal proceedings had started, knowing full well that there is little chance that a court would uphold its policy of refusing access to MMT to inmates who have not been on such treatment before being imprisoned. However, while in previous cases the inmates settled their cases against CSC,[14] in this case the inmate, Barry William Strykiwsky, has not settled and argues that it is in the public interest to obtain a judgment on the issue of MMT initiation in prison.

On 1 December 1997, CSC had announced that it would provide methadone to inmates *who had already started this treatment before being incarcerated*, a measure that was implemented in April 1998. In early 1999, CSC adopted a policy to permit inmates in "exceptional circumstances" to begin MMT in prison even if they had not previously been receiving it before incarceration. It was widely expected that CSC would announce in early 2000 that its MMT program would be further extended to allow opiate-dependent prisoners who were not on MMT before incarceration to start it in prison, not just in "exceptional circumstances," but as part of the treatment options for dependent prisoners.[15] However, as of May 2000 no such announcement had been made. In part, this could be due to the federal government's failure to dedicate funds to Canada's Drug Strategy. Many had hoped that such funding would be announced in the 2000 budget, and that some of the funding could be used to expand MMT in prisons. But that did not happen, with dire consequences for Canada's efforts to reduce the harms from drug use in and outside prisons.

Health-care problems in prisons highlighted

In an article published in the *Canadian Medical Association Journal*, Drs Peter Ford and Wendy Wobeser point out that prison administrators

> have not only an opportunity, but a moral duty to address the health care issues of a population that might otherwise not access the health care system until their problems are well advanced. Injection drug users are especially unlikely to access health care outside prison, and incarceration may be the only opportunity to address their addiction and their other health problems.[16]

However, they say that

> [t]here is little evidence that Correctional Service Canada is making any serious effort to provide treatment to any drug users, whether they take drugs by injection or other means. Drug rehabilitation programs are inadequate or nonexistent, and, on the whole, methadone is available only for heroin addicts who were enrolled in methadone programs before imprisonment. The physician who attempts to provide appropriate treatment often meets with resistance from prison authorities. Failure to address the addiction makes treatment of HIV or hepatitis C difficult, given that compliance with therapy is linked to treatment of the addiction. Inadequate treatment of HIV may lead to resistant forms of the virus in an environment where sharing of injection equipment facilitates the spread of infection. [reference omitted][17]

The authors conclude:

> Certainly, improved medical care for prisoners in Canada is a humane course of action, but it will also serve the best interests of society as a whole. At present there is clear evidence that prison authorities are failing in their responsibilities. The 1994 report of the Expert Committee on AIDS in Prisons ... recommended treatment of drug addicts and control of the spread of HIV in prisons. In the subsequent 5 years, very few of these recommendations have been implemented. This situation may be due to lack of funding, lack of political will

or public indifference, but most likely a combination of all 3 of these factors. The broad issue of health care in prisons is too important to be left to prison administrators. We need rigorous national standards for accreditation of health care facilities in prisons, adequate funding to allow those standards to be met and supervisory bodies (independent of prison authorities) at both the provincial and the federal levels to ensure compliance. [references omitted][18]

United States

Supreme Court refuses to review segregation policy

On 18 January 2000, the US Supreme Court left intact a lower court's ruling[19] permitting Alabama prisons to segregate hundreds of HIV-positive inmates and keep them from educational programs and even from religious services where they might mix with other prisoners (for more details on that decision, see R Jürgens. HIV/AIDS in prisons: new developments. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(4): 61-66, at 65). The Supreme Court justices turned down the prisoner's appeal without comment, in an action that does not set a legal precedent.[20]

In the months since the decision, efforts have been mounting in Alabama and elsewhere to press for changes in Alabama's policy. However, a second lawsuit challenging the policy has also been turned back. A class of inmates led by Paul D Edwards tried a new avenue by invoking the *Americans with Disabilities Act*, but they were no more successful than the earlier group of inmates whose suit under the federal *Rehabilitation Act* was rebuffed by the Supreme Court. In granting summary judgment to the state and to prison officials, US District Judge Myron H Thompson pointed out that the claims under the Edwards suit were identical to those that failed in the previous case. The judge applied the doctrine of *res judicata* in dismissing the claim. That doctrine holds that a lawsuit must be precluded if there has been a final judgment by a court of competent jurisdiction on the merits of an earlier suit, and the parties and the causes of action in both suits were identical.[21]

Female inmates had AIDS rates that were 23 times the national rate for AIDS among women.

In Canada, a 1991 decision by the Ontario Court of Justice held that segregation of inmates with HIV or AIDS is justified only in exceptional cases. Specifically, the Court held that segregation might be warranted not because of an inmate's HIV infection, but because of behaviour that could expose others to HIV.[22]

Important ruling on jail detainees and medications

The 9th Circuit Court of Appeals ruled on 21 April 2000 in *Sullivan* v *County of Pierce* (2000 Westlaw 432368) that a pretrial detainee with AIDS who was on a protease cocktail regimen was entitled to continue receiving medications in jail without interruption. Sullivan claimed that he was deprived of his medications for two days after his arrest because jail officials did not respond in a timely way and took two days to get in touch with his family to bring his medication to the jail. Sullivan claims that as a result of the interruption in treatment, his viral load skyrocketed and the cocktail he was on became ineffective. He brought a claim against the county and the jail officials.

The district court granted summary judgment to the defendants, finding no evidence of deliberate indifference to Sullivan's medical needs, finding that the jail officials had qualified immunity from suit, and finding that there was no basis for concluding the county had an official policy or practice of denying needed medication.

The appellate panel reversed on all counts, finding that if Sullivan's allegations were true, there was evidence to show deliberate indifference, evidence to overcome the officials' immunity, and even evidence that the county had a practice of violating jail inmates' rights to medical care.[23]

Atlanta: Judge demands progress on "disgraceful" conditions at jail

A federal judge in Atlanta has intervened to correct what he called the "appalling" conditions in Fulton County Jail, where an inspection showed that HIV-positive inmates continue to be denied proper medical care. Calling conditions at the 3000-inmate facility "disgraceful and totally unacceptable," US District Senior Judge Marvin Shoob ordered county officials to report to him by 24 March 2000 on their progress in complying with a settlement agreement they signed in January promising to remedy the problems.[24]

AIDS rate in prison six times national rate

Researchers at the Centers for Disease Control and Prevention have found that incarcerated people with AIDS in the US are more likely to be male, African American, injection drug users, and younger at the time of diagnosis, compared with all people with AIDS. The study of prison inmates from 1994 to 1996 found that the prevalence of AIDS was 199 per 100,000, six times the national rate of 31 per 100,000. Female inmates had AIDS rates that were 23 times the national rate for AIDS among women.[25]

– *Ralf Jürgens*

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[1] Jürgens R. HIV/AIDS in prisons: new developments. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(4): 61-66.

[2] Correctional Service of Canada. *Evaluation of HIV/AIDS Harm Reduction Measures in the Correctional Service of Canada*. Ottawa: The Service's Performance Assurance Sector, April 1999.

[3] Correctional Service of Canada. *HIV/AIDS in Prisons: Final Report of the Expert Committee on AIDS in Prisons*. Ottawa: The Service, 1994.

[4] Supra, note 2 at 2. Unless otherwise indicated, all quotes in the following section are taken from the evaluation report.

[5] Ibid at 3.

[6] Ibid at 26.

[7] Ibid at 25-26. For more details on the outbreaks, see also Jürgens, supra, note 1, at 61-62.

[8] Ibid at 4.

[9] Ibid at 5.

[10] Ibid.

[11] Ibid at 6.

[12] Ibid at 9.

[13] See the Notice of Application and the Notice of Motion in the case of Barry William Strykiwsky v David Mills, the Commissioner of Corrections, and the Correctional Service of Canada, on file.

[14] See, eg, Prisoner settles case for right to start methadone in prison. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 5(1): 34-35.

[15] For more details on MMT in prisons, see info sheet 7 in the series of info sheets on HIV/AIDS in prisons produced by the Canadian HIV/AIDS Legal Network (Prevention and Treatment: Methadone. The Network, 1999).

[16] Ford PM, Wobeser WL. Health care problems in prisons. *Canadian Medical Association Journal* 2000; 162(5): 664-665, at 665.

[17] Ibid.

[18] Ibid.

[19] *Onishea* v *Hopper*, 171 F3d 1289 (1999).

[20] Cert denied 10 January 2000, US Supreme Court, No 98-9663 (sub nom *Davis* v *Hopper*); 2000 WL 29361.

[21] *Edwards* v *Alabama Department of Corrections*, No Civ A 97-T-1746-N (MD Ala, 1/14/00). Reported in *AIDS Policy & Law* 2000; 15(3): 8.

[22] *Ratte* v *Kingston Penitentiary (Warden)*, [1991] OJ No 1745 (Ontario Court of Justice – General Division).

[23] This is an edited version of a summary posted on the HIV-Law listserv (hiv-law-digest@Web-Depot.com) on 25 April 2000 by Prof Arthur S Leonard, New York Law School, (Leonard@nyls.edu or ASLeonard@aol.com).

[24] *Foster* v *Fulton County*, No 1:99-cv-900-MHS (Nd Ga, 3/13/00). Reported in *AIDS Policy & Law* 2000; 15(6): 3.

[25] Dean-Gaitor H, Fleming P. *AIDS* 1999; 13: 2429-2435, 2475-2476.

Surveillance and Prevention of Hepatitis C in Australian Prisons

Hepatitis C (HCV) prevalence rates in prisons are even higher than HIV prevalence rates. Studies undertaken in the early and mid 1990s in Canadian prisons revealed rates of between 28 and 40 percent, and rates continue to rise. In one federal prison, 33 percent of study participants tested positive in 1998, compared to 27.9 percent in 1995; and at the Burnaby Correctional Centre for Women in British Columbia, over 78 percent of 69 inmates tested for HCV between 1 January 1996 and 8 August 1996 were seropositive. Similar figures are reported from other countries, including Australia.[1] This raises many challenges for prison systems: how best to provide care and treatment to HCV-positive inmates; and how to prevent the further spread of HCV. Most HCV-positive inmates come to prison already infected, but the potential for further spread is high: HCV is much more easily transmitted than HIV, and transmission has been documented in prisons in several countries, including Canada.

In Australia, an action plan for the surveillance and prevention of HCV in prisons has been developed as a result of meetings held in 1998 and 1999.[2] We reproduce here the executive summary of the plan.

Executive Summary

Over 50 percent of Australian injection drug users (IDUs) test positive for hepatitis C infection. With similar proportions of IDUs reporting a history of imprisonment, it is not surprising that hepatitis C infection is one of the most prevalent bloodborne viral infections in prison populations. Approximately one-third of inmates are infected with hepatitis C. No data exist on incidence of hepatitis C among incarcerated IDUs in Australia. However, hepatitis C incidence is likely to be higher among IDUs in prison than in the community.

The study of hepatitis C infection and its prevention in the prison setting is a crucial part of the response of the broader community to the hepatitis C epidemic. Prison systems provide major challenges when conducting

research – such as gaining access to inmates, obtaining representative samples, ensuring reports of risk behaviours are reliable and collecting conclusive evidence of transmission in prison. Despite indications that the incidence of bloodborne viral infections are higher in prison than in the community, only a handful of cases of HIV and hepatitis C transmission among prisoners have been documented in the world.

The aims of this Action Plan are: (1) to encourage the development of a nationwide program for monitoring hepatitis C infection among prisoners in Australia; and (2) to reduce hepatitis C transmission among prisoners by facilitating the introduction or expansion of effective prevention measures.

The Plan addresses the following areas:

- rationale for an Action Plan on hepatitis C infection in prison populations;
- the nature and extent of hepatitis C infection in prison;
- risk behaviours associated with infection;
- methods for the surveillance of hepatitis C infection and transmission in prison populations;
- identification of prevention measures to reduce hepatitis C transmission in prison populations;
- priorities for research;
- priorities for prevention measures;
- implementation of prevention measures;
- key recommendations.

The study of hepatitis C infection and its prevention in the prison setting is a crucial part of the response of 15%the broader community to the hepatitis C epidemic.

It makes the following key recommendations relating to the surveillance of hepatitis C infection in prison:

- establish a working group with representation from all Departments of Corrective Services, New South Wales Corrections Health Service and Australian Capital Territory Community Care;
- measure HCV prevalence in prison populations in Queensland, South Australia, Western Australia and Northern Territory;
- measure HCV incidence in prison populations in Victoria, Queensland, South Australia, Western Australia and Northern Territory;
- collate entry test data at a national level;
- develop a definition for incident cases of hepatitis C infection occurring in prison;
- monitor the prevalence and incidence of HCV among inmates on methadone; and
- estimate the number of IDUs in each prison system in Australia and the demand for methadone treatment.

It further contains the following key recommendations relating to the prevention of hepatitis C infection in prison:

- expand or introduce community methadone maintenance programs;
- expand community-based needle and syringe programs;
- expand or introduce prison-based methadone maintenance programs;
- expand or introduce syringe cleaning programs in prison;
- educate prisoners about HCV infection and transmission modes;
- target high-risk inmates for prevention measures;
- decrease the number of inmates with HCV;
- allow professional tattooists to visit prison;
- train and license selected inmates in infection control procedures for tattooing purposes;
- provide them with the necessary equipment; and
- trial a pilot needle and syringe exchange program in prison.

– Kate Dolan

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[1] See: HIV/AIDS and Hepatitis C in Prisons: The Facts. *HIV/AIDS in Prisons (Info sheet 1)*. Montréal: Canadian HIV/AIDS Legal Network, 1999 (available at www.aidslaw.ca).

[2] Dolan K. *Surveillance and Prevention of Hepatitis C Infection in Australian Prisons. A Discussion Paper*. Sydney: National Drug and Alcohol Research Centre, National Centre in HIV Epidemiology and Clinical Research, UNSW, 2000.

SPECIAL SECTION: HIV/AIDS AND THE LAW

This section presents developments from four countries: Australia, Switzerland, England and Wales, and India. Overviews from Canada, South Africa, the United States, and Germany will follow in the next issue.

HIV/AIDS and Legal Issues in Australia

In Australia, a "blueprint" for HIV and AIDS-related law reform was produced in the early 1990s, but progress in achieving reform has been uneven. In 2000, discrimination against people with HIV/AIDS continues, and there are new threats to some of the very measures that are responsible for Australia's remarkable success in fighting the HIV/AIDS epidemic among injection drug users. This article, by Chris Ward, a member of the Legal Working Group of the Australian National Council on AIDS, Hepatitis C and Related Diseases, provides an overview of the law reforms achieved in Australia, and of current and future challenges. It concludes that the overarching challenge Australia faces in promoting an enabling legal environment is the waning impetus for reform, at a time when substantial areas of legislation and practice still warrant attention.

Introduction

In 1992 the federal government of Australia produced a "blueprint" for HIV and AIDS-related law reform, and much of Australia's subsequent effort has been based on this blueprint. The federal government's National HIV/AIDS Strategy, released in August 1989, led to the creation of a national HIV/AIDS Legal Working Party that consisted of state, territorial, and federal Attorney-General and Health departments, and was responsible for reviewing and reporting on changes to legislation relevant to the Australian response to HIV/AIDS. The final report of the Legal Working Party, published in November 1992, made far-reaching recommendations for law reform in the areas of public health, civil liability, discrimination, homosexuality, prostitution, employment law, injection drug use, therapeutic goods, and broadcasting and censorship.

Consistent with the principles of the Ottawa Charter for Health Promotion and the Jakarta Declaration on Leading Health Promotion into the 21st Century, the Legal Working Party's report, and successive national HIV/AIDS strategies, have characterized the role of the legal system as one of contributing to an "enabling environment" that supports effective health promotion in the context of the epidemic.

Epidemiology

The cumulative number of HIV infections in Australia to the end of 1998 was estimated to be 17,600, with an estimated 11,800 people living with HIV infection.[1] Transmission of HIV in Australia continues to be overwhelmingly through sexual contact between men, with over 85 percent of all HIV transmissions estimated to have been via such contact.[2] Approximately eight percent of HIV diagnoses have been in people with a history of injection drug use, of whom about half were men who also reported having had sex with men.[3] One of the reasons injection drug users form a relatively small proportion of the Australian epidemic was the early introduction of government-funded

needle and syringe programs. HIV prevalence among people entering Australian prisons between 1991 and 1998 also remained at a relatively low 0.5 percent, with no difference in prevalence between the sexes.[4] Finally, figures from sexual health clinics since 1992 indicate that HIV prevalence in women identifying as sex workers remains low, at around 0.1 percent.

The Structure of Government

Australia is a federation of states, with powers divided between the (national) federal government, six states, and two territories. Much of the necessary HIV/AIDS-related law reform identified by policymakers falls within the jurisdiction of the states and territories, and thus requires legislative change by eight different governments. This situation has led to uneven progress in achieving reforms.

Reforms Achieved

Responsibility for reforms proposed by the Legal Working Party rests mainly with the various state and territorial governments rather than the federal government, and progress in achieving reforms has been uneven across jurisdictions. Most of the significant reforms occurred during the period during which discussion papers were being developed and national consultations held, rather than subsequent to publication of the final report. An assessment by the Commonwealth Attorney-General's Department in 1999 was based on self-reporting by all jurisdictions, and showed that less than half the recommendations had been implemented. The Australian National Council on AIDS and Related Diseases has described progress in achieving reform as "slow and generally unsatisfactory."[5]

Discrimination

Discrimination against people with HIV/AIDS in Australia is well documented, widespread,[6] and can coexist with high levels of factual knowledge about how HIV can (and cannot) be transmitted.[7] All Australian jurisdictions prohibit discrimination on the grounds of HIV and AIDS. Discrimination on the ground of disability was prohibited by federal law in 1992, when the federal Parliament passed the *Disability Discrimination Act*. There are equivalent laws in each state and territory, with the exception of South Australia, where the wording of the legislation means that discrimination based on symptomatic HIV infection and AIDS is prohibited, but discrimination on the ground of asymptomatic HIV infection is not.

The *Disability Discrimination Act* has been useful as a tool to address HIV and AIDS-related discrimination, particularly where complainants have identified systemic discrimination by government or private-sector entities. Respondents have included the Australian Defence Forces, the federal government's employment agency, prison administrations, and insurance companies. Litigation pursuant to the *Disability Discrimination Act* has demonstrated that the Act can promote respect for the principle of non-discrimination against people with HIV and AIDS. Some of the significant cases to have come before the courts are discussed below.

Discrimination by a government service provider

In 1993 the Commonwealth Employment Service, a national employment agency funded by the federal government and controlled by the Minister for Employment, issued guidelines for dealing with HIV-positive job seekers. The guidelines required disclosure of an applicant's HIV status to prospective employers for a range of jobs, including hospital laundry and cleaning staff, police and prison officers, beauty therapists who perform electrolysis, tattooers, sanitation workers, and firefighters. Where an HIV-positive person seeking work in any of these occupations refused permission for their HIV status to be disclosed to a prospective employer, they would not be referred for a job interview.

Early in 1994 a job seeker lodged a complaint with the Human Rights and Equal Opportunity Commission (HREOC) about the guidelines. The Minister for Employment initially defended the guidelines, but in response to a request from the Australian Federation of AIDS Organisations that they be immediately withdrawn, announced that the guidelines would be reviewed. Following negotiations between representatives of the Minister's department, the complainant, and the Australian Federation of AIDS Organisations, the guidelines were withdrawn, and replaced by a non-discriminatory policy.

Discrimination by the Australian Defence Forces

Australian Defence Forces (ADF) policy on HIV requires all new recruits to the Australian Regular Army to be tested for HIV. Those

who test positive are discharged. The Australian High Court recently heard an appeal from a man who was discharged under this policy.[8] The man – known in the proceedings as "X" – applied to join the army in November 1993. At the time of applying, X was a serving member of the Army Reserves, a part-time force trained for deployment in times of war.

X successfully argued before HREOC that the ADF policy contravened the *Disability Discrimination Act*. The Commonwealth conceded it had discriminated against X in discharging him, but asserted the discrimination was not prohibited by the Act, which exempts discrimination in employment where the employee is unable to fulfill the "inherent requirements" of the job.[9] The ADF said the inherent requirements of the job of soldier include being capable of deployment in combat and combat-related duties, without undue risk of HIV transmission to other soldiers. The HREOC Commissioner who heard the case took a narrower view of the meaning of "inherent requirements" and ruled that the phrase did not encompass the issue of the potential risk of HIV transmission from X to another person during deployment.

The Commonwealth successfully appealed the case to the Federal Court, and from there X appealed to the High Court. The High Court dismissed X's appeal, and ruled that the case be reheard by a different HREOC Commissioner. The majority of the High Court ruled that the term "inherent requirements" encompasses the question of whether X can be deployed as required in combat and combat-related duties, and ordered the Commission to reconsider and determine this question.

In his lone dissenting High Court judgment, Justice Kirby took the view that there had been no error of law on the part of the Commission. He also commented on the historical attitudes of the armed forces in various countries to human rights and discrimination issues, and their approach to litigation of this type:

> Recorded experience shows that the military usually resist such actions in the courts. However, when obliged to do so by court orders, they commonly review their discriminatory policies. They often find that they were needlessly inflexible, unnecessary and wrong-headed. Generally speaking, the courts in the United States and Canada have been consistent and principled in recent years in their insistence that the civil norms of non-discrimination reach into the military and must be obeyed by them. This is certainly what happened when challenges were mounted in the courts against unjustifiable and universal exclusions expressed in terms of race, the exclusion of women from military institutions or combat duties, and the automatic discharge of military personnel on grounds of their sexuality. None of these exclusions now operates in the [Australian Defence Forces].
>
> The universal exclusion of recruits on the grounds of their HIV status is simply the latest in a succession of such grounds.

The courts have yet to deal with the substantive issue in this case – whether an HIV-positive person can perform the job of soldier. Can a soldier with HIV "bleed safely" (that is, without risk to other soldiers) when deployed in combat? And should the "ability to bleed safely" be a requirement of employment as a soldier? One Australian newspaper editorialized that the ADF should at least be expected to "debate the matter and decide whether service requirements appropriate to the pre-HIV, pre-antibiotic era of bayonets and trench warfare are appropriate to the era when the next war could well be waged by computer hackers."[10]

Vilification Laws

The state of New South Wales is the only Australian jurisdiction to prohibit vilification on the grounds of HIV and AIDS. The state's *Anti-Discrimination Act* defines vilification as "a public act inciting hatred towards, serious contempt for, or severe ridicule of, a person or group of persons on the ground that the person is or members of the group are HIV/AIDS infected or thought to be HIV/AIDS infected …." Public acts include public speaking, writing, printing, displaying notices, telecasting, screening, and playing recorded material.[11] There is also a criminal offence of "serious HIV/AIDS vilification" carrying a maximum penalty of imprisonment for six months or a $10,000 fine, or both.

The HIV/AIDS vilification provisions were inserted into the Act in 1995. There is still debate on whether vilification laws constitute an unwarranted restriction on free speech – interestingly, the debate being among those who support the objectives of the law. Some

Victoria, New South Wales, and the Australian Capital Territory have all announced they will trial safe injecting rooms.

commentators argue that vilification laws are misconceived and that in the long term there is greater protection to be had from absolute freedom of expression, even if that entails abuse and vilification. Others assert that the continuum from hate speech to hate violence is too powerful to ignore and too compelling not to do something about.

To date there has been no criminal prosecution for serious HIV/AIDS vilification, but civil complaints have been dealt with. One was a complaint by a man with HIV who lived in high-density public housing in an inner suburb of Sydney. Neighbours abused and physically threatened him because of his homosexuality and HIV status. Abusive messages were left on his front door, and rubbish was thrown at his apartment. As well as seeking police protection, the man asked the state housing department to relocate him, but the only accommodation to which the department would transfer him was in a different city, where access to specialist HIV medical services would be difficult. Rather than compromise his access to health care, the man remained where he was.

The Equal Opportunity Tribunal found that unlawful vilification had occurred, and ordered each of the two respondents to pay the complainant $25,000 compensation, and to post a written apology on the public notice board at the housing complex. The Tribunal accepted the complainant's evidence that the respondents' conduct had aggravated the complainant's health condition, saying: "There can be little conduct more serious."

Another case involved a complaint against a regional radio station, on which the host of a phone-in program told an HIV-positive caller: "You're a sick individual and I hope you die horribly." He also vilified homosexuals, saying they were "The antithesis of humankind.... I would like to see someone dig a very big hole and drop the whole stinking lot of them down it." Following complaints by community HIV/AIDS organizations in two states in which the program was broadcast, the announcer was dismissed and the radio station published apologies in eight gay and lesbian community newspapers in the two states.

Current and Future Challenges

Threats to harm reduction

Some legal and policy initiatives to reduce harms associated with injection drug use were developed early in the Australian epidemic, but new initiatives generate controversy. Most recently, there has been public disagreement between the Prime Minister and three state and territorial leaders over the legality and efficacy of supervised injecting facilities for injection drug users. Victoria, New South Wales, and the Australian Capital Territory have all announced they will trial safe injecting rooms. In response, the Prime Minister has invited representatives of the United Nations' International Narcotics Control Board (INCB) to visit Australia to advise him on the proposals. Although the decision is one for states and territories, the federal government can nevertheless exert significant political pressure on the issue.

The risk of severe overdose is 10 times higher when injecting occurs on the street, compared with the risk of severe overdose in an injecting facility where immediate help is available.

The INCB has become well known in Australia as an opponent of supervised injecting facilities. In its annual report released in February 2000, the INCB said supervised injecting rooms facilitate drug trafficking and are a step in the direction of drug legalization. Australian proponents of supervised injecting facilities dismiss these claims. They question whether permitting a small number of street users of heroin to inject that heroin under supervision will have any impact at all on the annual $600 billion international trade in opiates.

The INCB states that supervised injecting facilities breach the international drug conventions. Australia is a signatory to the Single Convention on Narcotic Drugs (1961), the Convention on Psychotropic Substances (1971), and the UN Convention Against Illicit Traffic in Narcotic Drugs and Psychotropic Substances (1988). Australian jurisdictions proposing to trial safe injecting rooms believe the INCB's views do not accurately reflect the content of these conventions. Both the 1961 and 1988 conventions are aimed particularly at "trafficking" conduct, and neither requires criminal prosecutions for personal consumption. The conventions do not

take an exclusively prohibitionist approach to illegal drugs, but contain provisions allowing signatories to adopt harm-reduction measures.

Available evidence suggests that supervised injecting facilities are effective in reducing harm. Germany and Switzerland are both signatories to the relevant conventions. Germany has 13 officially supervised injecting rooms, and more are planned. All are funded wholly or partly by local authorities, and run by non-government organizations in consultation with the community and police. None has ever had a fatal overdose on the premises. Statistics from the George Soros–funded Lindesmith Center in the US show that fatal overdoses in Frankfurt declined from 147 in 1991 to 25 in 1997. Switzerland introduced injecting rooms in response to the increasing rate of HIV transmission through injection drug use. The cities of Zurich, Berne, and Basel have established supervised injecting facilities. A study in the *International Journal of Drug Policy* in 1999 found that the Swiss injecting rooms were good for the health of drug users, reduced the presence of syringes on the streets, and decreased the prevalence of unsafe sex.[12]

By comparison, overdose deaths in Australia rose from 1.3 per million in 1964 to 71.5 per million in 1997. Overdoses are more likely to result in death where there are delays in alerting health services. Delays often occur because others aware of the overdose fear criminal prosecution for their own use of illegal drugs. Injecting facilities reduce overdoses by ensuring a safe supervised environment for injecting, and remove the threat of prosecution. Figures from one of the safe injecting rooms in Frankfurt, Germany, indicate the risk of severe overdose is 10 times higher when injecting occurs on the street, compared with the risk of severe overdose in an injecting facility where immediate help is available.

Human rights bodies need to play a more active role in promoting human rights through more frequent public inquiries into discrimination.

Access to legal remedies for discrimination

While Australian legislation provides mechanisms to redress HIV/AIDS discrimination, the accessibility of these mechanisms has diminished in recent years.

Research commissioned by the Legal Working Group of the Australian National Council on AIDS, Hepatitis C and Related Diseases examined barriers to the use of anti-discrimination laws by people with HIV and hepatitis C.[13] The research examined statistics from Australia's national human rights body, HREOC, and from a comparable state body, the Anti-Discrimination Board of New South Wales (ADB).

Statistics showed that while complaints to HREOC under the federal *Disability Discrimination Act* had declined by 52 percent between 1994 and 1998, there was a general upward trend in disability complaints to the ADB. The research found that funding cuts to both HREOC and to legal aid had contributed to the decreased use of the national human rights body by people with a disability. In 1997, funding to HREOC was cut by approximately 43 percent, with cuts spread over three years. The cuts were estimated to have resulted in job losses of at least one-third, and the consequent delays in processing discrimination complaints are discouraging people from using HREOC's services.

At around the same time, government-funded legal assistance was reduced by $120 million per year, with the reduction spread over three years. There is now little legal aid funding for civil cases, including discrimination cases. For many people living on a low income, legal redress for discrimination is now out of reach.

The research concluded that federal funding for legal aid must be increased so that complaints under the *Disability Discrimination Act* that have merit can be pursued, and so that complainants who cannot afford the cost of legal representation are not denied access to legal remedies for discrimination. In addition, the research called for restoration of funding to HREOC, to enable the Commission to perform its complaints-handling function in a timely manner.

The research identified the need to reinvigorate community education that promotes awareness of anti-discrimination laws and the remedies such laws can provide. Taking a broader perspective, the report also notes the "current over-reliance" by Australian human rights and anti-discrimination bodies on individual complaints as a means of addressing societal discrimination. Human rights bodies need to play a more active role in promoting human rights through more frequent public inquiries into discrimination.

Commitment to law reform

The overarching challenge Australia faces in promoting an enabling legal environment is the waning impetus for reform. There is evidence of a growing belief in Australia that we have "dealt with" HIV, that we no longer face the crisis we faced in the early years of the epidemic. There is also evidence of less willingness to adopt innovative and courageous legal and social policy responses.

In an attempt to reinvigorate our efforts around HIV/AIDS law reform, the Australian National Council on AIDS, Hepatitis C and Related Diseases has commissioned a rights analysis instrument designed to measure the extent to which Australian law and policy complies with the International Guidelines on HIV/AIDS and Human Rights.[14]

In Australia, the approach based on a rights analysis instrument was first developed in the mental health area. In 1996 Australian lawyer and consultant Helen Watchirs developed such an instrument to evaluate Australian legislation on mental health against international human rights norms for the National Mental Health Working Group of the Australian Health Ministers' Advisory Council. State and territorial governments gave a commitment under the National Mental Health Strategy to have legislation that was in compliance with international human rights norms by 1998. Similarly, the Australian National Council on AIDS, Hepatitis C and Related Diseases will seek federal government support for the HIV/AIDS rights analysis instrument, with a view to it being adopted for use by all Australian governments, thereby raising awareness of and commitment to further reforms.

Substantial areas of legislation and practice still warrant attention. Laws governing the sex industry in some states and territories still take a prohibitionist approach to the industry, making health promotion for sex workers difficult. In some jurisdictions, the age of consent for male-to-male sex is higher than for opposite-sex partners and lesbians (it varies from 16 to 21). Unequal and discriminatory age-of-consent laws hinder HIV education initiatives targeting young men who are attracted to men, and contribute to low levels of self-esteem, which themselves increase the risk of HIV transmission. There is no nationally consistent approach to the use of the criminal law in cases where reckless or negligent transmission of HIV is alleged, and the intergovernmental Standing Committee of Attorneys-General has recently endorsed the use of the criminal law in these circumstances. And for same-sex couples, the death toll on gay men from the epidemic has exposed the discrimination against same-sex couples in our retirement and income security laws. Reforms in these and other areas are necessary if we are to maintain the effectiveness of our response to date, and improve it in the future.

Key Resources

HIV/AIDS Legal Link: A quarterly newsletter on HIV/AIDS law and policy published by the Australian Federation of AIDS Organisations, Sydney. Email: cward@afao.org.au

HIV/AIDS and Your Rights: A booklet on legal issues for HIV-positive people. Published by the Australian Federation of AIDS Organisations, Sydney, 1998. Email: jsergeant@afao.org.au

Australian Gay and Lesbian Law Journal: Published by The Federation Press, Sydney. Email: Sales@fedpress.aust.com

Unjust and Counter-Productive: The Failure of Governments to Protect Sex Workers from Discrimination: Published by the Scarlet Alliance and the Australian Federation of AIDS Organisations, Sydney, 1999. Email: wise@apec.net.au; or cward@afao.org.au

– Chris Ward

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[1] National Centre in HIV Epidemiology and Clinical Research. *1999 HIV/AIDS, Hepatitis C & Sexually Transmissible Infections in Australia Annual Surveillance Report*. NCHECR, 1999. www.med.unsw.edu.au.

[2] Ibid at 9.

[3] Ibid at 16.

[4] Ibid at 17.

[5] Australian National Council on AIDS and Related Diseases. *Status Report on Implementation of the Final Report of the Legal Working Party*. Canberra, Commonwealth of Australia, 1999.

[6] New South Wales Anti-Discrimination Board. *The Other Epidemic: Report of the Inquiry Into HIV/AIDS Related Discrimination*. Sydney, 1992; Malcolm A et al. HIV related stigmatisation and discrimination – its forms and context. *Critical Public Health* 1998.

[7] New South Wales Anti-Discrimination Board, supra, note 6 at 6.

[8] *X* v *Commonwealth* [1999] High Court of Australia, 2 December 1999.

[9] *Disability Discrimination Act*, section 15(4).

[10] Army needs to keep up with the times. *Canberra Times*, 6 December 1999, at 8.

[11] *Anti-Discrimination Act 1977* (NSW), section 49ZXC(1).

[12] de Jong W, Weber U. The professional acceptance of drug use: a closer look at drug consumption in the Netherlands, Germany and Switzerland. *International Journal of Drug Policy* 1999; 10: 99-108 at 100.

[13] Cabassi J. *Access to and effective use of anti-discrimination remedies for people with HIV and HCV*. Unpublished. Sydney, 1999.

[14] United Nations. *HIV/AIDS and Human Rights – International Guidelines*. New York and Geneva, 1998.

Switzerland, the Law, and HIV: An Overview

From the first appearance of HIV/AIDS in Switzerland in the mid 1980s, various legal tools have been implemented to combat the disease, most of them based on legislation already in force. To date, there has been no specific AIDS-related legislation, but if the formal legal framework has changed very little, practice has developed and demonstrates the extent to which the law reflects current societal values. At the risk of "giving the game away," it must be said at the outset that there are virtually no major HIV/AIDS-related legal problems in Switzerland.

Introduction: Switzerland – A Snapshot

Switzerland is a country of seven million inhabitants in the middle of Europe, whose population is divided into three major language regions – French, German and Italian, and a fourth region where Romansh, very much a minority language, is spoken. Switzerland is a federal state: legislative jurisdiction is divided between the federal government – the Confederation – and the 23 cantons, three of which are "dual" cantons, for a total of 26 cantons and demi-cantons, each with its own particular laws. Their geographic size and populations (from 25,000 to 1,000,000 inhabitants) vary widely. Public health, education, and court procedures fall for the most part under the jurisdiction of the cantons, whereas jurisdiction over criminal law and the fight against epidemics are the responsibility of the national government. Practically speaking, there is a permanent – and sometimes unclear – overlap between federal (ie, national) and cantonal standards, where common regulations have not yet been put in place (eg, social welfare or benefits).

The division of powers sometimes leads to a weakening of, and even competition between, decision-making bodies. Unfortunately, people with HIV/AIDS who are in the process of being expelled from the country provide an excellent illustration of the difficulty of finding the person responsible for a file when each cantonal or federal official pleads their relative lack of authority ("I'm merely carrying out orders").

Switzerland is a direct democracy: at the three political levels – national, cantonal, and communal – the population is regularly consulted in elections and referendums on practically all conceivable issues. In 1999 the Swiss people adopted a new federal constitution that entered into force in January 2000. They also accepted the principle of medical prescription of heroin, in addition to other minor matters. There have been many referendums on drug use–related issues, and these referendums have given work on drug use unquestionable legitimacy, while they have also been tempered with a strong element of pragmatism.

Switzerland from an epidemiological point of view

In epidemiological terms, Switzerland is also in the middle of Europe: it has been strongly affected both by homosexual transmission, largely from northern Europe, and by injection drug use, largely from southern Europe, with a relative increase in heterosexual transmission over the past few years. Since the beginning of the epidemic there have been more than 25,000 HIV infections in Switzerland, and 5000 people have died.[1] In Europe as a whole, Switzerland is one of the countries most affected by HIV/AIDS.

A successful public sector/ private sector partnership

It can be said that Switzerland has been able to respond rapidly to the public health emergency presented by HIV/AIDS: there have been public information campaigns, and financial support to non-governmental organizations, with a real concern for partnership between the public and private sectors. The significance and the role of private-sector organizations are related as much to the clearsightedness of Swiss public authorities and to Swiss democratic and associational traditions (there are over 60,000 private associations in Switzerland) as to freedom of expression and the rights of assembly, gathering, and association, all of which are fundamental rights guaranteed under the Swiss Constitution.

The Law and AIDS: A Few Examples

In a country such as Switzerland, governed by the rule of law, the law is naturally everywhere. AIDS is not only a disease; it is also a social indicator that cuts across many areas, so

that interactions between AIDS and the law in Switzerland have become a difficult matter to define in summary fashion. The following is therefore somewhat arbitrary, an attempt to cover a few areas in which such interactions are numerous and problematic.

Absence of specific AIDS-related legislation

As mentioned in the introduction, Switzerland does not have any really specific AIDS-related legislation. Although some legal provisions have been enacted since 1985, they cover minor subjects such as AIDS research, mandatory disclosure, or certain administrative standards.[2] That said, several internal directives have been adopted or amended, and various procedures reviewed and adapted, on the medical (eg, hospitals), occupational (AIDS in the workplace), and associational (physicians' insurance) levels.

Right to health and health insurance

It is difficult to guarantee a right to health as an abstract proposition, but rights to health care and assistance are in theory guaranteed to every individual residing in or passing through Swiss territory. In the event of an accident or a medical emergency, every person will be cared for and treated, with some unavoidable exceptions.

However, non-emergency medical services are not available to all persons because they are based on a public/private health insurance system. Since 1996, the principle of mandatory health insurance was instituted, following a referendum, and provided for the following:

> 1. Every person domiciled in Switzerland must have insurance to cover care in the event of illness, or be insured by his legal representative, within three months after becoming domiciled or being born in Switzerland.[3]

The advantage of this new legislation has been to prevent health insurance companies from refusing to insure a person by reason of their state of health. The disadvantage has been that persons residing "irregularly" in Switzerland are expressly excluded from this new legislation – in contrast with the former practice, which "tolerated" providing persons who did not have the proper papers with health insurance.

Switzerland now has a dual health-care system – the public system that covers access to basic treatment and care, including hospitalization, and a private health-care insurance scheme (often managed by the same companies) that makes it possible to extend insurance coverage, with possible restrictions based on the applicant's state of health. It is thus almost impossible today for a person with HIV/AIDS to obtain such insurance. On the other hand, basic care for people with HIV/AIDS, including antiretroviral treatment, is entirely paid for by the public system. It should be repeated that the public system is fee-based: each insured person must pay a premium that amounts on average to 200 Swiss francs (approximately CAD$180 per month), except those who receive welfare benefits.

Labour law and insurance law

The contrast between labour law and insurance law is interesting: it highlights the fact that a concept like HIV/AIDS may have a different meaning in each area. In labour law, the mere fact of being seropositive is not in itself significant: the determining factor is one's ability – in particular, one's physical ability – to carry out a particular task, not one's serological status. A seropositive person who is entirely capable of working will thus not benefit from the legal provisions against dismissal because of absenteeism by reason of disease (Article 336c, Code of Obligations), because HIV is not considered to be a disease.[4] At the very most, dismissal on the ground of seropositivity could be considered unfair within the meaning of Article 336, 1(a), Code of Obligations (HIV being related to the health of a person and therefore to their personal characteristics), which, in practice, is very difficult to prove. The relevant part of the article in question reads as follows:

> Art. 336
> 1. The dismissal is unfair when given by a party:
> (a) for a reason based on the personal characteristics of the other party, unless such reason is related to the employment relationship or causes serious harm on a matter essential to the conduct of the business....

This is not the case with insurance. In general, HIV-positive people are considered to have a disease. A decision of the Federal Insurance Tribunal, the court of last resort in Switzerland in matters of insurance law, affirmed this in relation to health insurance: HIV = disease.[5] The fact that an HIV-positive person may be in good health did not disturb the Tribunal. Consequently, with

respect to certain health insurance benefits – but also because of provision for professional liability – health-related reserves may be set, and this in fact limits and may even exclude access to some benefits. With respect to private insurance, the freedom to contract allows for every kind of variation on the theme of "no one insures a burning house."

Knowing as we do that many HIV-positive people are living – with or without treatment – for many years without having any particular health problems, it is our view that these insurance limitations and exclusions are for the most part unjustified, and thus discriminatory. And they are not to be underestimated. A whole series of "normal" (according to Swiss standards!) everyday services – such as bank loans, insurance against loss of income, provision for professional liability, and additional health-care insurance – are not accessible to people with HIV/AIDS, and make some occupational activities completely impossible. The difficulties of maintaining an occupation can be the beginning of the end of a working life, which is sometimes the same thing as social marginalization.

Criminalization of HIV transmission and the prison system

While it does not make any direct reference to AIDS, the Swiss Penal Code (PC)[6] nevertheless contains a chapter entitled "Crimes or Offences against Public Health." According to a provision dating from 1942, Art 231 PC (propagation of a human disease) states: "A person who intentionally propagates a dangerous and transmissible human disease shall be liable to imprisonment for a period of one month to five years." It should be noted that this article was not very often used at the time it was enacted – the last time it was applied was in 1947 with respect to gonorrhea – and fell into disuse until the mid 1980s with the advent of HIV/AIDS.

Since then, several people have been sentenced under this article. More recently, the Federal Tribunal has reaffirmed not only the applicability of the provision, but also the fact that the transmission of HIV constitutes aggravated assault under Art 122 PC (but not intentional homicide under Art 111 PC).[7] According to the Tribunal, the development of the disease and the possibility of a fatal outcome depend on various circumstances, including new combination therapies, and do not allow a direct and absolute causal link to be made between infection and death.

It is legitimate to question the criteria for applying a provision that has lain dormant for so long. Moreover, only those who have infected or attempted to infect their sexual partner have been sentenced. What about bloodborne (needle sharing) or mother-to-child transmission? It would be easiest – although absolutely undesirable! – to prosecute mothers, but this doesn't happen: is this because it is politically incorrect? Although this is clearly advantageous to women, there are questions to be raised about a criminal system that punishes some and does not concern itself with others. Should conduct considered to be less "moral" than others be punished? And what of the fact that black Africans are overrepresented among the people sentenced?

Paradoxically, those sentenced are likely to be imprisoned, and in prisons HIV seropositivity is much higher than on the outside and the risk of HIV infection is greater than average. What is the ambiguous role of a state that imprisons people for HIV transmission without itself taking the measures necessary to prevent such transmission? In terms of public health, prevention, and the effectiveness of the fight against AIDS (perhaps 20 sentences per 25,000 infections), the criminal law is an ill-suited tool.[8] It should nevertheless be noted that the practical nature of the fight against AIDS and drug policies have made it possible to launch pilot projects that make syringes available in some prisons, without any particular problems having come to light.

Discrimination or stigmatization?

In 1997, a study on institutional discrimination in Switzerland that used a UNAIDS protocol was undertaken.[9] The results were clear: in formal, legal, and regulatory terms, discrimination is very rare. At least "officially," there is no discrimination in Switzerland, except in limited instances (eg, systematic screening without consent in hospitals). But the results are misleading. On the one hand, they don't mention discrimination against people with HIV/AIDS as opposed to any other person who might be considered to have a disease (discrimination is not connected solely with HIV/AIDS, but also with health, as in the case of insurance); on the other, they do not take into account the repercussions of cases of stigmatization of individuals.

What difference does it make for a person who loses their job that their

employer stigmatizes them as an individual rather than apply a discriminatory policy suggested by the employer's association? The result remains the same – loss of employment. The difference – and this is the most severe problem in my opinion – is that it is easier to denounce, and therefore fight, a discriminatory law or regulation than the conduct of individuals.

Rights of aliens and HIV/AIDS

What some call the "non-rights of aliens" is a complex system of permissions granted on specific terms and conditions and having varying effects. The principle is that there is no entitlement to any particular permission and that renewals of such are not automatic: the power of appreciation of a public authority is enormous, and abuses of power are that much more difficult to discover because a whole system of sub-legal norms, such as internal directives, governs this area.

Any alien may therefore enter Switzerland and reside there as long as they have specific permission to do so: an entrance visa and provisional or final authorization to reside. As discussed above, a person's legal status will either allow or prevent them from benefiting from medical care and treatment, making legal status all the more crucial. For persons with no status or whose status has become precarious, this creates serious problems in the medium term because they will effectively be excluded from the health-care system, since only emergency treatment is guaranteed.

The paradox is that Switzerland welcomes certain aliens with HIV/AIDS *because of* their state of health (authorization to enter for limited periods on humanitarian grounds) and deports others *in spite of* their state of health. For many reasons, a person many be "requested" to leave the country. Under current practice, persons seriously ill or hospitalized are not deported. New treatments have had their effect here: the state of health of many people with HIV/AIDS has improved, regardless of whether their rights as aliens are precarious or non-existent. The resulting situation is absurd: persons who could have remained in Switzerland for humanitarian reasons if they had not begun to receive treatment are deported on the ground that their state of health makes it possible for them to be deported! And this does not even take into account the fate of such persons on their arrival in the country to which they have been returned, where the beneficial effect of their treatment may have been terminated because of the impossibility of continuing such treatment in that country or of benefiting from adequate medical follow-up.[10]

However, it should be pointed out that Switzerland does not have any restriction as to entry upon its territory, for tourism or for immigration purposes, relating to a person's health status, and certainly not with respect to HIV/AIDS.

Conclusion

This overview could not be a comprehensive look at the subject. Issues such as social security (disability benefits and loss of earning power in cases of long-term illness); reintegration into the workforce (the link between social security, unemployment, and working life); the reduction of risks relating to drug use; the (absence of) rights of same-sex couples; and confidentiality issues such as medical privilege and the protection of personal information – all deserve further consideration.

To conclude, Switzerland has a satisfactory legal system that can be described as excellent when compared with that of most other countries. This excellence is qualified by certain exceptions, such as the lack of rights of persons who are about to lose or are without legal status. Although this has not become an overwhelming problem, as in too many other countries ("small country, small problems"?), Switzerland is still a country in which it is not always pleasant to have to live with a virus or with any other pathological condition that forces you to live outside the "norm," a concept as undefinable as it is non-existent.

– *Florian Hübner*

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A few interesting websites:

- Swiss AIDS Federation (French, German and Italian; a few pages in English): www.aids.ch
- AIDS Information Centre (in French and German, English only on home page): www.aidsnet.ch
- Federal Office of Public Health: www.admin.ch/bag
- Swiss federal legal database (in French, German and Italian): www.admin.ch/ch/f/rs.html
- Case law of the Swiss Federal Tribunal (in French, German and Italian): www.eurospider.ch/BUGE

A few interesting documents:

- AIDS Info Docu Switzerland. *Infothèque sida* (national periodical on AIDS), legal newsletter published since 1996 (French and German only): www.aidsnet.ch/f/legal.html

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- Swiss Aids Federation. *Réinsertion professionnelle des personnes qui vivent avec le VIH/sida*. Zurich, 1999 (in French and German): www.aids.ch./pdf/Reinsertion.pdf
- Pärli K, Wagner P. Seropositivité/sida et les assurances sociales: dossier. *Sécurité sociale*. Berne: Federal Office for Social Security, 1998.
- Aids Info Docu Switzerland. *Emploi et Sida. Aspects médicaux et juridiques*. 2nd ed. Berne: October 1996.

HIV/AIDS and Legal Issues in England and Wales

In England and Wales, the only HIV specialist legal advice service is currently observing "a return of many of the problems that were encountered in the 1980s but which we thought had been resolved." Ignorance about HIV and about how HIV is (and is not) transmitted continues, while the many benefits from new treatments have been accompanied by complacency, misunderstanding, and new forms of discrimination. This article, by members of the Advice Centre of the Terrence Higgins Trust, which includes the HIV specialist legal advice service, provides an overview of some of the legal issues currently facing people with HIV/AIDS in the UK, from discrimination to the rights of HIV-positive parents and their children, from housing to immigration and criminal law.

Introduction

In England and Wales there is no body of law relating specifically to people with HIV/AIDS, so the adviser in the field has to adopt an imaginative approach in finding the protection or remedy a client with HIV or AIDS requires. Any overview of the legal issues arising from HIV and AIDS in England and Wales (Scotland, being a separate jurisdiction, is outside the scope of this article) necessarily roams widely over many different areas of law.

The Advice Centre of the Terrence Higgins Trust is well placed to provide an overview. Founded over ten years ago, the Centre includes the only HIV specialist legal advice service in England and Wales, and can monitor developments in all areas of law as they affect people with HIV.

The Advice Centre provides assistance in a number of ways, from simple telephone advice to representation before courts and tribunals. All services are free, and legal advice is provided by qualified lawyers, both paid staff and volunteers. Many clients are people with HIV seeking help with a legal issue unrelated to their HIV status, but whose health is suffering as a result of the stress their problem is causing. Such is the stigma that still attaches to HIV in this country that even a simple matter (such as a plea in mitigation on behalf of a person with HIV for drunken driving) requires careful handling. Our newspapers still seem to think that a person's HIV status makes newsworthy what would otherwise be an everyday court appearance. There are gay clients whose legal problems arise not because they are HIV-positive but because, for example, the law of inheritance does not recognize same-sex relationships; a will is the only way a client can ensure that their partner will be the

Our newspapers still seem to think that a person's HIV status makes newsworthy what would otherwise be an everyday court appearance.

[1] Regularly updated national statistics are available in French and German at: www.admin.ch/bag/infekt/aktuell/f/index.htm

[2] See, for example, the Order respecting the control of blood, blood products, and transplants (consolidated Swiss laws and regulations – RS 818.111.3); Order respecting epidemiological studies to collect data on the human immunodeficiency virus (HIV Studies Order – RS 818.116); Evaluation of projects to prevent drug use and to improve the living conditions of drug users (RS 812.121.5).

[3] Federal Law on Health Insurance of 18 March 1994 (RS 832.10), art 3, para 1 (persons obliged to be insured).

[4] Code of Obligations of 30 March 1911 (RS 220).

[5] Decision of 12 March 1998, K 66/95 Vr, which confirmed the earlier case law – ATF 116 V 239.

[6] Swiss Penal Code of 21 December 1937 (RS 311.0).

[7] ATF 125 IV 242 and ATF 125 IV 255.

[8] Guillod O. Lutte contre le sida : quel rôle pour le droit pénal? *Revue pénale suisse* 1997; 115(2): 130-146. Hübner F. Faut-il encore pénaliser la transmission du VIH en Suisse? *Plaidoyer* 1996(6), 46-50 (with bibliography), available at www.hivnet.ch/gsg/transmission.htm

[9] Dubois-Arber F, Haour-Knipe M. *Identification des discriminations institutionnelles à l'encontre des personnes vivant avec le VIH en Suisse*. Lausanne: Institut universitaire de médecine sociale et préventive. 1998 (Raisons de santé 18).

[10] See in this connection the case of "Mister M.", which captured the attention of the World AIDS Conference, Geneva, 1998, and which was heard before the European Commission of Human Rights. The Commission held that his expulsion to the Democratic Republic of Congo did not constitute inhuman treatment within the meaning of Article 3 of the European Convention on Human Rights: see decision of 18 September 1998, *M.M. v Switzerland*, Application No 00043348/98. The case law of the European Commission is available at www.echr.coe.int/

beneficiary after their death. However, many problems do have at their core the HIV status of the client, and these will be the focus of this article.

It is perhaps worth mentioning that there has been a return of many of the problems that were encountered in the 1980s but that we thought had been resolved. At the heart of many of these problems lies ignorance about HIV and its transmission, and the solution is often to be found not in legal action but rather in education and explanation. Unfortunately, it appears that the complacency that has accompanied the improvements in medication and all the benefits that new treatments have brought have perhaps led to misunderstanding and discrimination.

Discrimination, Including Employment

In England and Wales, discrimination against a person with HIV is not in itself unlawful. However, an argument can be raised under anti-discrimination legislation. The principal statute relied on is the *Disability Discrimination Act* of 1995. The employment provisions of the Act came into force in December 1996 and have been used successfully in cases of discriminatory treatment of people with HIV.

To bring an action, the claimant needs to show that they have a disability. According to section 1 of the Act, a person has a disability "if he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities." Schedule 1 of the Act defines these terms, and paragraph 8 further clarifies "progressive conditions" in such a way that a person with HIV need only establish that their HIV has some effect on their ability to carry out day-to-day activities. This may, however, exclude many people with asymptomatic HIV infection from the protection afforded by the Act.

The issue of HIV, children, and the law is a big one that may yet get bigger.

The Act makes it unlawful to discriminate against someone with a disability. It protects both existing employees and job applicants. An employee does not need to have worked for an employer for any particular length of time to bring a claim under the Act. The employment rights do not apply where there are fewer than 15 employees in the workplace. In addition, employers in certain fields are exempt from the provisions of the Act.

The Act says that an employer must not discriminate against a disabled applicant or disabled employee in recruitment and selection, in its terms of employment in the opportunities for promotion, training, and other benefits, or by dismissing the employee or subjecting him or her to any other detriment, such as harassment.

Discrimination occurs when an employer treats a disabled person less favourably for a reason relating to the disabled person's disability without justification or fails to comply with the duty to make reasonable adjustments, again without justification. An employer who can show a justification will have a defence.

Notwithstanding the possible problems arising from the definition of disability, the Act has been used successfully by people with HIV/AIDS against their employers.

The Act also prohibits discrimination in the provision of goods and services, by both public and private service providers, as long as a service is provided for the public. The prohibition has, for example, been used successfully in a case where a person was refused dental treatment because he was HIV-positive.

Children

The issue of HIV, children, and the law is a big one that may yet get bigger. The increasing number of babies born to HIV-positive mothers, and the availability of medication for HIV-positive babies, may well lead increasingly to the involvement of the courts in the decision-making process concerning the treatment of babies of HIV-positive mothers. There have already been proceedings for care orders for the babies of HIV-positive mothers who insist on breast-feeding, and in 1999 a court ordered that a baby be tested for HIV against the wishes of the HIV-positive mother.[1]

Housing

Legislation in relation to homelessness is contained in Part VII of the *Housing Act 1996*, which imposes a legal duty on housing authorities to ensure that suitable accommodation is made available for a person whom the authority has reason to believe is homeless or is threatened with homelessness, is eligible for assistance, is in priority need, is not intentionally homeless, and has "a local connection."

The definition of homelessness includes accommodation that it is not reasonable to continue to occupy, because of violence, threats of violence or harassment (whether from inside or outside the home),[2] overcrowding,[3] poor condition of property,[4] high cost of rent or mortgage,[5] and disability or illness.[6]

In addition to the *Housing Act 1996* there is the Code of Guidance,[7] which encourages local authorities to consider people with HIV/AIDS-related illnesses to be in priority need on grounds of vulnerability because the "manifestations or effect of their illness or common attitudes to it make it difficult … to find stable or suitable accommodation." The Code suggests that people with HIV are vulnerable whether or not they are symptomatic.

Many people with HIV/AIDS have housing needs similar to those of the general population. However, inadequate or unsuitable housing can cause greater hardship to them, and their health can suffer from the stress caused by the threat or experience of inadequate housing, homelessness, harassment, or violence. The homelessness application procedure can be particularly daunting for them, and can be accompanied by fears about confidentiality; unless a person is in priority need for any reason other than HIV/AIDS, it will usually be necessary to inform the local authority of their status. It is therefore important to check if the authority has a confidentiality policy, and request that information about the person's status be kept separately and not be generally accessible.

Immigration

Two developments in immigration law relating to HIV/AIDS are particularly noteworthy: applications under Home Office policy BDI 3/95; and cases in which HIV/AIDS has been recognized as a ground for political asylum, where applicants have a well-founded fear of persecution on return as a result of their HIV/AIDS status.

Home Office Policy BDI 3/95 – "the HIV policy"

Under this policy, a person can make an application outside the immigration rules to enter or remain in the UK on grounds of illness.

The key to successful applications has been the level of illness, with a need by the applicant for combination therapy being considered significant. The more controversial factor is the level of treatment available in the country of origin. For a case to be successful, the applicant must show that they cannot access appropriate treatment if they are returned. Cases are successful if the applicant can show that the lack of access to treatment on return would result in an unacceptable level of suffering. This can relate to either physical or psychological health. If treatment is available but expensive, evidence of this must be submitted and arguments made that the applicant cannot access this treatment if they are returned.

The majority of those applying under the policy have been black Africans. During the 1990s a very large number came from Uganda, Zimbabwe, and Zambia. The remainder were mainly from central and southern African countries. This trend seems to follow the underlying colonial ties, with fewer people from formerly French or Portuguese colonies coming to the UK.

The Home Office has proved increasingly resistant to applications from Ugandan nationals and has recently relied on evidence suggesting that some European nationals prefer to stay in Uganda, claiming that the quality of treatment for HIV/AIDS there is superior to that in Europe. This, however, is not a view endorsed by practitioners in the field, who are in the process of bringing evidence countering this opinion.

The rapidly increasing number of applications under the policy may ultimately lead to a review, especially as allowing people to remain on the grounds of HIV/AIDS has a clear impact on health expenditure as well as immigration policy. The fact that more African countries import some antiretroviral drugs (even if the cost is prohibitive for the average citizen) is increasingly relied on as a reason for refusing applications by nationals of those countries, even where the actual treatment available is derisory.

Asylum

The case of *R* v *SSHD ex parte M* (CO/4975/98, unreported) raised HIV/AIDS as a ground for asylum where the applicant has a well-founded fear of persecution on return as a result of their HIV/AIDS status. Although this point was not taken up in the judgment, this is a fertile area that representatives have successfully argued in relation to Colombia. Further cases are expected, especially in relation to certain African countries – eg, Malawi and Namibia – and Caribbean countries.

Living Wills

Terrence Higgins Trust has distributed over 30,000 living will forms since it developed the first edition of the form in conjunction with King's

College London in 1992. While the living will of course does not apply uniquely to the needs of people with HIV, it was developed with them in mind as a document enabling the patient to retain control of their medical treatment even after they had lost the capacity to express their wishes themselves.

After a period of consultation, the government recently decided that it would not be putting the living will on a statutory basis, preferring to leave it to the courts to develop this area of law. The living will is therefore dependent on common law for its binding effect. The case of *Re: T (Adult: Refusal of Treatment) [1993] Fam. 95* (Court of Appeal, 30 July 1992) sets out the three conditions that must be satisfied for an advance refusal of treatment to be valid:

- the patient must have capacity at the time the directive was made;
- the patient must not have been the subject of the undue influence of another person at the time the decision was made; and
- the decision was intended to be applicable in the circumstances that later occurred.

Criminal Law and HIV Transmission

Discussion about the clarification of the law on the transmission of HIV reached a peak in 1998 when the government published a draft *Offences Against the Person* bill. This followed the publication in November 1993 of a Law Commission paper that proposed changing the law so that intentional or reckless transmission of HIV and other infections would certainly be criminalized. Case law had left uncertainty about whether the deliberate transmission of HIV alone was a criminal offence. The bill as drafted sought to criminalize the intentional transmission of an infection but not its reckless transmission, proposing to limit the criminalization of transmission to cases in which a person "deliberately transmits a disease intending to cause a serious illness." The bill specified that "a person acts intentionally with respect to a result when it is his purpose to cause it or when although it is not his purpose to cause it he knows that it would occur in the ordinary course of events if he were to succeed in his purpose of causing some other result." This second part of the definition leaves open the possibility of the criminalization of transmission when it is not an intended result of an act but is nonetheless a secondary and obvious outcome.

The bill has not yet been presented to Parliament and the current position is uncertain. In the meantime, the law remains uncertain and is, as such, unsatisfactory.

Human Rights Act

The *Human Rights Act 1998* was given Royal Assent in November 1998 and comes into force on 2 October 2000. The Act incorporates the European Convention on Human Rights into the law of the United Kingdom. Our courts and legislators will have to take account of the provisions of the Convention at all stages of the legal process. Precisely what the consequences of incorporation will be is a matter of fierce debate in the UK at the moment. However, it can be anticipated that several articles, including article 2 (Right to Life), article 8 (Right to Respect for Family and Private Life), and article 14 (Prohibition of Discrimination) will be used in litigation concerning the rights of people with HIV/AIDS.

Outlook

It is anticipated that the *Disability Discrimination Act* will be amended to extend the definition of disability to include people with asymptomatic HIV and so afford them protection from discrimination. Otherwise, it is the incorporation of the European Convention on Human Rights that will present the biggest single challenge – and opportunity – in the area of law and HIV/AIDS. No lawyer will in future be able to approach any of the issues raised in this article without knowledge of the Convention and without giving very careful consideration to its application on behalf of people with HIV/AIDS. While the precise effects of the new law can only be guessed at, it is bound to be of use for the protection of the rights of people with HIV/AIDS.

– Stephen Deutz, Sue Pitt, and Lucia Joseet

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[1] See: Elliott R. HIV testing & treatment of children. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 5(1): 1, 3-8 at 3-5.

[2] *R* v *Broxbourne BC ex p Willmoth* (1989) 22 HLR 118; Code of Guidance para 5.8.

[3] *R* v *Westminster ex p Ali* 11 HLR 72.

[4] *R* v *South Hertfordshire BC ex p Miles* (1985) 17 HLR 82.

[5] *R* v *Hillingdon ex p Tinn* (1988) 20 HLR 150.

[6] *R* v *Wycombe DC ex p Homes* (1988) 22 HLR 150.

[7] Code of Guidance on parts VI and VII of the *Housing Act 1996*.

India – Workshops on "HIV/AIDS: The Law and Ethics"

The Lawyers Collective HIV/AIDS Unit is a non-governmental organization providing legal aid, advice, and support to people with HIV/AIDS in India. This article summarizes a series of workshops on "HIV/AIDS: The Law and Ethics" organized by the Unit to empower people with HIV/AIDS and educate the Indian judiciary.

Workshop for People with HIV/AIDS

Every person has fundamental rights in the eye of the law, irrespective of caste, community, religion, gender, etc. Theoretically, these rights do not change because of one's HIV status. Unfortunately, however, we find that people with HIV/AIDS do encounter stigmatization and discrimination daily in many walks of life.

In August 1999, the Lawyers Collective HIV/AIDS Unit conducted a two-day workshop in Mumbai on HIV/AIDS-related legal and ethical issues exclusively for people with HIV/AIDS. Thirty-nine people attended the workshop, which was presented in Hindi and English. Participants were selected on the basis of their capacity to disseminate and share knowledge gained at the workshop with affected communities.

The main objectives of the workshop were:

- to create an environment of awareness and information with respect to the rights of people with HIV/AIDS vis-à-vis the legal and ethical issues related to HIV/AIDS;
- to initiate a process whereby people with HIV/AIDS may be empowered to assert their rights when faced with the violation of such rights or with discrimination; and
- to address legal and ethical issues of concern that people with HIV/AIDS face, with a view to helping them develop practical solutions and strategies to deal with them.

The topics were chosen in consultation with the planning committee for the workshop, which comprised representatives of local groups of HIV-positive people and members of the Lawyers Collective HIV/AIDS Unit. The issues discussed were: public health and the law, consent and HIV testing, confidentiality, discrimination (in health care and employment), the right to marry, dubious medical practices, and research (including vaccine trials, clinical drug trials, and behavioural research). The presentations focused on discussing the legal position and ethical issues and identifying remedies to problems faced by people with HIV/AIDS.

After the presentations, the participants were divided into four groups to discuss issues or problems faced in relation to each of the topics presented, with a view to developing solutions. The participants then made presentations on the results of their group work. The majority of the issues or problems discussed related to access and delivery of health-care services. Consequently, the solutions suggested were based in a large part on sensitizing and conducting advocacy work with doctors and other health-care workers.

There was also an informal evening session on treatment and alternative therapies, facilitated by allopathic and homeopathic practitioners; this question-and-answer session allowed participants to share their experiences with vaious treatments.

A similar workshop is being planned for the Northern region of India in the near future.

Judges and HIV/AIDS: Challenges in the New Millennium

The National AIDS Control Organization estimates that there are 3.5 million people with HIV/AIDS in India. No longer can HIV/AIDS be viewed as an issue affecting only certain sections of society. The epidemic is spreading rapidly, affecting all social strata and urgently requiring a response from all sectors. HIV/AIDS is not merely an issue to be addressed by health professionals, but rather one to which the judiciary must respond with sensitivity and a commitment to justice. It must do so as part of a comprehensive effort to create an enabling environment consonant with the principles of equality, privacy, and non-discrimination.

In December 1999, the Lawyers Collective HIV/AIDS Unit conducted two workshops for judges in Delhi and Ahemdabad on the legal and

The question posed by the late Mahatma Gandhi – "how will it affect the humblest and the poorest of people?" – must also be asked of our responses to HIV/AIDS.

ethical issues arising from the HIV epidemic. The workshops were well attended by judges from various courts in both cities. Two eminent jurists from the highest courts of Australia and South Africa, Justice Michael Kirby and Justice Edwin Cameron, addressed the workshops and shared their experience of the HIV/AIDS epidemic. Both jurists, with the greatest diffidence and respect, emphasized the importance of learning from the experiences of other countries and their response to the HIV/AIDS epidemic.

The workshops explored the many facets of the HIV/AIDS epidemic and the numerous legal and ethical issues it presents to the courts and to the legal system of every country. Issues included: informed consent for HIV testing; confidentiality and discrimination; and vulnerable groups such as women and children, who as result of systemic discrimination become even more vulnerable to HIV/AIDS.

Justice Michael Kirby of the High Court of Australia pointed out that HIV/AIDS is no longer a remote, exotic problem for judges. It has become a regular issue in the courts in India as it has in many other countries. The unique position of judges in society imposes upon them a responsibility of leadership. Nowhere has the responsibility of leadership been tested more than it has with an unexpected and complex issue such as HIV. It is the responsibility of the judiciary to lead society toward informed, intelligent, and just responses to the issue.

Justice Kirby is well known for articulating the insight that the only way to deal effectively with the rapid spread of HIV is by respecting and protecting the human rights of those already exposed to the virus and of those most at risk. He shared with the participants the following four simple principles required for an effective response to the HIV/AIDS epidemic:

- strategies, interventions, laws, and policies based on good science, rather than "highly ineffective laws" and policies based on myth, fear, and prejudice;
- a shared sense of urgency;
- decisive and proactive political will to mobilize efforts to combat the epidemic; and
- promotion and protection of the rights of those who are infected and those most at risk.

Justice Kirby expressed his grave concern that in the land of Kama Sutra, it is still incredibly difficult to discuss issues of sex and sexuality. Both he and Justice Cameron emphasized the importance of breaking out of the ghettos of silence and fear if the HIV/AIDS epidemic is to be effectively tackled. Justice Kirby went on to say that what was urgently required was a social movement to remove myths, prejudices, and stereotypes from our minds. He pointed out that the question posed by the late Mahatma Gandhi – "how will it affect the humblest and the poorest of people?" – must also be asked of our responses to HIV/AIDS.

Countries such as South Africa and India must challenge the pharmaceutical companies and the current international patent regimes to ensure that antiretroviral drugs do not remain prohibitively expensive, so they may be available to people living in the developing world.

Justice Edwin Cameron, Acting Justice of the Constitutional Court of South Africa, outlined the following similarities between South Africa and India:

- valued legal traditions of rule of law, common law, and written constitutions;
- despite written constitutions that aspire to great ideals, there is pervasive inequality and injustice; and
- profound vulnerability to HIV infection (both countries have approximately four million people with HIV/AIDS).

Justice Cameron agreed with Justice Kirby that the law must be used to create a climate of rationality, non-discrimination, equality, tolerance, and compassion. It is only in such a climate that those affected by the virus will seek testing, counseling, care, and support. He reiterated that any response characterized by coercion will only serve to exacerbate the epidemic.

In a profound and valiant testimonial, steeped in commitment and compassion, Justice Cameron shared with the participants his personal experience as a person with HIV/AIDS, and said that the three

principal reasons why he was able to come out publicly as a person with HIV were:

- a secure job and a constitution that protects him from discrimination in employment based on his HIV-positive status;
- the support of family, friends, and colleagues, and a climate of tolerance, acceptance, and compassion; and
- access to treatment (ie, access to antiretroviral drugs).

He reminded participants that 90 percent of HIV infections today are in the developing world, in countries such as South Africa and India, yet 90 percent of the world's health-care resources are accessible only to those in the developed world. Countries such as South Africa and India must challenge the pharmaceutical companies and the current international patent regimes to ensure that antiretroviral drugs do not remain prohibitively expensive, so they may be available to people living in the developing world. Justice Cameron went on to say that it is our moral imperative to find ways to make these treatments available to everyone who may require them. With millions of people dead and millions of people infected with the virus, we simply cannot accept the claim that there are insufficient resources to make antiretroviral drugs available and accessible in the developing world.

Public Meetings

Along with the workshops, the Lawyers Collective HIV/AIDS Unit coordinated the organization of several public meetings in New Delhi, Ahmedabad, and Surat. The meetings were organized in conjunction with the National AIDS Control Organization (New Delhi), the Gujarat Legal Aid Services Authority (Ahmedababd), the Institute of Women and Child Development (Surat), and the Bombay Bar Association (Mumbai). The meetings, addressed by Justice Kirby, Justice Cameron, and Anand Grover, Director of the Lawyers Collective HIV/AIDS Unit, were well attended by judges, lawyers, activists working in the field of HIV, the media, and sex workers.

Justice Kirby astutely observed that what was missing at these public meetings was the participation of policymakers, key stakeholders such as the police and politicians. According to him, Australia has been able to control the spread of the HIV/AIDS epidemic because of the initiative and vision of a few motivated politicians and policymakers who rose above their political differences and personal ambitions. In recognizing the critical nature of the epidemic, they acted quickly and decisively, often making difficult and unpopular decisions, such as ensuring the continuation of needle/syringe exchange programs in spite of the national war against drugs.

The Road Ahead

SN Variava, Chief Justice of the Delhi High Court, gave an eloquent inaugural address at the Delhi workshop, charting the direction for future efforts with the judiciary on issues of HIV/AIDS. Both Justice Variava and Justice Verma, Chair of the National Human Rights Commission, commended the efforts of the Lawyers Collective HIV/AIDS Unit in organizing these workshops for the judiciary. Justice Variava recommended that a national-level workshop on the legal and ethical issues arising from the HIV/AIDS epidemic be held for judges of the High Courts. The participants at the Delhi workshop said that all judges should attend these workshops. Many of the workshop participants expressed the need for more such workshops, with more time for discussion of the issues at hand.

– Mandeep Dhaliwal & Nidhi Dubey

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