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An Ethical Analysis of the Mandatory Exclusion of Immigrants Who Test HIV-Positive

On 20 September 2000, Canadian newspapers reported that Health Canada recommended to Citizenship and Immigration Canada (CIC) that testing all prospective immigrants for HIV, and excluding those testing positive, constitutes "the lowest health risk course of action."[1] Subsequently, the Minister of Citizenship and Immigration stated that CIC is indeed considering implementing mandatory HIV testing for all prospective immigrants to Canada, and excluding all those testing positive (with the exception of refugees and family-class sponsored immigrants) from immigrating to Canada on both public health and "excessive cost" grounds. This proposal was met with vehement opposition from a broad range of organizations and individuals. In particular, they pointed out that, as stated in the International Guidelines on HIV/AIDS and Human Rights (UNHCHR/UNAIDS, 1998: para 105), "[t]here is no public health rationale for restricting liberty of movement or choice of residence on the ground of HIV status."

At the time of going to print, no final decision had been made about whether mandatory HIV testing for all immigrants would be implemented.

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CANADIAN HIV•AIDS LEGAL NETWORK
RÉSEAU JURIDIQUE CANADIEN VIH•SIDA

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Canadian Strategy on HIV/AIDS

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Legal, Ethical, and Human Rights Issues at Durban 2000

At the XIII International AIDS Conference in Durban in July 2000, legal, ethical, and human rights issues related to HIV/AIDS took centre stage. For the first time the Conference saw a full-day satellite conference focusing on legal and human rights issues, and a specific track dedicated to "Rights, Politics, Commitment and Action" (Track E). But legal, ethical, and human rights issues were not confined to the satellite conference and to Track E. The issue of global inequity broke across all tracks and resounded through every plenary, emerging as the key issue of AIDS 2000. In this special edition of the Review, with funding from UNAIDS, we print the proceedings of the satellite conference and reproduce some of the most relevant presentations on legal, ethical, and human rights issues given at the Conference – a must-read for all those in governments, the United Nations system, professional associations, and non-governmental and community-based organizations who are interested in the broader legal, ethical, and human rights implications of HIV/AIDS.

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Comments?

We would like to hear your views and opinions regarding the* Review, *its content and format. We also encourage comments on or responses to individual articles, and letters to the editor.

CANADIAN HIV/AIDS POLICY & LAW REVIEW

The *Review* 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 at arenaud@aidslaw.ca.

EDITORIAL

The XIII International AIDS Conference, held this summer in Durban, South Africa, was the first such conference that "put third first," meaning that it focused on those issues most relevant to people with HIV/AIDS in resource-poor countries, and on the issues affecting the most marginalized in the so-called developed world. Thanks to the efforts of treatment activists, particularly the members of the South African Treatment Action Campaign (TAC), the silence with regard to access to treatment in resource-poor countries has been broken, as has the silence with regard to the centrality of political leadership. Legal, ethical, and human rights issues related to HIV/AIDS were everywhere at the Conference. For the first time, the Conference saw a full-day satellite conference focusing on law, ethics, and human rights, and a specific track dedicated to "Rights, Politics, Commitment and Action." But these issues were not confined to the satellite conference and to the new track. Indeed, the issue of global inequity cut across all tracks and resounded through every plenary.

In the words of Justice Edwin Cameron,

> the position of people living with AIDS or HIV in Africa and other resource-poor countries poses a ... moral dilemma for the developed world today. The inequities of drug access, pricing and distribution mirror the inequities of a world trade system that weighs the poor with debt while privileging the wealthy with inexpensive raw materials and labour. Those of us who live affluent lives, well-attended by medical care and treatment, should not ask how Germans or white South Africans could tolerate living in proximity to moral evil. We do so

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Canadian HIV/AIDS Policy & Law Review

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Back issues are on QUICKLAW and on the Legal Network's website. Hard copies can be obtained at $12/issue (outside Canada payable in US dollars).
Please direct your enquiries to Éric Nolet (enolet@aidslaw.ca).

> ourselves today, in proximity to the impending illness and death of many millions of people with AIDS.

Those readers who do not have the time to read all articles in this issue of the *Canadian HIV/AIDS Policy & Law Review* should make sure that they do not miss the full text of Justice Cameron's presentation, entitled "The Deafening Silence of AIDS," at page 79. Many of the other presentations given at the Conference and satellite conference (which we were able to include in this issues thanks to co-funding received from the Joint United Nations Programme on HIV/AIDS) also deal with the issue of global inequity, as well as with ways to overcome it.

These articles pose important and urgent questions and challenge us to take action. Issues include: What are we going to do to ensure that the energy, commitment, and passion demonstrated by so many at the conference will translate into action, so that the gap between what is available for people with HIV/AIDS in the developed world and people with HIV/AIDS in resource-poor countries will indeed become smaller? What are we going to do to assist treatment activists in resource-poor countries, respecting that *they* are the experts and that they do not need teachers and preachers from the North. What will we do to ensure that the next international AIDS conferences will "put third first," particularly those in Barcelona in 2002 and in Toronto in 2004 or 2006?

One small but concrete step that we are taking with the *Canadian HIV/AIDS Policy & Law Review* is the inclusion of a new section on "Patents and Prices," which will regularly cover developments in the area of patent laws and the impact of laws on drug prices. The Conference highlighted the role of laws on intellectual property and of international trade agreements in creating barriers to global health by maintaining drug prices beyond the reach of most developing countries and most of the world's people with HIV/AIDS and other serious illnesses. With the new section (see page 25), we hope to contribute to greater "trade literacy," since we must all become able to articulate a critique of international and domestic laws that place profits ahead of people and their human rights to health and life.

For the first time, the Conference saw a full-day satellite conference focusing on law, ethics, and human rights, and a specific track dedicated to "Rights, Politics, Commitment and Action."

This issue is also the first to appear under a new name. When we started 23 issues ago, we published a newsletter with 15 English and 17 French pages, called the *Canadian HIV/AIDS Policy & Law Newsletter*. Many of you have seen the publication grow into what could no longer be appropriately be called a "newsletter" – hence the change of name to *Canadian HIV/AIDS Policy & Law Review*. The "Canadian" in the name remains because we continue to be committed to exhaustive coverage of Canadian developments. This, however, does not mean that the *Review* has not become a must-read for everyone, worldwide, interested in policy and legal issues related to HIV/AIDS.

In the next while, you will see more changes to the *Review* as we continue implementing the suggestions made by readers during the ongoing evaluation of the publication. One important addition is that of a table of content of all issues, which is already available on our website at http://www.aidslaw.ca/Maincontent/otherdocs/Newsletter/newsletter.htm#tocoai. Soon, we hope to produce a printed version as well. My thanks go to those of you who have taken part in the evaluation of the *Review*. Everybody else's comments and suggestions are still appreciated. Please fill out the questionnaire at http://www.aidslaw.ca/Maincontent/otherdocs/Newsletter/newsletter-survey.htm.

HIV/AIDS IN CANADIAN COURTS

This section 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, between May 2000 and October 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 readers are asked to draw these to our attention.) The cases reported below deal with litigation against the government and the Red Cross for HIV infection through tainted blood or blood products, and with challenges to the criminalization of marijuana. Criminal cases (both in Canada and other jurisdictions) are summarized elsewhere in this issue.

Red Cross and Federal Government Held Liable for Hemophiliacs' HIV Infection

After eight years of litigation, on 21 June 2000 three hemophiliacs infected with HIV finally won a judgment against the Canadian Red Cross Society and the federal government. An Ontario trial court ruled the Red Cross and the government were negligent for having delayed the implementation of heat treatment for blood products, which resulted in the plaintiffs' infections. Since starting their lawsuits in 1992, two of the three plaintiffs died of AIDS before the trial judgment.[1] But the damage awards were criticized by the plaintiffs' lawyer.

The Canadian Red Cross Society ("Red Cross") was operating a free, national, blood transfusion service throughout Canada, funded by the governments of Canada and the provinces and territories.

Justice Ellen Macdonald of the Ontario Superior Court of Justice found that "by the fall of 1984, the informed medical community knew that HIV was a blood borne virus that could be transmitted through [blood] factor concentrates, and that hemophiliacs who used these products were at risk of contracting HIV and developing the Acquired Immune Deficiency Syndrome ("AIDS"). By then, it was also known that heat-treating factor concentrates inactivated the virus."[2]

The federal government health department issued a directive in November 1984 to the Red Cross that the use of non–heat treated products could no longer be justified. The government instructed the Red Cross to make a transition to heat-treated products as soon as possible. Yet the Red Cross continued to distribute blood products that had not been heat treated at least until July 1985 – each of the three plaintiffs received their last untreated products in June or July 1985, even though the Red Cross had been instructed seven months earlier to stop using them.

> The government instructed the Red Cross to make a transition to heat-treated products as soon as possible. Yet the Red Cross continued to distribute blood products that had not been heat treated at least until July 1985.

Plaintiffs' Claims against the Red Cross and Ontario Government

Robb, Rintoul, and Farrow argued that the Red Cross (and the province of Ontario) breached their duties of care to the plaintiffs because they

- failed to implement adequate blood donor screening in a timely fashion (this claim was abandoned during the trial), and
- failed to implement heat treatment of blood-factor concentrates either in 1983 (when the process was first commercialized) or in October 1984, when it was announced that heat treatment inactivated HIV.

They also alleged that the Red Cross and the Ontario government were negligent in their response to the Directive from the federal health department in that they

- delayed the transition to heat-treated product,
- failed to explore options to make the transition as quickly as possible, and
- failed to warn the plaintiffs or their doctors that HIV could be transmitted through the factor concentrates.

The Red Cross argued that in October 1984 the medical and scientific community merely "suspected" that factor concentrates transmitted the virus then known as HTLV-III, now known as HIV. It also claimed that it was an agent of the governments, and that through the Canadian Blood Committee, the governments assumed responsibility for the safety and supply of blood products. The Canadian Blood Committee was created in 1981, with representatives from the provinces, the territories, and the federal government. An Advisory Subcommittee, consisting of physicians and other persons knowledgeable in the blood industry, met at least twice a year. In the fall of 1984, it recommended that a consensus conference of all key people in the blood industry be held to consider whether factor products should be heat-treated. When the November 1984 directive was issued, the focus of the planned conference shifted from whether or not to introduce heat-treated products to how the directive should be implemented.

Claims against the Federal Government

The plaintiffs themselves brought no lawsuit against the federal government. In 1990, Robb, Rintoul, and Farrow received assistance from the federal government under the Extraordinary Assistance Program. In exchange for a sum of $120,000 each, they signed a release of any claims against the federal government.

However, shortly before the trial began, the Red Cross and the Ontario government added the federal government as a third-party defendant. The Red Cross sought indemnity from the federal government for any liability that might be found on the part of the Red Cross, arguing that the federal government unjustifiably delayed in issuing regulatory permission for the distribution of heat-treated blood-factor concentrates in Canada. It also alleged that the federal government failed to adequately assist the various parties in their efforts to comply with the November 1984 directive.

The Ontario government also claimed indemnity from the federal government based on: (1) the federal government's membership in the Canadian Blood Committee; (2) the possible failure of the Committee to convey necessary information and documentation; and (3) the "pace of conversion" to heat-treated products. (However, this claim became moot because Justice Macdonald found on the evidence that the Ontario government's involvement in the blood transfusion service was limited to "policy and planning issues" and that it was not involved in "operational matters." She therefore dismissed the claims against the Ontario government, and its third-party claim against the federal claim.)

In response to these third-party claims, the Canadian government argued that there was no evidence of undue delay on its part in issuing the regulatory approval for heat-treated product and that the nature of its role on the Blood Committee did not give rise to any liability.

The Judgment

The court ruled that the Canadian Red Cross Society faced an "exacting and high standard" of care to the plaintiffs, for at least three reasons. First, as Canadian hemophiliacs they were part of

> a sick and vulnerable population ... [who] depended on the CRCS for the supply of factor concentrates that were essential to their survival. Since the CRCS was in the unique position of being the only supplier of blood products in Canada, hemophiliacs had no other options. Their relationship with the CRCS was one of total dependency. Although not pleaded, it is very close to a fiduciary relationship.[3]

Second, the Red Cross was "a specialized body, with specialized knowledge. As a blood banker, the CRCS can be likened to a medical or legal specialist who must be held to a higher standard of care than a general practitioner."[4] The court noted that this same finding was made by the trial judge in the *Walker* and *Osborne* cases.[5] (See below for an update on those cases.)

Third, a high duty of care arose from

> the state of medical knowledge in the fall of 1984 and earlier. By the time the ... Directive was issued on November 16, 1984, the CRCS was facing a clearly identified crisis. It was accepted that HIV was a blood-borne virus and that hemophiliacs were a high-risk population. It was also accepted that the process of heat-treatment of factor concentrates could inactivate the virus. Since an emergency was identified, and a course of action was mandated by an authoritative regulatory body, the CRCS must be held to a high standard of care when its responses to the ... Directive are assessed.
>
> The unambiguous wording of the ... Directive provides the clearest and most compelling measure of the precise content of the standard of care. Since the lives of between two and three thousand Canadians were at risk, the CRCS was instructed to make the transition to heat-treated product "as soon as possible, since the continued use of non-heated product could no longer be justified." From this, I find that the CRCS had a duty to take immediate action to manage this crisis by doing everything possible to facilitate the transition from non-heated to heat-treated products.[6]

The court concluded that implementing the use of heat-treated products should have taken two to three months, but that the Red Cross took eight months because (1) it wanted to use up its existing inventory of unheated product, and (2) it assumed that "all but virgin hemophiliacs had almost certainly been exposed to the putative AIDS agent." But as the court pointed out:

> The evidence on the rate of infection in late 1984 demonstrates that this assumption was not correct. The fact that it was not correct is best illustrated by the reality that none of Mr. Robb, Mr. Rintoul or Mr. Farrow were infected by the fall of 1984. If this assumption was one of the reasons for the delay or inherent slowness on the part of the CRCS, it is a shocking illustration of breach [of the duty of care].[7]

The Court also found that the federal government had breached is duty of care to the plaintiffs because it failed to expedite the process of approving heat-treated products:

> Canada, as regulator of the blood industry, owed a duty of care to the plaintiffs. The [Bureau of Biologics within the federal department of health] was dealing with hemophiliacs, a sick and vulnerable population in the midst of the AIDS epidemic. The hemophiliac population was totally dependant on the [Bureau] for regulatory approval of the heat-treated blood products. Thus, the [Bureau], like the CRCS, must be held to a high standard of care. Given that the language of the second recommendation of the Consensus Conference contemplated that the [Bureau] would expedite licensing, the content of the [Bureau's] duty of care was exactly this, to expedite the licensing.
>
> The breach of this duty of care was the delay caused by the BoB's bureaucratic lethargy in failing to respond to the crisis in a manner that was commensurate with the magnitude of that crisis....
>
> Given the language of the [Bureau's] own Directive [to the Red Cross] and its recognition that the continued use of non-heat treated blood products "could no longer be justified," its "normal" approach to obtaining regulatory approval constitutes a breach of the duty of care. The new drug approval submission was received in July, 1984. In December, 1984, the CRCS anticipated regulatory approval by January of 1985. The NoC was not issued until April 10, 1985.[8]

Justice Macdonald therefore found that the Red Cross did have a legitimate third-party claim against the federal government. She found that the Red Cross was responsible for 75 percent of the plaintiffs' damages, and the federal government was responsible for the remaining 25 percent, and she apportioned the damages accordingly. The Robb estate was awarded roughly $631,000, the Rintoul estate was awarded roughly $392,000, and Farrow, who is still living, was awarded $614,000. (These figures include the awards to family members under the *Family Law Act* for their loss of guidance, care, and companionship.)

– Richard Elliott

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[1] *Robb* v *Canadian Red Cross Society*, [2000] OJ No 2396 (QL) (joint judgment in the cases of *Robb* v *CRC et al*, *Rintoul* v *CRC et al*, and *Farrow* v *CRC et al*).

[2] Ibid at para 4.

[3] Ibid at para 72.

[4] Ibid at para 73.

[5] For a summary see: Elliott R. HIV/AIDS in Canadian courts in 1999: Part 1. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(4): 21 at 23.

[6] Supra, note 1 at paras 74-75.

[7] Ibid at paras 88-89.

[8] Ibid at paras 139-40, 146.

Court Approves Final Red Cross Bankruptcy Plan to Compensate Blood Victims

Following two years of negotiations, the insolvent Canadian Red Cross Society received court approval on 14 September 2000 of its plan to compensate victims of Canada's tainted blood tragedy (and pay other creditors).[1]

In 1998, the Canadian Red Cross recognized that its potential liabilities far outstripped its assets and ability to meet those liabilities, and therefore applied to the court for bankruptcy protection. The federal, provincial, and territorial governments – which faced, and continue to face, liability for their role in the mishandling of the blood system – decided that control and management of the Canadian blood supply should be transferred to a new entity, and imposed as a condition of this transfer that the Red Cross obtain bankruptcy protection. The funds from the sale of the Red Cross's assets relating to the blood system to the new agency (Canadian Blood Services and Héma Québec) were to be made available to compensate those infected by contaminated blood and blood products.

That protection was granted, staying the claims against the Red Cross while negotiations have proceeded. The negotiations have also incorporated other proceedings against the Red Cross and the various governments – including class actions in Ontario, Québec, and British Columbia – and the negotiation of a broader agreement between the governments and those infected by blood transfusions *between 1986 and 1990*.

As a result of this latter settlement, under the Plan submitted by the Red Cross for court approval, the funds from the sale of its assets relating to the blood system are primarily directed to meeting the claims of those infected *before* 1986 and *after 1990*. These are complemented by contributions negotiated from various co-defendants in the various lawsuits (and insurance companies).

Under the Plan, claimants will get 100 percent of proven claims of up to $10,000, and 67 percent of the amount of any proven claim beyond that amount. The Plan also establishes a $79 million trust for transfusion claimants, which will provide about $63 million for those class action claimants alleging they were infected before 1986 or after 1990, $13.7 million for those infected with HIV, $1 million for claimants in a class action alleging infection with hepatitis C from blood obtained from US prisoners, $600,000 for claimants infected with Creutzfeld-Jakob disease, and $500,000 for claimants with transfusion claims not otherwise covered.

Justice Blair of the Ontario Superior Court of Justice spoke of the "deep human, and indeed, institutional tragedy which has given rise to the restructuring of the Canadian Red Cross," and noted that the "honourable tradition and the reputation which has accompanied [the Red Cross] have been badly sullied in recent years.... [T]he well-known Red Cross symbol, for many unfortunately, has become a 'symbol of death.' Nothing that the Court can do will take away these diseases and bring back to life those who have died."

Noting that all classes of creditors – including the transfusion claimants – voted overwhelmingly in favour of accepting the Plan, Justice Blair issued his own conclusion that the Plan was fair and reasonable, and balances the competing interests "in an equitable fashion." He also noted that the Plan

> will permit the Canadian Red Cross to continue to carry on its non–blood related humanitarian activities. There is a deep-seated anger and bitterness towards the Society amongst many of the victims of these terrible blood diseases. To them, it is not right that thousands of people have been poisoned by tainted blood yet the Society is able to continue on with the other facets of its business. These feelings are understandable. However, the Red Cross currently continues to employ approximately 7000 Canadians in other aspects of its work, and it makes valuable contributions to society through these humanitarian efforts. That it will be able to continue those works, if this Plan is implemented, is important.

– Richard Elliott

The three volumes of the final Report of the Commission of Inquiry on the Blood System in Canada (the Krever Commission) can be found online at the Health Canada website (www.hc-sc.gc.ca).

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[1] *Re Canadian Red Cross Society*, [2000] OJ No 3421 (SCJ) (QL).

Supreme Court to Hear Appeal in Negligence Claim against Red Cross for HIV Infection

As previously reported, in March 1999 the Ontario Court of Appeal issued a joint ruling in two cases against the Canadian Red Cross for negligence in the screening of blood donors in the mid-1980s, resulting in HIV infection of two plaintiffs.[1] In the *Osborne* case,[2] the Court found that the Red Cross had been negligent because, in December 1984, its written material and questionnaire to screen blood donors "did not constitute a reasonable measure to protect the safety of the blood and blood products provided" by it. In the *Walker* case, the claim arose out of blood donated in September 1983. While the trial judge ruled against Ms Walker, the appeal court overturned this decision, saying it had "no difficulty" in finding that the Red Cross had failed to implement a program at donor clinics to screen out donors at "high risk" of HIV infection.[3]

The Red Cross has appealed the *Walker* and *Osborne* decisions to the Supreme Court of Canada.[4] The appeal was heard on 7 November 2000, and judgment was reserved.

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[1] See: Elliott R. HIV/AIDS in Canadian courts in 1999: Part 1. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(4): 21 at 23.

[2] *Osborne* v *Canadian Red Cross Society et al* (1997), 43 OR (3d) 461, 39 CCLT (2d) 1 (Ont Ct Gen Div), aff'd [1999] OJ No 644 (QL) (CA).

[3] *Walker Estate* v *York Finch General Hospital et al* (1997) 43 OR (3d) 461, 39 CCLT (2d) 1 (Ont Ct Gen Div), rev'd [1999] OJ No 644 (QL) (CA).

[4] [1999] SCCA 228 (QL); [1999] SCCA 229 (QL).

Recent Court Rulings on Medical and Non-Medical Marijuana

The last several months saw important victories but also disappointments in litigation over criminal prohibitions of marijuana in Canada. Four cases are summarized below – two deal with claims regarding medical marijuana, the other two with recreational use.

Wakeford: Court Rejects Application for Caregiver Exemptions and Safe Supply of Drug

Since May 1999, Jim Wakeford, who is living with HIV, has had an exemption from prosecution for possession or cultivation of marijuana. However, he cannot grow sufficient crop for his needs and so relies upon caregivers to secure marijuana illegally for him. No exemption from prosecution for his caregivers was forthcoming from the federal Minister of Health, and in fact two of his caregivers have been charged with drug trafficking for supplying him.[1] Furthermore, Wakeford is concerned about the health risks for an immunocompromised person of possible impurities in product purchased illegally.

However, in May 2000 the Ontario Superior Court of Justice ruled that, in order to review the failure of the Minister to exempt his caregivers, he would need to apply to the Federal Court of Canada.[2] As for Wakeford's argument that the government was breaching his Charter rights to liberty and security of the person by not providing a safe supply of the drug, the court noted that Health Canada had moved to locate a source of research-grade marijuana and to initiate clinical trials of the drug.[3]

> In view of the fact that the Government does not have, within Canada, a source of licit marijuana, and that the Government is moving at a reasonable pace to provide clinical trials of marijuana, and that Mr Wakeford

> has no real difficulty in obtaining marijuana, and that marijuana is not the only avenue by which Mr Wakeford may improve his quality of life, the principles of fundamental justice are not infringed by the failure of the Government to supply marijuana directly to Mr Wakeford.... To be in accordance with the principles of fundamental justice does not mandate a perfect system of government which is required to meet the desires and demands of its citizens even in the area of personal health.[4]

Wakeford and his lawyers criticized the decision as "putting procedural obstacles in the way of sick people vindicating their constitutional rights," arguing that Wakeford is a person who is sick, "not an experimental guinea pig."[5] Wakeford's appeal of this decision was expected to be heard before the end of 2000.[6]

"The marijuana laws force Parker to choose between commission of a crime to obtain effective medical treatment and inadequate treatment."

Parker: Appeal Court Rules Prohibiting Medical Marijuana Is Unconstitutional

Terry Parker was charged under the *Controlled Drugs and Substances Act* (s 4) with possession of marijuana, which he was cultivating in order to control his severe epileptic seizures. At trial, the court stayed the charges, ruling that the prohibition infringed his constitutional rights.[7] On 31 July 2000, the Ontario Court of Appeal dismissed the Crown's appeal in a unanimous and forceful ruling criticizing the injustice of criminally prohibiting marijuana for medical use.[8]

Right to Liberty

The Court of Appeal agreed with Parker that the criminal prohibition violated his right to "liberty" and his right not to be deprived of his liberty except "in accordance with the principles of fundamental justice." These rights are protected under section 7 of the *Canadian Charter of Rights and Freedoms*.

> First, the threat of criminal prosecution and possible imprisonment itself amounts to a risk of deprivation of liberty and must therefore accord with the principles of fundamental justice. Second, as this case arises in the criminal law context (in that the state seeks to limit a person's choice of treatment through threat of criminal prosecution), liberty includes the right to make decisions of fundamental personal importance. Deprivation of this right must also accord with the principles of fundamental justice. I have little difficulty in concluding that the choice of medication to alleviate the effects of an illness with life-threatening consequences is such a decision.[9]

Right to Security of the Person

Citing a series of decisions from the Supreme Court of Canada (and in particular the 1988 ruling protecting a woman's right to choose an abortion[10]), the Court of Appeal concluded that Parker's right to "security of the person" was also infringed:

> deprivation by means of a criminal sanction of access to medication reasonably required for the treatment of a medical condition that threatens life or health constitutes a deprivation of *security of the person*.... Depriving a patient of medication in such circumstances, through a criminal sanction ... constitutes a serious interference with both physical and psychological integrity.... [T]he marijuana laws force Parker to choose between commission of a crime to obtain effective medical treatment and inadequate treatment.[11]

The Court focused exclusively on the issue of the criminal prohibition, and expressly avoided dealing with "the much more difficult question [of] whether security of the person would be engaged if the lack of access is due not to a criminal sanction but government inaction."[12]

The Court invoked the right to health under international human rights treaties in striking down a draconian drug law infringing access to treatment.

"Principles of Fundamental Justice"

The Court then analyzed whether the infringement of Parker's liberty and security of the person was in accord with the "principles of fundamental justice." In putting "legal content" into the application of these principles, the Court considered the common law of Canada, the history of the statutory prohibition on marijuana, and international law.

Canadian common law

The Court emphasized that the common law doctrine of informed consent has been well established as including the right to not only refuse medical treatment, but also to choose among alternative forms of treatment. Furthermore, the common law criminal defence of *necessity* lends support for a claim to access drugs with a therapeutic value even if those drugs are prohibited.

History of prohibition in Canada

Noting the history of marijuana prohibition in Canada set out in the *Clay* case (see below), the Court concluded that "regulation of marijuana has a very short history and lacks a significant foundation in our legal tradition. It is, in fact, an embarrassing history based upon misinformation and racism."[13] The Court also noted that in 1999, the House of Commons overwhelmingly passed a motion urging the government to legalize the medicinal use of marijuana, and to establish clinical trials and a legal supply of the drug.

International treaties do not require prohibition of medical marijuana

The Court also rejected the government's claim that international treaties tie its hands:

> In this case, the Crown asserts that one of the objectives of the marijuana prohibition is to satisfy Canada's international treaty obligations with respect to the control of illicit drugs. It is ironic then that the preamble of the international convention that led to the enactment of the *Narcotic Control Act* [the *Single Convention on Narcotic Drugs, 1961*] recognizes what Parker asserts – that "the medical use of narcotic drugs continues to be indispensable for the relief of pain and suffering and that adequate provision must be made to ensure the availability of narcotic drugs for such purposes."[14]

The Court did agree that international treaties subsequent to the 1961 Convention have been more restrictive in controlling narcotics and pyschotropic substances (including marijuana). But the Court also concluded that these do not require the government to completely prohibit marijuana in order to satisfy its treaty obligations. The 1971 UN *Convention on Psychotropic Substances* allows the use of illicit drugs for limited medical purposes by duly authorized persons. And the 1988 *Convention Against Illicit Traffic in Narcotic Drugs and Psychotropic Substances* requires states to prohibit possession of marijuana, but subject to the country's "constitutional principles and the basic concepts of its legal system." The Court therefore concluded:

> "Prohibiting possession or cultivation of marijuana for personal medical use does nothing to enhance the state's interest in fulfilling its international obligations."[15] In any event, the Court noted, Canada's Constitution takes precedence over treaty obligations.[16]

Just as encouraging, the Court of Appeal pointed out that "in considering Canada's treaty obligations, it should be borne in mind that Canada is also a party to the *International Covenant on Economic, Social and Cultural Rights.*"[17] Article 12 of that treaty states that signatories "recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health," and that in pursuit of realizing this right, states that sign the treaty *shall* take the necessary steps to create "conditions which would assure to all medical service and medical attention in the event of sickness." It is significant that an international human rights treaty – in particular one that protects the less well-defined economic and social rights – should be invoked by a domestic court to reject overly draconian drug laws as infringing the human right to health.

"Using a criminal prohibition to bar access to a drug for a person ... who requires it to treat a condition that threatens his life and health, is antithetical to our notions of justice."

Court's conclusion: Criminally barring access to treatment violates constitutional rights

Based on all these considerations, the Court concluded that

> Using a criminal prohibition to bar access to a drug for a person…who requires it to treat a condition that threatens his life and health, is antithetical to our notions of justice. It is inconsistent with the principle of sanctity of life.... Permitting access to medicine that may relieve debilitating symptoms of illness is consistent with the common understanding about the purpose of proper medical care.[18]

Right to Security of Person Cannot Depend on Ministerial Discretion

The government argued that its criminal prohibition could be upheld because there were three legal means by which Parker could possess marijuana:

- Health Canada could approve marijuana as a new drug to be manufactured for sale in Canada;
- Parker could apply to the Emergency Drug Release Program (now known as the Compassionate Use Program) at Health Canada; or
- Parker could apply to the Minister of Health for an exemption from prosecution under the *Controlled Drugs and Substances Act* (section 56).

The Court dismissed the first two options as non-existent. Since no manufacturer has come forward to get approval for marijuana as a "new drug" for sale in Canada, there is no legal source of marijuana. Furthermore, the process of obtaining such approval is time-consuming and expensive, meaning Parker himself could not obtain such approval. Practically speaking, this defence to criminal liability is unavailable. The same problem exists with the notion that Parker could obtain marijuana through the Compassionate Use Program – there is no licensed source.

The Court also found the third option did not pass constitutional scrutiny:

> [Section 56] reposes in the Minister an absolute discretion based on the Minister's opinion whether an exception is "necessary for a medical ... purpose" [...] Even if the Minister were of the opinion that the applicant had met the medical necessity requirement, the legislation does not require the Minister to give an exemption. The section only states that the Minister "may" give an exemption.... In effect, whether or not Parker will be deprived of his security of the person is entirely dependent upon the exercise of ministerial discretion. While this may be a sufficient legislative scheme for regulating access to marijuana for scientific purposes, it does not accord with fundamental justice where security of the person is at stake.... The right to make decisions that are of fundamental personal importance includes the choice of medication to alleviate the effects of an illness with life-threatening consequences. It does not comport with the principles of fundamental justice to subject that decision to unfettered ministerial discretion.[19]

Violation of Charter Rights Not Justified

The Court considered whether the government could justify the infringement of Parker's rights under section 1 of the Charter, which allows for such "reasonable limits prescribed by law as may be justifiable in a free and democratic society." The Court concluded that the "plenary discretion vested in the Minister" created a standard "so vague as to be incomprehensible" and that there were insufficient safeguards to ensure that Parker's constitutional right will not be infringed more than necessary. Therefore it could not be a "reasonable limit" on his rights.

Furthermore, the broad prohibition failed to meet the requirement of only "minimally impairing" Parker's rights: "There is no need to prosecute people like Parker who require marijuana for medical purposes to achieve any of the three objectives identified by the Crown: preventing harm, international treaty obligations, and control of the trade in illicit drugs. Less intrusive means are available to meet these objectives."[20]

Remedy Ordered by the Court

Having ruled in Parker's favour on all the constitutional issues, the Court of Appeal disagreed with the trial judge only on what the appropriate remedy should be. Rather than "read in" a medical exemption to the legislation, the Ontario Court of Appeal decided to declare the entire section of the *Controlled Drugs and Substances Act* prohibiting marijuana possession invalid. However, it agreed to suspend this declaration for 12 months, to give Parliament a chance to put replacement legislation in place. In the meantime, the Court ordered that Parker is entitled to a constitutional exemption from the possession offence.

Subsequent Developments

Following the ruling, federal Justice Minister Anne McLellan said she was willing to consider the possibility of decriminalizing marijuana generally (at least for small amounts). On 29 September 2000, the Department of Justice announced it would not be appealing the *Parker* ruling.[21] It remains to be seen what legislation the government will put in place before the end of July 2001 (the end of the 12-month period set by the Court). It seems unlikely that the government will simply let prohibition on marijuana be struck down entirely, given the decisions in the *Clay* and *Malmo-Levine* cases, discussed below.

At the end of September 2000, federal Health Minister Allan Rock promised that, within the year, a government-controlled supply of marijuana will be grown and federal regulations governing medicinal use will be enacted.[22] But litigation continues in the meantime. On 15 September 2000, a Vanier man with HIV and epilepsy filed a motion in the Federal Court of Canada, asking for a court order that he be allowed to import marijuana because he cannot grow sufficient quantities himself.[23]

Appellate Courts Uphold Prohibition on Recreational Marijuana: Malmo-Levine and Clay

Malmo-Levine: BC Marijuana Activist Appealing Conviction to Supreme Court

In June 2000, the BC Court of Appeal issued its ruling in the *Malmo-Levine* case, rejecting a constitutional challenge to the criminal prohibition in Canada on simply possessing marijuana.[24] The defendant is a marijuana freedom activist, who argued that prohibiting marijuana possession violates the right to liberty and security of the person protected by section 7 of the Charter. In particular, he argued that

> the State has no right to interfere with the personal freedom and liberty of an individual unless that individual causes harm to other persons or to society in general. Therefore, the State has no right to imprison individuals for activities that only cause harm to themselves.... [P]ossessing or smoking marihuana may in some cases have harmful effects on the smoker, but it does not harm others. Imprisoning a person for possessing marihuana would thereby violate the "harm principle" in the same way as imprisoning somebody for consuming caffeine or fatty foods.[25]

But the Court disagreed, ruling that as long as there was a "reasoned apprehension of harm" to other individuals or society, it is consistent with the principles of fundamental justice for Parliament to use the criminal law. It adopted this standard after reviewing a variety of leading Canadian court decisions, in particular the 1992 *Butler* decision in which the Supreme Court held that Parliament was justified in infringing freedom of expression by criminalizing "obscenity" as long as it had a "reasonable basis for concluding that harm will result." (It also found support for this test in the Supreme Court's *Cuerrier* decision, in which it was decided that there need not be actual harm, only a "significant risk" of harm, in order to invoke the criminal law. That case dealt with the criminal liability of an HIV-positive person for engaging in unprotected sex without disclosing his infection.)

The Court concluded that

> the deprivation of the appellants' liberty ... is in accordance with the harm principle. I agree that the evidence shows that the risk posed by marihuana is not large. Yet, it need not be large in order for Parliament to act. It is for Parliament to determine what level of risk is acceptable and what level of risk requires action. The Charter only demands a "reasoned apprehension of harm" that is not significant or trivial. The appellants have not convinced me that such harm is absent in this case.[26]

The Court therefore upheld Malmo-Levine's conviction. This ruling is under appeal to the Supreme Court of Canada.[27]

Clay: Store Owner's Conviction Upheld

In a very similar decision, two months later the Ontario Court of Appeal also upheld the criminal prohibition on the possession of marijuana for recreational use, in the *Clay* decision[28] (issued in conjunction with its *Parker* ruling). Christopher Clay, the proprietor of a store selling hemp products, marijuana pipes, and plant seedlings, was charged with trafficking marijuana and possession for the purposes of trafficking. He challenged the constitutionality of the law, but lost at trial. On 31 July 2000, he also lost his appeal.

The Court of Appeal did agree with the trial judge's findings of fact, including that:

- marijuana consumption is relatively harmless compared to so-called "hard drugs," tobacco and alcohol;
- there is no hard evidence that marijuana causes any irreversible organic or mental damage or induces psychoses;
- cannabis is not addictive, and it is not probable that it leads to the use of hard drugs for the vast majority of consumers;
- marijuana does not make people more aggressive or violent, and there is no evidence that it causes criminality;
- there have been no recorded deaths from consuming marijuana, and the health-related costs of using cannabis are negligible compared to the costs attributable to tobacco and alcohol consumption.

Despite this, the Court also agreed that "the jury is still out respecting the actual and potential harm from the consumption of marijuana."[29]

Clay argued that the right to use intoxicants in the privacy of one's home is a fundamental aspect of personal autonomy and human dignity that is protected by the Charter. The right to liberty and to security of the person has been held by the Supreme Court of Canada to extend to making decisions "of fundamental personal importance" and the right to "make choices concerning one's own body."

But the Court rejected this argument. It stated that Clay's decision to use marijuana for recreational purposes is not a decision that is "basic to human dignity" and the cases protecting the right to make decisions regarding medical care are "of an entirely different order from the right to intoxicate oneself in the privacy of one's home."[30] But the Court failed to explain why the right to make choices concerning one's own body should be limited only to those cases where there are serious medical consequences at stake (such as access to abortion services or to assisted suicide).

As did Malmo-Levine, Clay also argued that the "harm principle" is a one of the principles of fundamental justice – in other words, that the criminal law should not be used unless there is a reasonable basis for finding that the prohibition is directed to harmful conduct. But the Ontario court agreed with the approach taken by the BC court in *Malmo-Levine* that Parliament was entitled to criminalize the possession of marijuana as long as there was a "reasonable basis for concluding that harm will result." The Court also accepted the argument that international conventions "obligate" Canada to prohibit marijuana except in narrow circumstances (such as the medical use sought in the *Parker* case).

– Richard Elliott

Further resources and information on medical marijuana and drug policy in general, see: Canadian Foundation for Drug Policy (www.cfdp.ca); the Canadian Centre on Substance Abuse (www.ccsa.org); the Canadian Harm Reduction Network (www.canadianharmreduction.com); the Marijuana Policy Project (www.mpp.org); Drug Reform Coordination Network (www.drcnet.org); the Lindesmith Centre – Drug Policy Foundation (www.lindesmith.org); the International Harm Reduction Network (www.global-voice.org). See also the Canadian HIV/AIDS Legal Network's report *Injection Drug Use and HIV/AIDS: Legal and Ethical Issues*, the volume of three *Background Papers* accompanying the report (providing an analysis from the perspectives of law, policy, and ethics), and a series of info sheets summarizing these reports (all available at http://www.aidslaw.ca/Maincontent/issues/druglaws.htm).

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[1] C Cunnington. PWA caregivers arrested. *Xtra!* 18 May 2000: 20.

[2] *Wakeford* v *Canada*, [2000] OJ No 1479 (SCJ) (QL).

[3]. Health Canada. News Release: Health Canada to establish source of research-grade marijuana. 5 May 2000 (www.hc-sc.gc.ca).

[4] *Wakeford* v *Canada*, supra, note 2 at paras 45-47.

[5] B Rogers. AIDS victim wants to appeal ruling Ottawa can't be forced to give him medicinal pot. *The Lawyers Weekly* 2 June 2000: 22.

[6] Ibid; T Tyler. First medical marijuana crop harvested. *Toronto Star* 30 September 2000: A8.

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

[8] *R* v *Parker* (2000), 49 OR (3d) 481 (CA), (2000) 146 CCC (3d) 193, [2000] OJ No 2787 (QL).

[9] Ibid at OR 513 (para 92).

[10] *R* v *Morgentaler*, [1988] 1 SCR 30.

[11] *Parker*, supra, note 8 at OR 514 (para 97) and OR 518 (para 107).

[12] Ibid at OR 514 (note 6).

[13] Ibid at OR 524-25 (para 126).

[14] Ibid at OR 526 (para 129).

[15] Ibid at OR 53-32 (para 147).

[16] *Canada (Attorney-General)* v *Ontario (Attorney-General)*, [1937] AC 326 (PC).

[17] (1976), 993 UNTS 3.

[18] *Parker*, supra, note 8 at OR 528 (paras 137-138).

[19] Ibid at OR 542-545 (paras 178-179, 184-185, 188).

[20] Ibid at OR 547 (para 194). The Court pointed to legislation in California and Hawaii as examples of how to reconcile these objectives with the needs of patients requiring access to marijuana. Those two statutes are appended to the *Parker* decision of the Ontario Court of Appeal.

[21] Pot ruling won't be appealed: Ottawa will not fight Ontario court striking down marijuana law. *Toronto Star* 30 September 2000: A8.

[22] L Chwialkowska. Ottawa will grow, supply pot for use by the sick: Rock. *National Post* 25 September 2000.

[23] D Stonehouse. Man with HIV wants right to import drug. *Ottawa Citizen* 16 September 2000.

[24] *R* v *Malmo-Levine*, 2000 BCCA 335, 145 CCC (3d) 225, [2000] BCJ No 1095 (QL).

[25] Ibid at paras 100-101.

[26] Ibid at para 158.

[27] [2000] SCCA No 361 (QL); SCC Bulletin 2000, p 1434.

[28] *R* v *Clay* (2000), 49 OR (3d) 577, 146 CCC (3d) 276, [2000] OJ No 2788 (CA) (QL) .

[29] Ibid at para 10.

[30] Ibid at para 13.

CANADIAN NEWS

Panel Recommends Significant Changes to Federal Law against Discrimination

In a report released on 23 June 2000, the Review Panel tasked by the federal Minister of Justice with reviewing the *Canadian Human Rights Act* made some welcome recommendations for improving the Act and the way the Canadian Human Rights Commission functions. Three are of particular significance: the recommendation that "social condition" be added to the prohibited grounds for discrimination listed in the Act; the recommendation that the Canadian Human Rights Commission should have, under its governing legislation, the duty to monitor and report to Parliament and the UN Human Rights Committee on the federal government's compliance with international human rights treaties regarding economic, social, and cultural rights; and the recommendation that "gender identity" should be expressly added to the Act as a prohibited ground of discrimination.

Prohibit Discrimination Based on "Social Condition"

The Review Panel recommended that "social condition" be added to the prohibited grounds for discrimination listed in the Act. It noted that Québec is the only province to include in its anti-discrimination legislation a prohibition against discrimination based on social condition. Some of the other jurisdictions do offer more limited protections, such as prohibiting discrimination based on "social origin" (Newfoundland), "lawful source of income" (Nova Scotia, Alberta, British Columbia, Manitoba, Prince Edward Island, and Yukon), or "receipt of public assistance" (Ontario, Saskatchewan). However, often the protection provided is limited – for example, to prohibiting discrimination in relation to housing on the basis of a person's receipt of welfare. The Panel reported that

> During our consultations, we heard more about poverty than any other single issue.... Our research papers and the submissions we received showed ample evidence of widespread discrimination based on characteristics related to social condition, such as poverty, low education, homelessness and illiteracy.... We believe it is essential to protect the most destitute in Canadian society against discrimination.... The best way to combat poverty and disadvantage remains private and public activity aimed at improving the conditions of the socially and economically disadvantaged.[1]

To leave the law as it stands would fail to acknowledge the situation of transgendered individuals and allow the issues to remain invisible.

The Panel therefore recommended adopting a definition of "social condition" like that in Québec's Charter, which courts and tribunal have clarified as follows:

> The definition of "social condition" contains an *objective* component. A person's standing in society is often determined by his or her occupation, income or education level, or family background. It also has a *subjective* component, associated with perceptions that are drawn from these various objective points of reference. A plaintiff need not prove that all of these factors influenced the decision to exclude. It will, however, be necessary to show that, as a result of one or more of these factors, the plaintiff can be regarded as part of a socially identifiable group

> and that it is in this context that the discrimination occurred.[2]

The goal is to eliminate discrimination based on stereotypes about the poor, who are often seen and treated as a distinct group. The Panel therefore cautioned that:

> There have been cases in Québec where the ground was held to prohibit discrimination against individuals with above average incomes or prestigious occupations. In our view, this is not appropriate for two reason. First, we feel that the protection here is aimed at those who suffer disadvantage because of their social condition. Second, we do not want to propose a ground that is too broad.... The Act should condition a definition [that provides] that social condition includes characteristics relating to social or economic disadvantage.[3]

The Panel was also clear that the private sector should be bound by this prohibition against discrimination, and that as the Supreme Court of Canada has already ruled, courts and tribunals considering a claim of discrimination based on social condition should not extend to the private sector the kind of deference given to governments making broad decisions based on competing claims for public resources.

Monitor Respect for Economic, Social, and Cultural Rights

The Panel also recommended that the Canadian Human Rights Commission should have, under its governing legislation, the duty to monitor and report to Parliament and the UN Human Rights Committee on the federal government's compliance with international human rights treaties regarding economic, social, and cultural rights. But the Panel stopped short of recommending that social and economic rights be added as enforceable rights under the Act at this time. Nonetheless, if such a recommendation were implemented, it would offer an additional opportunity to pressure Canada to live up to its obligations to protect such rights as the right to health.

Prohibit Discrimination Based on "Gender Identity"

Finally, the Panel recommended that "gender identity" should be expressly added to the Act as a prohibited ground of discrimination. The Panel noted that this follows a recommendation similar to that of the British Columbia government to amend that province's human rights code, as well as emerging tribunal decisions (see elsewhere in this issue). Although the Panel noted that the practice of some commissions so far has been to accept complaints of discrimination against transgendered people on the basis of "sex" and or "disability," in the Panel's view:

> to leave the law as it stands would fail to acknowledge the situation of transgendered individuals and allow the issues to remain invisible. While these issues are clearly related to sex, this ground may not cover all those encountered in the transgendered experience, especially in the decision to undergo a sex change and its implementation. To say transsexualism is a disability seems to make it a medical matter rather than a matter of life experienced in the opposite gender.[4]

– Richard Elliott

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[1] Canadian Human Rights Act Review Panel. *Promoting Equality: A New Vision*, 23 June 2000, at 106, 107, 110 (www.chrareview.org).

[2] *Commission des droits de la personne du Québec* v *Gauthier et al* (1993), TDPQ Montréal, No 500-53-000024-925, available online (http://www2.lexum.umontreal.ca/qctdp/fr/decisions/1993/GAUTHIER.ROU.html).

[3] Supra, note 1 at 111.

[4] Ibid at 105.

Victory for Transgendered People in Gaining Protection against Discrimination

On 7 June 2000, the BC Supreme Court rejected an attempt by the Vancouver Rape Relief Society to prevent the provincial human rights commission from hearing a complaint that it had discriminated against a transgendered woman. Kimberly Nixon filed a complaint with the BC Human Rights Commission in August 1995, alleging that the Vancouver Rape Relief Society had refused to allow her to work as a volunteer counselor because she had not been biologically female at birth.

The Society is an organization assisting women in crisis because of male violence. In 1977, it received approval from the BC Human Rights Commission for its "women-only" policy for employees and volunteers. The Rape Relief Society defends its decision to prevent transgendered women from volunteering as counselors on the basis that only a woman who has grown up with experience as a girl and a woman will have "the attendant insights into the relationship between male violence and women's inequality in order to assist women in crisis because of male violence." The Society also argued that some of its clients requiring counselling may not be comfortable with a counselor whom they may believe is not or may not be a woman.

On several other occasions, the BC Human Rights Tribunal had ruled that discrimination against a person because they are transsexual is prohibited, as has the Québec Human Rights Tribunal. However, before Nixon's case could be heard, the Society brought a petition before the BC Supreme Court, seeking an order preventing the Human Rights Tribunal from hearing Nixon's complaint.

Among other things, the Society argued that the tribunal had no jurisdiction to hear her complaint because, while discrimination on the basis of "sex" is prohibited by BC's *Human Rights Code*, interpreting this to include "transsexualism" or "gender identity" would be to go beyond what was intended by the BC legislature. It argued that the legislature

> intended to limit discrimination based upon "sex" to social and economic issues of discrimination arising between men and women which were the product of a male dominated society.

> This appears to be the first Canadian *court* case clearly recognizing that transgendered people are protected against discrimination under human rights statutes prohibiting "sex" discrimination, marking a significant step for transgendered people in Canada.

The Society acknowledged that transgendered people could also be oppressed and subjected to discrimination, but that the legislature had deliberately refrained from extending protection to them, and it was not open to the Human Rights Commission or Tribunal to do so by interpreting "sex" in a manner never intended by the legislature.

But the Court rejected this argument. First, it noted that the BC legislature had also passed the *Vital Statistics Act*, one section of which says that the government must change the sex designation on the birth certificate of any person who has gender reassignment surgery. This showed that

> the legislature intended that post operative transsexuals such as Ms. Nixon would be entitled to the same legal status as other members of their post operative sex. It is therefore my opinion that in Ms. Nixon's case the discriminatory conduct which she now alleges against the petitioner may fairly be characterized as an allegation of discrimination against her as a woman, a complaint over which the Commission and the Tribunal both have jurisdiction just as they have jurisdiction over any complaint of discrimination by any woman based upon appearance.

Second, the Court added that if it was wrong about the significance of the *Vital Statistics Act*, it was still of the view that the Code's prohibition on "sex" discrimination includes discrimination based on transsexualism or gender identity. The Court ruled:

> I do not accept the petitioner's premise that by prohibiting discrimination on the basis of sex, the legislature intended to redress only male/female social, economic and political issues. I also do not accept that its failure to amend the…Code to specifically include gender identity or transsexualism as enumerated grounds of discrimination should be taken to mean that the legislature did not intend that human rights protection on the ground of sex did not extend to transsexuals. ... In my opinion to limit discrimination on the basis of sex to male/female issues places a far too narrow limit upon the purpose and intent of the…Code. While Canadian courts have indeed looked to issues which concerned the social, economic and political disadvantage of women in assessing what conduct may amount to discrimination on the basis of sex, many cases also reflect the less specific principle that human rights legislation is intended to preclude and rectify the wrongful oppression of the weak by the strong and the disadvantaged by the advantaged in society.

The Court therefore dismissed the Rape Relief Society's petition, and the BC Human Rights Tribunal was free to hear and decide her case.

As noted, there had previously been a handful of decisions by human rights tribunals. But this appears to be the first Canadian *court* case clearly recognizing that transgendered people are protected against discrimination under human rights statutes prohibiting "sex" discrimination, marking a significant step for transgendered people in Canada.

– Richard Elliott

[1] *Vancouver Rape Relief Society* v *BC Human Rights Commission*, 2000 BCSC 889, [2000] BCJ No 1143 (QL).

[2] *Ferris* v *OTEU Local 15*, [1999] BCHRTD No 55 (QL); *Mamela* v *Vancouver Lesbian Connection*, [1999] BCHRTD No 51 (QL); *Sheridan* v *Sanctuary Investments Ltd (cob BJ's Lounge)*, [1999] BCHRTD No 43 (QL).

[3] *CDP* v *Maison des jeunes*, [1998] JTDPQ No 31 (QL).

[4] *Vancouver Rape Relief Society*, *supra*, note 1 at para 51.

[5] Ibid at paras 41-42.

[6] Ibid at paras 52, 56.

Federal Law Recognizes Same-Sex "Common-Law Partners"

On 31 July 2000, legislation enacted by Parliament to amend 68 different federal statutes so as to recognize gay and lesbian common-law couples as having the same rights and obligations as heterosexual common-law couples came into force.

The *Modernization of Benefits and Obligations Act*[1] amends statutes ranging from the *Agricultural Marketing Programs Act* to the *War Veterans Allowance Act*. Of particular interest are amendments in such areas as the Canada Pension Plan and old-age security benefits, the *Criminal Code*, unemployment insurance, compensation for public servants, and income tax.

The basic definition incorporated into the various statutes is:

> "common-law partner", in relation to an individual, means a person who is cohabiting with the individual in a conjugal relationship, having so cohabited for a period of at least one year.

As a result of opposition by conservative Members of Parliament, and over the objections of gay and lesbian groups and supporters, the government amended the legislation before it was enacted to expressly preclude the argument that the statute affected the definition of marriage. The Act therefore states:

> For greater certainty, the amendments made by this Act do not affect the meaning of the word "marriage", that is, the lawful union of one man and one woman to the exclusion of all others.

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[1] SC 2000, c 12, s 1.1, in force 31 July 2000 (SI/2000-76).

Ontario Adopts Policy on Discrimination Based on Gender Identity

On 30 March 2000, as a follow-up to a discussion/consultation paper on gender identity,[1] the Ontario Human Rights Commission approved a "Policy on Discrimination and Harassment because of Gender Identity."[2]

The policy identifies that "gender identity" is not a prohibited ground of discrimination explicitly listed in the Ontario *Human Rights Code*. However, it says that what does exist in the statute "can support a progressive understanding of the ground of 'sex' to include 'gender identity' and protect individuals who are subject to discrimination or harassment because of gender identity."

> There are, arguably, few groups in our society today who are as disadvantaged and disenfranchised as transgenderists and transsexuals. Fear and hatred of transgenderists and transsexuals combined with hostility toward their very existence are fundamental human rights issues.[3]

The policy applies to the workplace; services, goods, and facilities; accommodation; contracts; and membership in vocational associations and trade unions. It includes a glossary of terms such as transsexual, transgenderist, intersexed people, etc, and provides a definition of gender identity as

> linked to an individual's intrinsic sense of self and, particularly the sense of being male or female. Gender identity may or may not conform to a person's birth assigned sex. The personal characteristics that are associated with gender identity include self-image, physical and biological appearance, expression, behaviour and conduct, as they relate to gender.

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[1] Ontario Human Rights Commission. *Toward a Commission Policy on Gender Identity*, October 1999 (www.ohrc.on.ca).

[2] Ontario Human Rights Commission. Policy on Discrimination and Harassment because of Gender Identity. Approved 30 March 2000 (www.ohrc.on.ca).

[3] Ibid.

Hiding Children to Avoid ARV Treatment

In the last issue, we reported on the case of a Montréal woman with HIV who lost custody of her two HIV-positive children after refusing to consent to their treatment with antiretroviral therapy.[1]

In January 2000, the court ordered that the two children be placed in the physical custody of their mother's parents (with contact with their mother guaranteed), and that the authority to make treatment decisions be placed with child-protection authorities.[2] The court's decision was to be revisited after six months, after a medical assessment of the course of treatment and the possibility of the mother reevaluating her position. The next hearing was therefore scheduled for June 2000. However, on 20 May 2000, national media reported that the mother had taken the two boys into hiding after a visit at the grandparents' home.[3]

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[1] R Elliott. Medical treatment of children with HIV/AIDS. *Canadian HIV/AIDS Policy & Law Newsletter* 2000; 5(2/3): 5-7.

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

[3] HIV-positive mom takes children into hiding to avoid drug treatment. *CP Wire*, 20 May 2000; Une mère cache ses enfants; Elle veut les soustraire à des traitements contre le sida. *Le Soleil*, 21 May 2000: A11; HIV-infected mom and sons in hiding. *Calgary Sun*, 20 May 2000: 23.

HIV/AIDS IN PRISONS

Needle Exchange Programs in Prisons in Spain

On 11 July 2000, at the XIII International AIDS Conference in Durban, yet another country – Spain – presented evidence that needle exchange programs in prisons work.[1] We reproduce here the text of the presentation entitled "Needle Exchange Program at the Bilbao Prison, Spain: Two Years of Experience (1997-1999)."[2]

Objectives

In 1995, the Spanish government and the government of the Basque Country made a decision to implement a pilot project involving the exchange of needles at the Bilbao prison. The aim was to determine whether a program of this type could be successfully carried out at a prison in our country, and to resolve any difficulties that may arise.

Methods

The first needle exchange program (NEP) in Spain – a community-based program – was set up in Bilbao in 1987 by a non-governmental organization (NGO). In 1992, NEPs were started up in pharmacies. Three years later, in 1995, drug users in the Basque Country used nearly half a million needles, 29 percent of which were obtained through pharmacies or NGO-run needle exchange programs. Evaluation of these programs has shown them to be effective in changing the behaviour of drug users.

The Bilbao prison is an all-male penal institution with 250 prisoners, with more convicts than remand prisoners. There is a high prisoner turnover. In 1995, other programs targeting drug users were already underway: methadone and abstinence programs, distribution of bleach and condoms, etc. Some of them were run by an external NGO.

Of the 180 prisoners admitted that year, 48 percent were regular drug users, of whom 75 percent were intravenous drug users and 46 percent of the latter were seropositive.

In January 1996, a NEP Planning Committee was created, and a year and a half later it made a number of recommendations:

- the prison NEP should be run by the staff of the NGO that was working at the prison, rather than use needle exchange machines;
- the prison rule preventing the possession of needles should be modified; and
- an external evaluation of the program should be undertaken.

There were four reasons behind preferring a NEP run by staff of an NGO over installing needle exchange machines:

- the possibility of providing health education;
- the positive experience with NGOs and community pharmacies;
- the negative experience with needle dispensing machines in Spain; and
- the fact that there was already an NGO working inside the prison.

The NEP got underway in July 1997, after education and information activities for correctional officers and inmates were undertaken. The slogan for one of these activities might be translated as: *One way of getting out of jail is needle exchange.*

The two places where needles could be exchanged were discreet and the service was available five hours a day.

Used needles were always returned in hard plastic containers and prisoners were given an "anti-AIDS" kit. These kits, like the ones that have been dispensed to drug users at pharmacies in Spain since 1989, contain a needle, an ampoule of distilled water, an alcohol-soaked disinfectant wipe, a hard container for carrying the needle, and a condom.

Results

Two and a half years later the program continues to run normally, with no incidents reported. During this time 16,500 needles have been exchanged, and over 600 drug users have been attended to.

Since the beginning of this experience, the needle exchange program has been extended to five additional prisons and it has been proposed that it be implemented in all prisons nationwide.

A Monitoring Committee has been in charge of ongoing program evaluation. Inmates and correctional officers participated in an evaluation process at zero, three, and six months. The process could not be repeated at 12 months, since most of the prisoners who had used the program when it started were no longer in the prison. NGO staff and correctional officer evaluations were carried out at 22 months.

Prisoners reported during the evaluation that:

- they had no program-related problems with the correctional officers;
- they saw the personalized aspect of the program (in contrast to a needle dispensing machine) and the fact that it was run by an NGO as positive;
- drug consumption had not increased; and
- their risk behaviours had been reduced.

Correctional officers indicated that:

- they had not experienced any conflicts due to the program;
- prisoners had at no time used needles as weapons;
- they considered the program positive; but
- they would rather see the program run by prison personnel than by external NGO staff.

The evaluation of the performing team (the NGO) and of the health personnel showed that:

- participation in the program did not influence prison benefits (eg, weekend leave privileges for good behaviour). In other words, inmates were not "punished" for exchanging needles;
- the program assists in the task of health education and encourages drug users to be channeled toward other types of programs (drug-free, methadone, etc); and
- a certain amount of flexibility must be allowed, instead of insisting that sterile needles can only be obtained in exchange for used ones.

This last point was intensely debated in the Monitoring Committee, with the NGO focusing on HIV risk reduction and the correctional officers on security. The NGO promoted giving out needles without a one-on-one exchange, whereas the correctional officers insisted that used needles be returned in exchange for new ones. A consensus involving an 80 percent needle-return rate was eventually reached. In our prison, we reached a return rate of 82 percent.

Since the beginning of this experience, the needle exchange program has been extended to five additional prisons and it has been proposed that it be implemented in all prisons nationwide. In some prisons this program has been overseen by the health-care personnel of the prison itself – doctors and nurses – who carry out these tasks as part of their regular health-care activities. It is still too early to evaluate whether prison NEPs undertaken by health-care staff are more or less successful than those run by NGOs, but they could help bring about the normalization of prison NEPs and make them a regular part of the job of the health-care team.

Conclusions

The conclusions of this experience can be summed up as follows:

- the program can be carried out in prisons in our country;
- it does not generate conflict;
- needles were not used as weapons at any time;
- the program does not give rise to greater drug use;
- it encourages drug users to turn to other kinds of drug programs; and
- the program should be carried out with some flexibility.

– C Menoyo, D Zulaica, F Parras

Dr Zulaica, who presented this paper in Durban on 11 July 2000, can be reached at dzulaica@apge.osakidetza.net.

Abstracts of the other presentations on HIV/AIDS and prison issues at the Durban 2000 conference can be viewed using an easy-to-use, simple search engine for the conference at http://sis.nlm.nih.gov/hiv.cfm. A search for the term "prison" or "inmate" will turn up dozens of abstracts.

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[1] See also the many other articles on this subject in previous issues of this publication, in particular Stöver H. Evaluation of needle exchange pilot projects shows positive results. *Canadian HIV/AIDS Policy & Law Newsletter* 2000; 5(2/3): 60-64.

[2] Menoyo C, Zulaica D, Parras F et al. Needle exchange programme (NEP) in the prison of Bilbao, 2 years experience: 1997-1999. XIII International AIDS Conference, Durban, 9-14 July 2000 (abstract TuOrD322).

CRIMINAL JUSTICE

Criminal Law and HIV/AIDS: Update IV

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. 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 February 2000, an HIV-positive sex worker in St John's was charged with "common nuisance" after it was alleged that he had engaged in prostitution. Media reports did not specify whether there was any additional evidence as to whether the accused had engaged in sexual activity that posed any significant risk of transmitting the virus. At the time of writing, the matter had not yet gone to trial.[1]

In August 2000, Raymond Mercer, one of the first people in Canada to be criminally charged for transmitting HIV, was denied parole for the third time in a row. He was sentenced in 1993 to over 11 years in prison, and has been eligible for parole since 1996. The parole board was reported as concluding that he still "poses a threat to the public" and shows "little remorse" for having infected two women. His full sentence will have been served by 2003.[2]

Manitoba

In June 2000, local media reported that an HIV-positive Winnipeg man failed to appear in court on charges of aggravated assault for allegedly having unprotected sex with his girlfriend without disclosing his status.[3]

Québec

On 16 June 2000, Éric Maisonneuve pleaded guilty to one count of aggravated sexual assault after being charged for having not disclosed his HIV-positive status to a woman with whom he had sex shortly after meeting her at a health club. His counsel argued that she should have known better than to have unprotected sex with a man she had just met, but the judge rejected this argument, saying Maisonneuve still had a duty to disclose. The complainant said they had sex several times before he informed her of his status, but Maisonneuve claimed it was only once, that she became aware of his status within the first week and then continued to engage in unsafe sex with him. The woman was not infected, but was so upset upon finding out his status that she attempted suicide. Maisonneuve had a previous criminal record. He was sentenced on 20 October 2000 to three years in jail.[4]

On 19 September 2000, a man with HIV and hepatitis C was sentenced to 16 months in prison by a trial court in Québec City after pleading guilty to aggravated assault for having stuck another person with a contaminated needle. Hugo Davanzo was drunk and injecting cocaine behind a residence when interrupted by an 88-year-old man who lives in the building and who grabbed his arm to remove him from the property. Davanzo stuck the man in the hand with the needle and said that he "had AIDS." The man later confronted Davanzo with a baseball bat, keeping him on-site until police arrived. Three months following the incident, the man had not shown any indication of having been infected.[5]

Jean-Roch Lefrançois, a 28-year-old HIV-positive prisoner, stood trial in September 2000 on charges of attempted murder and aggravated assault. The charges date back to an incident in December 1997, when he spat blood at two prison guards at a detention centre in Québec City during an altercation. One of the guards was struck by the spittle on her shoulder. At a pre-hearing conference on 8 August 2000, he pleaded guilty to two counts of uttering threats. Following the trial, he was convicted on the two counts of attempted murder and two counts of assault causing bodily harm.[6]

In October 2000, media reported that a 59-year-old man was detained by police in Trois-Rivières after he called police in distress. Upon arriving at a downtown café, police found him distraught, screaming at them that he had HIV and threatening to bite them. Police wearing netting to protect against possible spitting subdued him and he was detained.[7] On 24 October 2000, he was sentenced to six months in jail.[8]

New Brunswick

In October 2000, a Fredericton couple were charged with "spreading false news" that they knew was false and "was likely to cause injury or mischief to a public interest" (under section 181 of the *Criminal Code*). The prosecution alleges that the husband had an extramarital affair, and that later he and his wife (a municipal councillor) told the woman with whom he had the affair that he was HIV-positive. At the time of writing, the matter was still before the courts.[9]

United States

The state of New Jersey has now seen its first case of an HIV-positive person charged under its statute, enacted in 1997, criminalizing sexual activity by a person with HIV. A 40-year-old man who was a member of an AIDS awareness organization at a community college was charged in June 2000 with first-degree aggravated sexual assault, assault endangering the welfare of a child, sexual assault, and committing acts of sexual penetration while knowingly infected with HIV. Prosecutors alleged he had engaged in sex with a child under the age of 13. The statute makes it a crime for a person who knows they are HIV-positive to withhold that information from a sexual partner.[10]

China

In October 2000, the state media reported that the Ministry of Health was drafting regulations on the management of HIV prevention. Some unspecified "legal experts" were reported to be pushing for an amendment to the current criminal code to punish people who intentionally infect others with HIV as being guilty of "willful and malicious injury." Currently, Chinese law provides that individuals infected with STDs who participate in illegal sexual activities (such as prostitution) can be sentenced to five years in jail, but HIV is not included as one of the STDs under the legislation.[11] (The Marriage Law enacted in 1980 states that a marriage is not allowed to proceed in China if either partner suffers a disease that renders the person "unfit" for marriage. In May 1999, the media reported that HIV/AIDS is considered such a disease because it may be transmitted via pregnancy.[12] In 1999, China's Sichuan province ordered compulsory HIV blood tests during premarital physical examinations as an HIV prevention measure.[13])

Botswana

In August 2000, the BBC World Service reported that the Botswana Health Minister had informed UN officials that her country would be introducing a new law compelling people who are HIV-positive to disclose their status to their sexual partners. A UNAIDS official told the media that such legislation could prove unworkable, and discourage people from seeking testing and treatment; counseling and approaches that encourage voluntary disclosure to partners were likely to be more effective in preventing the spread of the virus.[14]

Swaziland

In July 2000, legislation was introduced in the Swazi parliament that would impose "mandatory sterilisation" on people with HIV. The members of parliament sponsoring the bill accused people infected with the virus of "intentionally" transmitting HIV to sexual partners. The Ministry of Health opposed the proposal, saying it is medically and ethically unsound and would not curb the spread of the disease, and AIDS and human rights organizations condemned it as a violation of human rights. At the same time, a Ministry of Education official told reporters that schoolgirls are responsible for spreading HIV because they entice teachers with their short skirts, and that girls 10 years and older will be required to wear skirts that are at least knee-length or face expulsion.[15]

In August, a high-profile government official proposed setting up camps to isolate people with HIV/AIDS; the suggestion was condemned by health-care workers.[16]

– Richard Elliott

For more information, Richard Elliott can be reached at relliott@aidslaw.ca. For a recent overview of criminal law and HIV in the United States, see the August 2000 issue of *POZ* magazine, containing a review of 101 cases (by L Whitehorn) and an article on a high-profile New York case entitled “The Miseducation of Nushawn Williams” (by L Kennedy). A state-by-state listing of US laws on this topic is available on the website of the Lambda Legal Defense and Education Fund (www.lambdalegal.org).

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[1] HIV-related charge for alleged sex worker. *The Telegram* (St John’s), 18 April 2000: 1; Confidential communication, 8 November 2000.

[2] AIDS spreader denied parole. *Gazette* (Montréal), 24 August 2000: A12; Nfld man who knowingly spread AIDS virus denied parole for third time. *CP Wire*, 23 August 2000.

[3] B Holliday. Suspects still at large: HIV positive man allegedly had unprotected sex. *Winnipeg Sun*, 26 June 2000: 4.

[4] *R* v *Maisonneuve*, Court File No 550-01-003220-995, Québec Provincial Court (Hull), 20 October 2000, Lapointe J; D Quan. Man with HIV guilty of assault: Gatineau man failed to disclose status before having sex. *Ottawa Citizen*, 21 October 2000: C4; JM Gauthier. Peine exemplaire de trois ans de pénitencier. *Le Droit*, Ottawa-Hull, 21 October 2000: 6; communication from B Guillot-Hurtubise, 23 October 2000.

[5] G Fontaine. 6 mois pour avoir tenté de transmettre le sida. *Journal de Québec*, 20 September 2000: 28; Homme piqué à la main avec une seringue: 16 mois au cocaïnomane séropositif. *Le Soleil*, 20 September 2000: A5.

[6] Court File No 200-01-033376-983, Court of Québec, Québec City; Procès de Jean-Rock Lefrançois. *Journal de Québec*, 8 September 2000: 20; R Hénault. Accusé de tentative de meurtre par…crachat. *Le Soleil*, 8 September 2000: A6; R Hénault. Accusé d’avoir craché du sang contaminé. *Le Soleil*, 20 September 2000: A5; communication with B Guillot-Hurtubise, 23 October 2000.

[7] La police utilise un “filet anti-crachat” contre un individu se disant sidéen. *Nouvelles Télé-Radio*, 24 October 2000.

[8] Prison-crachat. *Les Faits Divers*, 25 October 2000.

[9] New Brunswick: City councillor charged. *National Post*, 4 October 2000: A9.

[10] Sex-assault suspect charged under HIV law. *Associated Press*, 29 June 2000.

[11] Turning to the law in war on HIV and AIDS. *China Daily*, 6 October 2000 (www.chinadaily.com); China health officials debate AIDS prevention laws. *Reuters*, 6 October 2000 (www.reuters.com).

[12] Regulation protects HIV carriers and AIDS patients. *China Daily*, 21 May 1999 (www.chinadaily.com).

[13] Measure to curb spread of AIDS. *China Daily*, 27 July 1999 (www.chinadaily.com).

[14] Botswana plans HIV disclosure law. *BBC World Service*, 12 August 2000.

[15] K Ahmad. Swaziland debates sterilisation of HIV patients. *Lancet* 2000; 356: 321; Swaziland to mull sterilizing HIV-positive. *Reuters NewMedia*, 20 July 2000; A La Guardia. AIDS measures will force hemlines to the knees: Schoolgirl miniskirt ban: Move comes as Swaziland debates sterilization of HIV carriers. *National Post*, 19 July 2000: A2.

[16] Isolation camps proposed for Swazi HIV victims. *Reuters*, 16 August 2000 (www.reuters.com).

PATENTS AND PRICES

Following some articles on rulings by the World Trade Organization that appeared in the last issue, we are now establishing a new, regular section on "Patents and Prices." This section will cover developments in the area of Canadian and international patent laws and the impact of laws on drug prices.

At the XIII International AIDS Conference in Durban in July 2000, one of the key issues receiving long-overdue attention was that of access in developing countries to desperately needed drugs and other medical care. The Conference highlighted the role of laws on intellectual property and of international trade agreements in creating barriers to global health by maintaining drug prices beyond the reach of most developing countries and most of the world's people with HIV/AIDS and other serious illnesses.

The Conference also signaled the need for a global movement for access to treatment. Through the hard work of many organizations and activists, these issues of access to essential medicines are garnering public attention around the world. The Canadian HIV/AIDS Legal Network will work to ensure that the momentum generated at the Durban conference is not lost, and will contribute to treatment activism in Canada and internationally on the issue of drug pricing and access to treatment.

The AIDS movement has an inspiring history, born of necessity, of activists and ordinary people educating ourselves and our communities about complex medical matters – from the basics of virology to the design of clinical trials to the process for approving new drug treatments. Informed and empowered, "treatment literate" AIDS activists rejected the passive position of merely relying upon government authorities or medical experts, and demanded a voice in shaping laws, policies, and practices.

The increasing globalization of the corporate agenda is another challenge. Facing it requires that we become "trade literate," able to articulate a critique of international and domestic laws that place profits ahead of people and their human rights to health and life. The intricacies of intellectual property law can be daunting until the language and concepts of the law are understood. We hope that this new section will help, and we will try to keep articles simple yet accurate.

Canada Loses Appeal of WTO Panel Ruling on Minimum Patent Terms

In the last issue, we reported on a ruling of a Panel of the World Trade Organization (WTO) that Canada was in breach of the international Agreement on Trade-Related Aspects of Intellectual Property Rights (the TRIPS Agreement). The Panel found that Canada's *Patent Act* does not provide the minimum patent terms required by the trade agreement.[1] Canada appealed that decision, but on 18 September 2000 the WTO Appellate Body upheld the Panel ruling.[2]

This decision arose from a complaint by the United States that Canada's legislation allows some patents to expire too quickly. It was reported that the US brought the complaint largely on behalf of pharmaceutical company Bristol-Myers Squibb, which is seeking to keep generic versions of one its cholesterol-lowering drugs off the market.[3]

The TRIPS Agreement[4] says that every country that is a WTO member must provide a minimum patent term of 20 years from the date of filing the application for a patent on an invention (Article 33). Canada's *Patent Act* does provide a patent term of 20 years from the date of filing – for any application filed *after* October 1989. But for any patent applications filed *before* October 1989, the term of the patent is *17 years from the date the patent is granted by the government*.[5] This is the result of changes to the law enacted by Parliament in 1987 and that took effect in October 1989, years before Canada signed the TRIPS Agreement. The US complained that, in its treatment of these pre-October 1989 patents, Canada was not meeting its TRIPS obligations.

The TRIPS Agreement came into force for Canada (and other developed countries) in January 1996. The Agreement contains a "non-retroactivity" clause, which says that TRIPS "does not give rise to obligations in respect of *acts* which occurred before the date" that the Agreement applies to the country (Article 70.1). Canada argued that this clause meant that patents granted before TRIPS came into effect are not covered by the treaty's requirement on minimum patent terms, because the patents lasting 17-years-from-grant all arose from the *act* of applying before October 1989. Since TRIPS did not come into effect in Canada until January 1996, the TRIPS obligations should not apply to these pre-October 1989 patents.

However, the US argued that the patent term of 20-years-from-filing should apply to all patents existing in Canada as of January 1996, when the TRIPS Agreement came into force – regardless of whether the application for the patent had been filed before or after October 1989. They pointed to another clause in TRIPS, which states that it "gives rise to obligations in respect of all *subject matter* existing at the date [that the Agreement applies] ... and which is protected [ie, patented] on the said date" (Article 70.2).

> The increasing globalization of the corporate agenda is another challenge. Facing it requires that we become "trade literate," able to articulate a critique of international and domestic laws that place profits ahead of people and their human rights to health and life.

Both the original Panel and the Appellate Body at the WTO agreed with the US and disagreed with Canada's interpretation about non-retroactivity. They ruled that, even if the *act* of applying for a patent had occurred before TRIPS came into effect in January 1996 (as is the case with all the pre-October 1989 applications), as long as the patent was in effect as of January 1996, then the invention protected by that patent is *subject matter* for which Canada has obligations under TRIPS. And one of the applicable obligations is the obligation to provide a minimum patent term of 20-years-from-filing.

In October 2000, it was reported that the Canadian government was considering "several possible responses to the decision, including non-compliance."[6] However, there is some speculation that the government simply wanted to avoid having the issue of amending the *Patent Act* become an issue in the impending federal election, and that it would move to comply afterward. On 12 October 2000, the WTO Dispute Settlement Body adopted the rulings of its Panel and Appellate Body, and the WTO Secretariat reported that Canada had said it would inform the DSB about implementation at the next meeting on 23 October 2000.[7] As of mid-November 2000, Canada was still in negotiations with the United States over the time frame for bringing Canadian legislation into compliance with the WTO's ruling. It is anticipated that amendments to the *Patent Act* will be proposed, and consultations regarding the proposed amendments will be undertaken.[8]

– Richard Elliott

The text of all international trade agreements administered by the WTO, and decisions of WTO Panels and the Appellate Body, are available on-line at the WTO website (www.wto.org).

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[1] Canada – Term of Patent Protection. Report of the Panel. WT/DS170/R, 5 May 2000. For summary, see: R Elliott. Panel Rules against Canada on Patent Terms for Pre-TRIPS Patents. *Canadian HIV/AIDS Policy & Law Newsletter* 2000; 5(2/3): 43.

[2] Canada – Term of Patent Protection. Report of the Appellate Body. WT/DS170/AB/R, 18 September 2000 (AB-2000-7). Available on-line via WTO website (www.wto.org).

[3] M MacKinnon. Canada might ignore WTO ruling on patents. *Globe and Mail*, 12 October 2000: B1, B12.

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

[5] RSC 1985, c P-4, ss 44-45.

[6] MacKinnon, supra, note 3, at B12.

[7] WTO News: 2000 News Items, 12 October 2000, available at: www.wto.org; Canada – Term of Patent Protection. Action by the Dispute Settlement Body, 25 October 2000.

[8] Communication of 23 November 2000 with C Dickson, A/Director, Information and Technology Trade Policy Division, Department of Foreign Affairs and International Trade.

Canada Ordered to Implement WTO Ruling against "Stockpiling" of Generic Drugs

In the last issue, we reported on a mixed World Trade Organization (WTO) ruling regarding Canada's patent laws, based on a complaint by the member states of the European Communities (joined by the United States).[1] In March 2000, a WTO Panel accepted the provision in Canada's *Patent Act* that creates an "early working exception" to patent rights – in other words, that allows a third party to use a patented invention during the term of patent protection, as long as the use is for obtaining regulatory approval of an equivalent product to be sold once the patent expires. This was an important victory from the perspective of allowing earlier access to generic versions of patented drugs.

However, in the same ruling, the WTO found that Canada was in breach of its obligations under the Agreement on Trade-Related Aspects of Intellectual Property (the TRIPS Agreement) because its *Patent Act* contained a "stockpiling exception" to patent rights. This provision allowed competitors to manufacture and stockpile patented pharmaceutical products during the six months before a patent expired. The stockpiled goods could not be sold until the patent had actually expired, so the market monopoly of the patent holder was still protected by Canada's legislation during the full term of the patent. But brand-name pharmaceutical manufacturers sought to delay competitors' entry into the market, even after patents had expired, by preventing stockpiling in advance.

Canada did not appeal the Panel's decision that the stockpiling exception violated the international trade agreement. Canada and the EC engaged in ongoing discussions regarding a reasonable period of time for implementing the Panel's rulings, but could reach no agreement on this point. In August 2000, an arbitrator ordered that Canada would have six months from the date the Panel's report was adopted by the WTO, meaning that Canada was required to comply by 7 October 2000.[2]

Also in August, Industry Canada released for consultation a proposal to repeal the *Patent Act* regulations implementing the "stockpiling" section of the Act, "thereby rendering the stockpiling exception of no force and effect."[3] In the explanatory statement accompanying the proposal, the government stated that

> The nature of the generic drug industry is such that effective market penetration for a generic product is chiefly dependent on its being listed as interchangeable with the brand name on provincial drug formularies. There is typically a lag time of several months between the date a generic drug manufacturer obtains Health Canada's regulatory approval for a drug and the date the drug becomes listed as an interchangeable product. Given that generic drug manufacturers have expressed confidence in their ability to generate industrial scale production levels in a very short space of time, the loss of the ability to stockpile patented drugs within the six months preceding patent expiry is not expected to have significant economic consequences on the generic drug industry. Nor is the loss of stockpiling expected to impact measurably upon Canadian consumers' access to generic drugs.[4]

The industry group, Canada's Research Based Pharmaceutical Companies, supported the proposal. The group representing manufacturers of generic drugs, the Canadian Drug Manufacturers Association (CDMA), disagreed with the government's assessment of the impact of the proposal on generic drug manufacturers and Canadian consumers: "The CDMA asserts that the loss of stockpiling will, in certain circumstances, lead to the delay onto market of generic drugs."[5]

The new regulation, repealing the "stockpiling" regulations and bringing Canada into compliance with the WTO ruling, came into force on 7 October (and was officially published in the Canada Gazette shortly thereafter).[6]

– Richard Elliott

Federal regulations and notices published in the Canada Gazette may be found online (http://canada.gc.ca/gazette), as may WTO texts and rulings (www.wto.org).

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[1] Canada – Patent Protection of Pharmaceutical Products. Report of the Panel. WT/DS114/R, 17 March 2000. For summary, see: R Elliott. Mixed WTO ruling on generic drug development. *Canadian HIV/AIDS Policy & Law Newsletter* 2000; 5(2/3): 38-42.

[2] Canada – Patent Protection of Pharmaceutical Products. Arbitration under Article 21.3(c) of the Understanding on Rules and Procedures Governing the Settlement of Disputes. WT/DS114/13.

[3] Notice of proposed Regulations Repealing the Manufacturing and Storage of Patented Medicines Regulations, Canada Gazette, Part I, Vol 134(32), 5 August 2000: 2491.

[4] Ibid at 2493-94.

[5] Regulatory Impact Analysis Statement. Canada Gazette, Part II, Vol 134(21), 11 October 2000: 2282-2287 at 2286.

[6] SOR/2000-373.

US Files WTO Complaints against Brazil over Requirement for "Local Working" of Patents

At the end of May 2000, the US (later joined by the European Communities) filed a complaint against Brazil at the World Trade Organization (WTO), alleging Brazil was in violation of its obligations under the Agreement on Trade-Related Aspects of Intellectual Property Rights (the TRIPS Agreement) and the 1994 General Agreement on Tariffs and Trade.[1] Brazilian legislation that came into force in 1997 establishes that, in order to enjoy exclusive patent rights in Brazil, the holder of a patent on an invention must satisfy a "local working" requirement.[2] In other words, the patent holder must "work" the patent in Brazil to enjoy full patent protection. If it fails to do this, the law says it shall be subject to the possibility of the government issuing a compulsory licence, allowing someone else to use the invention and pay a royalty fee to the patent holder.

According to the legislation, a patent holder fails to work the patent if (a) in the case of a patent on a *product*, it fails to manufacture the product (or engages in incomplete manufacture), or (b) in the case of a patent on a *process*, it fails to "make full use of the patented process." The law specifies that simply importing the patented product into Brazil is not sufficient to constitute "local working" – it must be manufactured in the country.

Such legislation is a way for countries to insist that, in exchange for granting exclusive patent rights (and hence a very profitable market monopoly in that country), the patent holder must manufacture the product, or use the process, in the country that is giving this valuable protection. However, the US and the EC object to any such requirement, as they want their companies to be able to enjoy full patent rights simply by exporting their products, manufactured elsewhere, to countries such as Brazil. Their objective is to preserve market monopolies without any obligation to "set up shop" in the countries whose markets generate profits. Hence the allegation that Brazil is violating international trade law by imposing the "local working" requirement in order to enjoy exclusive patent protection.

This is an important case for people with HIV/AIDS, particularly those in developing countries and countries with well-established generic drug industries. Brazil has generally been seen as one of the "success stories" as a developing country with a strong generic drugs industry that has made it affordable for it to provide antiretroviral drugs to many Brazilians with HIV. However, Brazil must bring its laws into compliance with the TRIPS Agreement, and it is anticipated that this will seriously undermine its domestic generic drug manufacturers. At the same time, if this US complaint succeeds, it would not only require that Brazil give exclusive patent rights to brand-name pharmaceutical companies, but would also prevent Brazil from insisting that these companies produce their drugs locally in order to avoid the Brazilian government issuing a compulsory licence allowing a Brazilian generic drug manufacturer to make an equivalent drug. The cost of drugs will likely increase, and those who ultimately pay the highest price will likely be Brazilians with HIV and other illnesses.

This is an important case for people with HIV/AIDS, particularly those in developing countries and countries with well-established generic drug industries.

– Richard Elliott

Decisions and documents in WTO proceedings are available online (www.wto.org). For a good (although very technical) legal analysis presenting arguments why the TRIPS Agreement and the North American Free Trade Agreement (NAFTA) leave signatory countries with broad discretion to legislate both mandatory local working conditions and compulsory licensing, see: M Halewood. Regulating patent holders: local working requirements and compulsory licences at international law. *Osgoode Hall Law Journal* 1997; 35(2): 243-287.

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[1] Brazil – Measures Affecting Patent Protection, complaint by the United States. WT/DS199, 8 June 2000.

[2] Law No. 9,279 of 14 May 1996; effective May 1997.

Canada Files WTO Complaint against EC

In December 1998, Canada filed a complaint alleging that the European Communities (EC) had adopted regulations that amounted to a scheme to extend patent terms, limited to pharmaceutical and agricultural chemical products.[1]

Canada alleges that the regulations discriminate on the basis of field of technology because they only apply to pharmaceutical and agricultural chemical products, and that this is not permitted under the TRIPS Agreement (Article 27.1)

The United States, Australia, and Switzerland have requested to join the proceeding. No further developments on this complaint have been reported since, and the WTO Secretariat continued to list the case as "pending" as of the time of writing.

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[1] European Communities – Patent Protection for Pharmaceutical and Agricultural Products, complaint by Canada. WT/DS153, 7 December 1998.

Complaint against Argentina over Protection of Patents and Test Data

On 30 May 2000, the same day as the complaint against Brazil, the US (again joined by the EC) filed a complaint against Argentina, alleging that its patent laws violate the TRIPS Agreement in a number of ways.[1]

In particular, the US complains that Argentina:
- fails to protect against unfair commercial use of undisclosed test data submitted as required to get market approval of pharmaceutical products;
- fails to provide adequate provisional measures (such as preliminary injunctions) to prevent infringement of patent rights from happening;
- denies certain exclusive rights for patents, such as the patent holder's exclusive right to import the patented product into the country;
- fails to provide certain safeguards for compulsory licences granted on the basis of inadequate working of a patent; and
- denies holders of transitional patents the opportunity to amend their pending patent applications in order to claim certain any enhanced patent protection provided by the TRIPS Agreement.

As with the complaint against Brazil, if the WTO rules that Argentina is in breach of the TRIPS Agreement, it would undermine the ability of the government to grant compulsory licences to a generic drug manufacturer on the basis that the company holding the Argentinian patent on a drug was failing to adequately "work" the patent in the country.

– Richard Elliott

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[1] Argentina – Certain Measures on the Protection of Patents and Test Data, complaint by the United States. WT/DS196, 8 June 2000.

INTERNATIONAL NEWS

Namibia: Refusal to Enlist HIV-Positive in Army Ruled Discriminatory

On 10 May 2000, in *N* v *Minister of Defence*,[1] the Labour Court in Windhoek delivered a mixed ruling on HIV-based discrimination in employment that could have significant positive implications for armies throughout the region of southern Africa.[2]

Acting Judge Harold Levy ruled that the Namibian Defence Force (NDF) was guilty of unfair discrimination for refusing to enlist a man solely on the basis of his HIV status. The Labour Act provides that employers may not discriminate in "in an unfair manner" on the grounds of disability.[3] However, he also ordered more expanded HIV-related testing as part of the medical examination of recruits, and permitted the exclusion of those applicants who failed to meet certain thresholds on CD4 and viral load tests.

Levy AJ cited the "Guidelines for the Implementation of a National Code on HIV/AIDS in Employment" issued by the Namibian government in April 1998, which state that: there should not be pre-employment HIV testing; employers should not discriminate against HIV-positive employees; and such employees "should work under normal conditions so long as they are fit to do so and if they can no longer do so, they should be offered alternative employment without prejudice to their benefits."

Under the Defence Act, recruits for the NDF are required to undergo a medical examination. However, Levy AJ found that an HIV test alone will not determine whether a recruit is fit to serve in the forces, noting that:

> If the military does not and will not do [testing for CD4 count and viral load] then the HIV test should also be abandoned. It will not the achieve the purpose for which medical examinations are held.

A thorough medical examination showed that, at the time of his application, N was capable of properly performing the usual duties and functions of an NDF member. The Court also noted that there were already military personnel in the NDF who are HIV-positive, and the NDF states that it is already complying with its obligations of non-discrimination and accommodation for HIV-positive personnel.

The Court ruled that HIV status is not a reasonable criterion on which to exclude a person from enlisting in the armed forces, and that an HIV test alone does not indicate the person's current state of fitness for the job. The Court accordingly held that the applicant's exclusion from the NDF solely on the basis of his HIV status is discriminatory. However, the Court did not rule out all pre-employment HIV testing for the NDF, but rather ordered that the NDF's medical examination required of all recruits shall include not only an HIV test, but also a CD4 count test and viral load test. It also ordered that no person shall be excluded from the NDF solely on the basis of their HIV status if they are otherwise fit and healthy, unless their CD4 count is below 200 and viral load exceeds 100,000.

This decision could help efforts to challenge similar policies in other countries. For example, the South African National Defence Force currently requires recruits to undergo HIV testing, and excludes those testing positive.[4]

– Richard Elliott

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[1] *N* v *Minister of Defence*, Case No. LC 24/98, Labour Court of Namibia, 10 May 2000 (per Levy AJ), on file with communication dated 10 May 2000 from M Figueira, Legal Assistance Centre, Windhoek.

[2] Ruling on HIV could affect regional armies. *Business Day*, 12 May 2000 (www.bday.co.za).

[3] Labour Act (Act 6, 1992), s 107.

[4] See: C Ngwena. HIV tests in the military? South Africa's double-standards approach. XIII International Conference on AIDS, Durban, July 2000, Abstract MoORE153.

Ecuador: Police Force HIV Testing on Detained Transvestites

In September 2000, Amnesty International reported that nine transvestite sex workers were detained by police in Guayaquil, Ecuador on 5 July 2000 for over three weeks on charges of crimes against decency and violating "public morals." AI believes they were detained solely because of their identity as transvestites, and notes that these are not isolated cases.[1]

All the detainees are members of the Associación Coccinelle, a lesbian, gay and transgender NGO in Guayaquil. Colleagues from the association trying to arrange their release were told the detainees would not be released until they had been tested for HIV. The association submitted a habeas corpus application on behalf of the detainees, which yielded no response.

During their detention, the detainees were forced by police to provide blood samples, which were tested for HIV. According to reports, when the National Hygiene Institute refused to perform the tests as constituting a violation of professional ethics, the chief of police sent the samples to a private clinic for testing. The private clinic sent the results of initial ELISA screening tests to the police, including some positive results. No confirmatory testing was undertaken. The police chief instructed the private clinic to invoice the detainees' families for the tests. The detainees were eventually released between 21 and 27 July 2000.

Under Ecuador's constitution, all individuals are entitled to equality and enjoy the same rights, liberties, and opportunities without discrimination based on sexual orientation and health condition (Article 23.3). Similarly, everyone has the right to freely develop their personality (Article 23.5). Furthermore, under the Penal Code, the crimes alleged against the detainees are not punishable by imprisonment, but by fine only.

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[1] Amnesty International. Ecuador: Arbitrary detention of transvestites. September 2000 (AI Index: AMR 28/14/00).

News from Venezuela

A Venezuelan court has ordered a university to stop requiring HIV testing for admission, while shortly thereafter the Venezuelan Ministry of Health and Social Development authorized obligatory HIV screening of pregnant women.

On 1 August 2000, a Venezuelan court ordered the Universidad Pedagogica Experimental Libertador (UPEL), a powerful, sprawling government-subsidized university with eight main campuses and 20 other units throughout the country, to stop requiring an HIV test for admission. UPEL had argued that by refusing to train HIV-positive people as teachers it was just saving Venezuela money.[1]

On 8 August 2000, the Venezuelan Ministry of Health and Social Development published a resolution in the country's Official Gazette stating that all public and private health services institutions "should undertake, as an obligatory matter, the ELISA test for HIV antibodies on each pregnant woman as part of prenatal care."

The resolution stated that testing may only be done with the knowledge of the woman being tested, after proper counseling, and that the confidentiality of the woman's personal identity and test results must be preserved. However, no statement that the woman's consent to the test was required was included. The Ministry did commit itself to guaranteeing antiretroviral treatment for all HIV-positive women during pregnancy and labour, as well as for newborns, "in accordance with international norms."[2]

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[1] Press release. ACCSI – Acción Ciudana Contra el SIDA. Venezuelan court stops HIV testing as pre-employment condition in university. Caracas, 1 August 2000. For further information, or to obtain a copy of the judgment (in Spanish), contact Edgar Carrasco at ecarrasco@ccs.internet.ve.

[2] Resolución No 292 (7 August 2000), *Gaceta Oficial de la República Bolivariana de Venezuela* 37.009, 8 August 2000.

South Africa: Airline Found Guilty of Employment Discrimination

On 28 September 2000, the Constitutional Court of South Africa ruled that South African Airways (SAA) violated the constitutional rights of Jacques Hoffmann in September 1996 by refusing to employ him as a cabin attendant on the ground that he is HIV-positive.[1]

Hoffmann alleged that this refusal constituted unfair discrimination and violated his constitutional right to equality, human dignity, and fair labour practices. SAA asserted their practice was justified on safety, medical, and operational grounds, arguing that flight crew members had to be fit for worldwide duty. This included being vaccinated against yellow fever, as employees travel to countries where the disease is endemic, and HIV-positive people cannot take this vaccination. SAA also argued that HIV-positive people are prone to contracting other opportunistic infections, and that cabin attendants would risk not only becoming infected themselves, but could transmit yellow fever or other infectious diseases to others, including passengers.

At first instance, the High Court accepted SAA's position as being "based on considerations of medical, safety and operational grounds." It also noted that SAA did not exclude people with HIV from all positions with SAA, and that if SAA were obliged to employ people with HIV, the "public perception about it will be seriously impaired" and "it would be seriously disadvantaged as against its competitors."[2]

However, the Constitutional Court rejected SAA's assertions as unfounded:

> On the medical evidence, an asymptomatic HIV positive person can perform the work of a cabin attendant competently. Any hazards to which an immunocompetent cabin attendant may be exposed can be managed by counselling, monitoring, vaccination and the administration of the appropriate antibiotic prophylaxis if necessary. Similarly, the risks to passengers and other third parties arising from an asymptomatic HIV positive cabin crew member are therefore inconsequential and, if necessary, well-established universal precautions can be utilised…. [E]ven immunosuppressed persons are not prone to opportunistic infections and may be vaccinated against yellow fever as long as their CD4+ count remains above a certain level [found by the Court to be 350 CD4+ cells per microlitre of blood].[3]

Confronted by this evidence, SAA conceded that its practice of refusing to employ cabin attendants who are HIV-positive was medically unjustified and was unfair. The Constitutional Court nonetheless considered Hoffmann's constitutional claims, although it ended up basing its judgment solely on the right to equality. The Court noted that:

> People who are living with HIV/AIDS are one of the most vulnerable groups in our society… [D]iscrimination against them [is] an assault on their dignity. The impact of discrimination on HIV positive people is devastating. It is even more so when it occurs in the context of employment. It denies them the right to earn a living.[4]

Stating "there can be no doubt" that SAA discriminated against Hoffmann because of his HIV status, the Court concluded that

> neither the purpose of the discrimination nor the objective medical evidence justifies such discrimination…. The fact that some people who are HIV positive may, under certain circumstances, be unsuitable for employment as cabin attendants does not justify the exclusion from employment as cabin attendants of *all* people who are living with HIV.[5]

Furthermore, the Constitutional Court harshly criticized SAA's argument about harm to its commercial interests if it were required to hire HIV-positive flight crew members:

> Legitimate commercial requirements are, of course, an important consideration in determining whether to employ an individual. However, we must guard against allowing stereotyping and prejudice to creep in under the guise of commercial interests. The greater interests of society require the recognition of the inherent dignity of every human

> being, and the elimination of all forms of discrimination. Our Constitution protects the weak, the marginalised, the socially outcast, and the victims of prejudice and stereotyping. It is only when these groups are protected that we can be secure that our own rights are protected….
>
> [T]he devastating effects of HIV infection and the widespread lack of knowledge about it have produced a deep anxiety and considerable hysteria. Fear and ignorance can never justify the denial to all people who are HIV positive of the fundamental right to be judged on their merits. Our treatment of people who are HIV positive must be based on reasoned and medically sound judgments.... The constitutional right of the appellant not to be unfairly discriminated against cannot be determined by ill-informed public perception of persons with HIV. Nor can it be dictated by the policies of other airlines not subject to our Constitution….
>
> People who are living with HIV must be treated with compassion and understanding. We must show *ubuntu* [the recognition of human worth and respect for the dignity of every person] towards them. They must not be condemned to "economic death" by the denial of equal opportunity in employment. This is particularly true in our country, where the incidence of HIV infection is said to be disturbingly high.[6]

The Court therefore ordered that SAA employ Hoffmann as a cabin attendant effective from the date of the Court's order. Given that Hoffmann had not previously put SAA on notice that he would be seeking pay retroactive to the date that SAA had refused to hire him (September 1996), and that there was no evidence before the Court as to his lost income since then as a result of being denied the job, it refused to make its order retroactive to that date four years earlier. The Court also ordered SAA to pay Hoffmann's legal costs of the trial and appeal.

This ruling in *Hoffmann* follows an earlier case against the airline raising the same issue. Early in 2000, the SAA settled a case brought before the Labour Court by the AIDS Law Project on behalf of "A", who was found suitable for the position of cabin attendant but denied employment on the basis that he is HIV-positive. On the third day of trial, SAA admitted that it had, in the course of a pre-employment medical examination, tested A for HIV without his informed consent by failing to provide either pre- or post-test counselling. SAA also admitted failing to properly assess A's fitness for the job and that denying him employment because of his HIV status was "unjustified." The case was settled when A accepted SAA's offer of ZAR100,000 in compensation.[7] In an even earlier case, the AIDS Law Project had assisted a woman denied employment as a cabin attendant because she was HIV-positive and pregnant. That case settled for only ZAR5000.[8]

– Richard Elliott

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[1] *Hoffmann* v *South African Airways*, Case CCT 17/00, Constitutional Court of South Africa, 28 September 2000.

[2] *Hoffmann* v *South African Airways*, 2000 (2) SA 628 (W).

[3] *Hoffmann*, supra, note 1 at para 15.

[4] Ibid at para 28.

[5] Ibid at paras 29, 32.

[6] Ibid at paras 34-38.

[7] *A* v *South African Airways (Pty) Ltd*, Case J1916/99; AIDS Law Project. Press Release: Settlement in first Labour Court case on pre-employment HIV testing against South African Airways, 10 May 2000; see also: M Figueira & F Hassan. Discrimination on the basis of HIV: "A" versus South African Airways. *AIDS Legal Quarterly*, September 2000: 12.

[8] See: AIDS Law Project. *Annual Report 1999* (www.hri.ca/partners/alp).

PUBLICATIONS REVIEWED

Health and Human Rights: A Reader[1]

This volume is a collection of thirty previously published papers on health and human rights. It is dedicated to the memory of Jonathan Mann, who perhaps more than any other individual promoted a response to the HIV epidemics that is firmly grounded in the relationship between health and human rights. Thirteen of the papers in the collection originally appeared in the journal *Health and Human Rights,* which Mann founded.

The link between inequity, discrimination, stigma, violence, and HIV infection seems incontestable in light of the HIV epidemics among women, drug users, gay men, and Aboriginal peoples.

The collection is organized in six parts. Part I introduces the concepts of human rights and public health, and identifies three ways of understanding the relationship between health and human rights. The first explores the impact of health policies, programs, and practices on human rights. The second examines the impact of violations of human rights on health. And the third considers the inextricable links between health and human rights: one cannot be acted upon without affecting the other. These three approaches to the relationship between health and human rights are the subject of, respectively, Parts II, III, and IV of the collection. Part V deals with human rights in the context of medical research and practice. The final part of the collection discusses ways to proceed from concept to action in promoting both health and human rights.

It will come as no surprise that the papers often refer to HIV/AIDS. (The index to the volume provides a handy list of references.) The HIV epidemics, like other diseases that reside among the marginal, have repeatedly exposed the relationship between health and human rights. For those informed about HIV/AIDS, the analysis will appear, on first reading, familiar. It seems obvious that overly inclusive coercive responses, such as quarantine of all people with HIV, are unjustified from the perspective both of public health and of human rights. Likewise, the link between inequity, discrimination, stigma, violence, and HIV infection seems incontestable in light of the HIV epidemics among women, drug users, gay men, and Aboriginal peoples.

And yet the implications of these insights have yet to be learned, or have to be learned time and again. For instance, in Part II of the collection, Lawrence Gostin and Jonathan Mann provide an instrument designed to assess the human rights impact of public health policies or interventions. This kind of assessment continues to be necessary as developments in the epidemics or in medical technology lead to changes in policies and interventions. The assessment should be applied, for example, to any proposals to make HIV tests required or mandatory – an issue that continues to surface in public debate.[2]

Similarly, it has proved difficult to act on the recognition that efforts to control the HIV epidemics must go beyond programs that focus on individual behaviour (important as they are) to strategies that address the social, economic, and political factors that render individuals vulnerable to infection. Several of the papers in Part IV are instructive in this regard. In “Human Rights and AIDS: The Future of the Pandemic,” Jonathan Mann provides a synopsis of the history of the response to the HIV epidemics and argues that only a human rights analysis provides a conceptual framework that addresses the roots of vulnerability to HIV infection. Jacques du Guerny and Elisabeth Sjöberg demonstrate how a gender analysis can identify required elements of programs to remedy women’s vulnerability to HIV infection, while Lynn Freedman’s “Reflections on Emerging Frameworks of Health and Human Rights” explains how a human rights paradigm can provide the values on which to base such programs.

Part IV includes several papers that raise important questions about the ethics of HIV research. In “Questing for Grails,” George Annas argues that a clear distinction between research and treatment, researcher and physician, and participant and patient is essential to the ethical conduct of research in accordance with the Nuremberg Code. Expanded access programs for experimental HIV drugs confuse this distinction. While one might wish to qualify Annas’s suggestions in light of the benefits to people with HIV from expanded access programs, the concerns he raises about “doublespeak” in research are important. Annas and co-author Michael Grodin offer similar trenchant advice in a paper on maternal–fetal HIV transmission prevention trials in Africa. In their view, research in impoverished populations is unethical in the absence of a realistic plan to deliver the interventions under investigation to the population; without a realistic plan, valid informed consent cannot be deemed to be offered or obtained.

The value of the collection extends beyond its application to HIV/AIDS, in two fundamental ways. First, the papers widen the scope of one’s perspective on health. When one approaches health from a human rights perspective, one necessarily broadens one’s view beyond a focus on a single disease. It is not a question of abandoning the focus that was the point of entry to an awareness of the importance of human rights for health. It is, rather, a matter of recognizing that efforts to protect human rights will influence positively the health of individuals in more ways than one. Thus, efforts to protect the human rights of, for example, gay men can lead to improvements in their health and well-being, including, but not limited to, reduced vulnerability to HIV infection. Conversely, efforts to prevent HIV transmission may, depending on a population’s circumstances, concentrate on changing the social environment in order to improve the effectiveness of prevention programs for a variety of diseases, including HIV/AIDS. These insights evidently have implications for budgetary allocations.

> Efforts to protect human rights will influence positively the health of individuals in more ways than one.

Second, the collection provides a basis for acting in areas that, traditionally, have been outside the scope of health professionals. A human rights perspective provides a normative basis for analysis, advocacy, and intervention on societal factors that predetermine health. As Jonathan Mann observes in the final paper in the collection, “Medicine and Public Health, Ethics and Human Rights,” public health has been prevented from taking action on the societal determinants of health by the absence of a coherent conceptual framework, a consistent vocabulary, and consensus about societal change. International codes of human rights provide not only the terms with which to analyze the determinants of health; they also articulate the values that justify actions to change them. The challenge is for public health to gather its evidence and apply its resources according to a conceptual framework based on human rights.

The appendices to the collection provide the texts of the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights, and the International Covenant on Civil and Political Rights. Readers may also wish to consult the health and human rights database on the Global Lawyers and Physicians website (www.glphr.org), as well as two recent bibliographies published in the 1999 issue of *Health and Human Rights*.[3]

– reviewed by Theodore de Bruyn

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[1] Mann JM et al (eds) *Health and Human Rights: A Reader.* New York and London: Routledge, 1999, 505 pages.

[2] See, eg, Elliott R Reform MP proposes compulsory testing. *Canadian HIV/AIDS Policy & Law Newsletter* 2000; 5 (2/3): 25-27.

[3] Amnesty International Publications on health and human rights themes: 1982-1998. *Health and Human Rights* 1999; 4: 215-264; Fluss SS. A select bibliography on health aspects of human rights: 1984-1999. *Health and Human Rights* 1999; 4: 265-276.

Drug Use and Prisons: An International Perspective[1]

For most social, political, and public health movements, prisons are the last frontier both because of the social and political stigma experienced by prisoners and the logistical difficulties of accessing prisons. This was true for the AIDS movement, which was slow in most countries to recognize the testing, treatment, and social service needs of prisoners and former prisoners. Indeed, it was not until the V International Conference on HIV/AIDS in Yokohama, Japan in 1994 that there was an official meeting devoted entirely to the topic of prisoners and former prisoners.

Such has not been the case for the sister movement to AIDS – harm reduction – in which practitioners and researchers alike quickly understood the inexorable link between drug and alcohol use (particularly injection drug use), AIDS, and incarceration. Significantly, many of the researchers, advocates, and social service practitioners who organized within the AIDS movement became the core group of people looking at how best to understand and minimize the harms associated with drug use in prisons.

Many of these individuals are contributors to Shewan and Davis's book, *Drug Use and Prisons*, which, as a whole, provides an outstanding overview of where research and practice stand in a wide array of countries, including Brasil, Canada, Switzerland, Scotland, and many in sub-Saharan Africa. The authors are top-flight and come from a range of professional backgrounds and perspectives. The articles are well written and highly detailed. As the book's title implies, the collection focuses on a single behaviour behind bars – namely drug use – and not on a population or on how government should respond to the behaviour. This academic perspective is either the book's great strength or weakness, depending on the reader's perspective.

In the Preface, the editors indicate that while the contributing authors by and large consistently raise a number of questions, which are discussed below, the editors accept that not everyone would agree on the answers to these questions. Although such an approach may embrace a wider readership, including prison officials who are just beginning to explore the issue, this approach prevents the editors from establishing a context for the information contained in the book. Such a framework, indicating where the field of drug use in prisons has been in the past, where it is now, and where the editors (or contributors) think it should or might go in the future, is a critical missing link. Since drug use behind bars is in most countries illegal, creating such a framework would almost by necessity require the editors to take a stand on some of the issues. Without this framework, the book's country-by-country information seems somewhat fragmented, lacking for instance a discussion on how non-industrialized countries or the countries of the former Soviet Union could learn from the experience of industrialized countries in this area.

> It is striking how much energy and resources have been devoted in industrialized countries to proving what every prisoner and prison worker knows: prisons are high-risk environments where drug users frequently engage in needle sharing and other high-risk behaviours.

If one steps back from Shewan and Davis's text and examines the field of drug use in prisons as a whole, it is striking how much energy and resources have been devoted in industrialized countries to proving what every prisoner and prison worker knows: prisons are high-risk environments where drug users frequently engage in needle sharing and other high-risk behaviours. Debunking the common institutional myth that prisoners do not engage in high-risk sex and drug use has been an expensive endeavour with only mixed results. Researchers in Scotland, Australia, the Netherlands, and Switzerland have used such research to combat institutional denial within prison administrations that high-risk behaviour occurs behind bars and that some programs need to be put in place to address such behaviour. Even in these countries, with the exception of Switzerland and the Netherlands, practitioners have strained to translate affirmative research findings of high-risk drug use into harm-reduction programs. Encouragingly, Switzerland has expanded needle exchange with users and even has a heroin maintenance program in one prison, and Australia has recently expanded methadone maintenance programs to more correctional institutions. But overall, progress on the issue of recognizing and addressing drug use in prisons has been hard won and easily lost to a range of forces, including changes in prison administration and the move toward prison privatization. While the very slow but steady progress in Western and, more recently, Eastern European countries on harm reduction behind bars has been heartening, it has only just begun to address high-risk behaviour in prisons.

Clearly, a country's ability to recognize and address the issues surrounding high-risk drug use behind bars is necessarily linked to how it perceives and addresses drug use. Thus, work on drug use in prisons must be done in a larger context of combating stigma and prejudice against users and on building public health and legal systems that effectively address problem drug use. Indeed, if the industrialized nations' knowledge of drug use behind bars has one lesson to offer developing countries such as Brasil and the countries of sub-Saharan Africa, it is that once a society chooses to use criminal law and incarceration as the first line of defence against drug use, it is difficult if not impossible to address the issue as a medical or public health concern. One additional lesson is that the criminalization of drug use is very expensive and largely ineffective.

– reviewed by Nancy Mahon

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[i] Shewan D, Davis JB (eds). *Drug Use and Prisons: An International Perspective.* Amsterdam: Harwood Academic Publishers, 2000, 256 pages.

HIV/AIDS AND THE LAW

We continue here our special section on HIV/AIDS and the law, which we started in the last issue with articles presenting developments from four countries: Australia, Switzerland, England and Wales, and India.[1] Overviews from Canada, Germany, and South Africa (originally scheduled for this issue) will follow.

HIV/AIDS Legal Issues in the United States

The HIV/AIDS epidemic continues to be a leading public health issue in the United States. During the past decade, the epidemic has shifted away from the gay community, although gay and bisexual men continue to be the largest single HIV exposure category. Now, HIV increasingly affects low-income people of colour in urban areas, as well as women. As AIDS becomes more and more a minority, inner-city disease, public focus on the epidemic as a significant social and political issue is waning. While a full survey of current issues in US law is beyond the scope of this article, the focus here is on current issues that are highly relevant to the direction the epidemic appears to be taking.

Largely as a result of the introduction of highly aggressive antiretroviral therapy in 1996, the AIDS mortality rate has declined significantly, with a concomitant increase in the number of individuals living with HIV disease. This means that individuals with HIV disease were progressing more slowly to AIDS, and those with AIDS were experiencing a reduced mortality rate. By mid-1999, however, the federal Centers for Disease Control and Prevention (CDC) reported that the decrease in AIDS incidence had slowed. By the end of 1999, the CDC concluded that "the slowing rate of the decline may indicate that much of the benefit of new therapies has been realized."[2]

The US Legal System

The United States has a federal legal and political system, in which a complex relationship exists between the federal (national) government and each of the 50 states, dependencies, and possessions. In each state, legal standards are based on state laws as well as on federal law. In addition, some local, municipal governments have also adopted laws that pertain to HIV issues. Because each state has its own legislature and court system, legal standards can vary from state to state. At all levels of government, legal standards are derived from legislative enactments, case law resulting within multi-tiered court systems, and administrative agency rules and recommendations. Although the federal government has sometimes taken the lead in addressing HIV/AIDS issues, many significant developments in HIV/AIDS law and policy have taken place at the state and local level.

Perhaps more than in any other country, the legal system in the United States has been called on to address the social and political disputes that have resulted from the epidemic. A litigation survey undertaken for the period from 1991 to 1997 catalogued more than 550 cases generating reported opinions in the federal and state courts.[3] These reported cases, it should be understood, are only a fraction of the total number of cases involving HIV/AIDS issues in the courts.

Similar levels of activity have also been seen in the legislatures.

Reporting and Confidentiality Standards

Since the beginning of the epidemic, all states have required that physicians or other health-care professionals report AIDS diagnoses to local or state health departments. The case reports, without identifying information, are then sent on to the CDC. For reporting purposes, the CDC's definition of AIDS is used. This definition has gone through several revisions, having been most recently revised in 1993 to make it more inclusive of symptoms experienced by women. While AIDS cases are uniformly reported to health departments, including identifying information regarding the patient, HIV-positive test results are not similarly reported, although the CDC has recommended that HIV reporting be undertaken along with AIDS reporting. This issue has been controversial; public health authorities have claimed that HIV test reporting will enhance efforts to track the epidemic, while many AIDS advocates fear that reporting, if it includes the individual's name, will deter many individuals from seeking testing. Most states, however, have instituted HIV reporting, although the manner of the reporting systems varies. Many states report HIV cases as they do with AIDS, but other states report HIV using "unique identifiers" that provide a greater level of confidentiality regarding the results.

Although there is no overall national confidentiality standard for HIV information in the health care or other contexts, most states provide some confidentiality protection, either by means of HIV-specific confidentiality laws or under more general medical or health-care information privacy laws.

Discrimination

Federal law, and that of most states, provides protection against discrimination based on HIV status.[4] The nondiscrimination protection broadly covers employment, access to commercial facilities, access to public or governmental services, and housing. While the precise contours of protection at the state level are complex and varied, the federal nondiscrimination standard, included in the Americans with Disabilities Act of 1990 (ADA)[5] and other federal statutes as well, uses a disability definition that is viewed as generally inclusive of all individuals with HIV infection or regarded as HIV infected. Federal law uses a three-point definition of disability: an individual with a disability has a mental or physical impairment that substantially limits a major life activity; or (2) a record of such an impairment; (3) or is regarded as having such an impairment. At this point, there is no dispute that HIV infection is an impairment. The only question is whether it imposes a "substantial limitation" on a "major life activity." Federal law does not explicitly define those terms. In 1998, in *Bragdon* v *Abbott*,[6] the United States Supreme Court considered whether a woman with HIV infection is an individual with a disability as defined by the ADA. The Court concluded that because of limitations imposed on reproduction, which it viewed as a major life activity, were substantial, she was indeed an individual with a disability. The substantial limitation was found from the risk of HIV transmission to her sexual partner or to the child during pregnancy and birth. Although the Supreme Court declined to hold that HIV is a disability per se, it concluded that HIV was viewed as a disability under the law prior to the ADA's adoption, and therefore, because the ADA incorporates those standards, HIV should be viewed as a disability in all cases. Additionally, in a more recent case, the Supreme Court noted that "some impairments may invariably cause a substantial limitation of a major life activity."[7]

The ADA provides some protection for job seekers by imposing limitations on an employer's pre-employment tests and inquiries. First, employers may not inquire as to whether an applicant for employment has a disability such as HIV or AIDS. They may, however, inquire as to the individual's ability to perform the essential functions of the job. An employer may also ask about an applicant's qualifications in terms of employment history, such as inquiring about any gaps in employment history. An employer may not require the applicant to undergo any tests or examinations, however, until after a "conditional" job offer has been made to the applicant. In that event, the employer can inquire as to the applicant's HIV status, or conduct HIV testing, provided the same examination is imposed on all applicants for similar employment. Confidentiality limitations are imposed on information concerning a disability that is disclosed as part of a pre-employment exam.

Federal law provides a defence against a claim of discrimination in the event that an individual with a disability poses a "direct threat" of harm to another. Because the risk of HIV transmission is remote in all but a few settings and activities, this defence has been successfully raised in only a handful of cases. Under guidelines issued by the Occupational Safety and Health Administration (OSHA) in 1991, the use of "universal precautions" has been deemed adequate to make workplaces reasonably safe with regard to the transmission of bloodborne pathogens such as HIV.[8] OSHA has identified the body fluids that transmit HIV and, significantly, saliva is not among them. Not surprisingly, then, cases involving access to preschool and school programs, even with children of an age in which biting is routine, have resulted in rulings in favour of the children with HIV.

Testing of Pregnant Women and Newborns

Beginning in 1996, studies have shown that the use of antiretroviral therapy during pregnancy, combined with delivery by cesarean section, can reduce the risk of transmission significantly. Since 1996, the rate of perinatal transmission has declined significantly, but the CDC estimates that 300 to 400 babies continue to be born with HIV infection in the United States each year.[9] On the national level, Congress addressed this issue in its 1996 amendments to the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act.[10] The CARE Act amendments emphasize pre-test counseling and voluntary, as opposed to mandatory, HIV testing of pregnant women, consistent with the CDC's recommendations.[11] Mandatory testing of newborns is not required. In 1998, the Institute of Medicine recommended a national policy of universal HIV testing, with patient notification, as a routine component of prenatal care.[12] This issue again arose in Congress with regard to legislation to renew the CARE Act in 2000.[13]

Immigration and US Travel Policies

In 1993, the US Congress included HIV in a statutory list of medical conditions that are a basis for exclusion from the United States.[14] This statutory enactment codified a policy that had been in effect since 1987. As a result, the United States denies entry to non-citizens (both immigrants and non-immigrant visitors) with HIV. Reform of US law on this issue will require another act of Congress to repeal the ban, which does not appear politically likely.

The prohibition against entry into the United States by those with HIV applies to both immigrants and non-immigrant visitors. Immigrants with HIV face significant problems in remaining permanently in the United States, although for some immigrants, a "waiver" of the exclusionary policy may be available, depending on the circumstances.

However, US citizens with HIV can freely travel from and return to the United States. HIV-positive non-citizens with a legal US immigration status may travel outside the United States, but must first determine whether they will be subject to the HIV exclusion upon their return and whether a waiver of the exclusion is available. Non-immigrants coming to the United States (for example, tourists, students, or other temporary visitors) are also subject to the HIV ban. In obtaining a non-immigrant visa, applicants are not required to be tested for HIV or undergo a medical exam, nor are they directly asked whether they are HIV-positive. The visa application form, however, does ask whether the individual has a "communicable disease of public health significance." If the applicant answers yes, they will be denied the visa unless they are successful in obtaining a waiver. Waivers can be obtained for 30-day visits to the United States to (1) visit family; (2) receive pre-paid medical treatment; (3) conduct business; or (4) attend a scientific or health-related conference. Waivers for longer visits can also be obtained if other requirements are met.

The US Immigration and Naturalization Service (INS) has issued an "advisory" policy on border inspections regarding HIV/AIDS. INS officials should not inquire about HIV status unless there are physical symptoms of illness or the individual makes an unambiguous and unsolicited statement of their status. Carrying literature pertaining to HIV/AIDS or related materials should not cause questioning regarding HIV status. However, discovery of medications used to treat HIV illness may result in questioning and a referral for a medical examination. As a result, some travelers carry their HIV-related medication in unmarked containers. A written prescription pertaining to the medication, however, should be carried in order to comply with US customs laws.

Syringe Exchange Programs

Syringe exchange programs have been among the most politically controversial of prevention programs. Although the CDC has concluded that such programs reduce the transmission of HIV without increasing use of illegal drugs, congressional support for such programs has been withheld. Instead, Congress has prohibited the use of federal funds for such programs. When they are undertaken, they are done so with state and local funding, where legal; many such programs, however, have been allowed to operate despite their questionable legality under state and local laws.

Criminal Law

Many states, as well as the federal government, have enacted HIV-specific criminal statutes. These statutes vary greatly in their details, ranging from prohibitions against the knowing or intentional transmission of HIV to another person, to more detailed statutes that attempt to define the precise conduct that is criminalized. The impetus for the enactment of such statutes on the state level came from the US Congress's requirement in the CARE Act that the award of certain federal funds to states is conditional upon the states' certification that their laws are adequate to prosecute any HIV-positive person who knowingly engages in activities posing a risk of HIV infection.[15] Additionally, persons engaging in sexual or needle-sharing activities that pose a known risk of HIV transmission have been prosecuted under other criminal statutes, such as assault and related crimes, that do not include specific reference to HIV.

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An Ethical Analysis of the Mandatory Exclusion of Immigrants Who Test HIV-Positive

(cont'd from page 1)

There are sound ethical, legal, and public policy arguments against imposing mandatory testing and excluding those who test HIV-positive.

Introduction

Should persons applying for immigrant status in Canada in order to improve their well-being or enhance their economic prospects be tested for HIV and refused permanent residence if they test positive? Should HIV-positive applicants automatically be excluded because they would be a threat to public health? Should they automatically be excluded on the presumption that they would cost Canadian society more than they could ever contribute?

Reactions to these questions can be sharp and uncompromising. Allowing HIV-positive immigrants into the country is perceived by some as a threat to public health: "To remove any screening procedures between Canada and the pool of infection south of the border or elsewhere (e.g., central Africa) is folly of the highest order and in nobody's best interests" (Parker 1990a: 525). Such a policy would not only be folly, it would be costly. Providing care for HIV-infected immigrants would allegedly impose "severe strains on the taxpayer-funded health care system" (Parker 1990a: 525).

Endorsing these claims is politically tempting. Politicians who support HIV testing can be portrayed as actively defending the interests of their constituents: "From the perspective of an uninformed and apprehensive public, for whom elected representatives want to be seen to be 'doing something,' screening seems an easy enough and necessary way by which to raise a barrier to the spread of disease and to protect the public purse" (Goodwin-Gill 1996: 64). Their support would court little political danger because those denied permanent residence would, of course, never vote.

Political expediency notwithstanding, how plausible are these claims? This is an important question, because HIV testing of immigrants could impose serious harms. Of greatest concern, perhaps, is that it would play upon and reinforce deep-seated fears and prejudices. It is easy to perceive immigrants as unlike "us" and to stereotype their beliefs, values, and behaviour. It is also easy to characterize HIV as a disease that is rampant among strange people with strange ways of life.[2] Discomfort with those who are perceived as different, and fear of a horrible disease, are a powerful combination and a powerful motivation for exclusion. Moreover, that stigmatization and rejection could spread to people with HIV who already live in Canada. The question is also timely because Citizenship and Immigration Minister Elinor Caplan recently announced that she accepts the public health rationale for HIV testing of immigrants. According to Minister Caplan, "The priority must always be what is in the public-health interests of Canadians" (Clark 2000: A4).

Given this setting and these dangers, proposals for HIV testing of immigrants require careful ethical scrutiny. Before proceeding to the arguments for and against testing, and mandatory exclusion of those who test positive, the legal situation in Canada will be quickly reviewed.

Canadian Law and Policy

Immigration law and policy in Canada are currently undergoing an extensive review, with the possibility of a major overhaul in the legislative framework. As one component of this review, Citizenship and Immigration Canada has sought advice from Health Canada about potential changes in the medical screening requirements of the immigration process. Currently, section 19 of the *Immigration Act* identifies as inadmissible on medical grounds:

(a) persons who are suffering from any disease, disorder, disability or other health impairment as a result of the nature, severity or probable duration of which, in the opinion of a medical officer concurred in by at least one other medical officer,
  (i) they are or are likely to be a danger to public health or to public safety, or
  (ii) their admission would cause or might reasonably be expected to cause excessive demands on health or social services....[3]

Thus, two distinct rationales exist for denying prospective immigrants admission on medical grounds, one related to public health and the other to public economy.

In 1994, then Minister of Immigration Sergio Marchi wrote to the Canadian AIDS Society that "persons living with HIV/AIDS do not generally represent a danger to the public under s. 19 of the *Immigration Act*" (cited in Jürgens 1998a: 199-200). According to Jürgens (1998a: 200), "This policy is still in place and is unlikely to change in the near future." But the current policy of the Canadian government, according to Jürgens (ibid), is that people with HIV/AIDS would impose excessive demands on Canada's health and social service systems, and consequently "immigration applicants who are found to be HIV-positive are assessed as 'medically inadmissible' and will not normally be allowed to immigrate to Canada."

The medical and visa officers who determine medical admissibility exercise broad discretion in applying the "excessive demand" criterion, however, because "excessive demand" is not defined in the *Immigration Act.* A review of the medical inadmissibility provisions undertaken a decade ago by Employment and Immigration Canada (1991: 33, see generally 33-37) recognized the "ambiguity that surrounds the concept of excessive demand." Recent commentators have noted that "[t]his strange and otherwise undefinable phrase is ... left to haphazard and casual definition" (Rotenberg & Lam 1995: 4).

In sum, Canadian law does not explicitly bar immigrants because they are HIV-positive. But Canadian law does, *in theory*, authorize the exclusion of prospective immigrants who are HIV-positive, either because they pose a threat to public health or because their care and support would consume too many resources. Canadian immigration policy, *in practice*, currently recognizes that HIV-positive immigrants do not represent a danger to public health, but it does allow that meeting their needs might impose an inordinate burden on Canada's health and social service systems and that their applications for permanent residence may be denied for that reason. Whether these positions are ethically defensible is examined in the sections that follow.

Specific Arguments

For Mandatory Testing and Automatic Exclusion

Danger to public health or safety

One of the reasons offered for screening prospective immigrants and barring those who test positive is a potential benefit to public health. A physician makes this point forcefully: "the threat of HIV infection to public health is at the core of the controversy [about testing immigrants], and it does not make much sense to me to deny that it exists" (Hall 1990: 172). If immigrants who test positive are not admitted to Canada, then obviously they cannot transmit HIV to people in the country. Would that not represent a substantial benefit to public health? The general answer to that question, which until recently has been accepted for purposes of Canadian immigration policy, is "no." In a report to British Columbia's Ministry of Health, the Special Advisory Committee on Ethical Issues in Health Care (1993: 1188) concluded: "The admission of immigrants who are HIV positive does not constitute a sufficient danger to public health to justify requiring applicants for immigration to undergo testing for HIV status and denying entry to those who test positive." How can this conclusion be defended?

Two lines of reasoning start from different premises but reach the same conclusion. The first begins with the concept of public health, which, as Somerville emphasizes, is not easy to define:

> [W]ho and what constitute a threat to public health[?] What is public health? How does this differ from the health of individuals? Do all infectious diseases constitute a risk to public health? If a risk is encountered in an occupational setting and that risk is an inherent part of that occupation, does it constitute a risk to public health or is it an occupational health risk? (1990: 172)

The notion of a "threat to public health" is commonly perceived to encompass a broad range of pathological conditions, including, for example, forms of environmental pollution (Somerville 1990: 173). A more precise sense of the term, the one used in public health protection legislation, limits it to controlling the spread of contagious diseases (Somerville 1990: 173).

When "public health" is understood in the narrower sense, the mere presence of HIV does not, Somerville argues, constitute a danger:

> I do not believe that this legislation should be interpreted as applying to people who are HIV antibody positive unless they engage in behaviour likely to transmit HIV. In such circumstances these people clearly are a threat to public health; in the absence of such behaviour they are not (1990: 173).

It is the possible behaviour of people with HIV, and not the disease itself, that poses a threat to public health.

Somerville marshals evidence to demonstrate that, in both comparative terms and absolute terms, the threat to public health posed by the behaviour of immigrants is insignificant. She cites statistics (old but nonetheless illustrative) to show that, compared with visitors to Canada, the potential contribution of immigrants to the risk of spreading HIV is tiny:

> [I]f we were thinking about potential transmission hours (the total number of hours during which conduct that could result in HIV transmission is engaged in) and opportunities, such people [HIV antibody–positive immigrants] would constitute a minuscule proportion of the risk presented by the total number of people entering Canada each year. In 1987, 152 000 immigrants entered Canada, as compared with approximately 40 million visitors (1989: 890).

And she adds that one mode of transmitting HIV – casual sexual encounters – is much more likely with tourists and business travelers than it is with immigrants, "many of whom have families with young children and are seeking a new life, a home and work" (1989: 890).

The second line of argument begins by rejecting Somerville's focus on behaviour that might constitute a threat to public health. The *Immigration Act*, in this view, does not require a medical officer to determine "*whether the exclusion of an individual applicant will in any way prevent the spread of a particular disease in Canada*" (Employment and Immigration Canada 1991: 45; emphasis in original). Consequently,

> the argument that screening immigrants ... for HIV/AIDS will not prevent the spread of the disease in Canada, since an estimated 50 million short-term visitors enter the country each year untested, is irrelevant. Otherwise, by analogy, there would be no point in testing for any infectious disease, including active tuberculosis. *What the [Immigration] Act does demand is the medical officer's opinion on whether an individual applicant's medical condition is such that the applicant is likely to be a danger to public health. The distinction is important; the Immigration Act is not intended to stand for a Public Health Act* (Employment and Immigration Canada 1991: 45; emphasis in original).

The relevant comparison, therefore, is between HIV and other conditions that pose recognizable dangers to public health.

> To refuse admission to immigrants solely because they test HIV-positive would be to deny society's collective responsibility for HIV/AIDS and to make immigrants scapegoats for society's failure to combat the disease more effectively.

Tuberculosis is a disease for which mandatory testing is required and which, in its active state, renders an applicant temporarily inadmissible under the "danger to public health" provision of the *Immigration Act*. HIV is, like tuberculosis, a communicable disease, but HIV, unlike tuberculosis, is not an airborne disease, so it cannot be transmitted by so-called "casual contact." Given that difference, consistency does not require mandatory testing for HIV.

What about syphilis, however? Like HIV, syphilis is a communicable disease that is spread only through "high-risk" behavior. Testing for syphilis is mandatory, and in its infectious phase, syphilis also renders an applicant temporarily inadmissible. But HIV, unlike syphilis, cannot be cured; despite all the research and therapeutic advances, HIV remains a chronic condition. To bar applicants because they test HIV-positive would mean that they could never immigrate. The consequence of a positive test for syphilis is delay; the consequence of a positive test for HIV would be permanent exclusion. Given that difference, consistency does not require mandatory testing for HIV.

The real point about a communicable disease such as HIV, however, is that it is not the mere presence of the disease that constitutes a danger to public health, but the possible behaviour of the person who has the disease:

> A person who is infected with the HIV virus is capable of infecting others and so such a person is potentially a threat to public health. *The real question is whether that person is "likely" to do so and, more importantly, whether the "risk" that the person will do so is sufficiently offset by public health education programs to consider such a person admissible under the Immigration Act* (Employment and Immigration Canada 1991: 46; emphasis in original).

That behaviour is, quite appropriately, located in its social context. HIV/AIDS already exists in Canada, and preventing the spread of the disease requires societal education about safe-sex precautions and individual adoption of those precautions.[4] The public health challenge is collective. The responsibility for prevention does not devolve to immigrants alone, so if immigrants were to transmit HIV to others, the responsibility for the spread of the disease would not be theirs alone. To refuse admission to immigrants solely because they test HIV-positive would be to deny society's collective responsibility for HIV/AIDS and to make immigrants scapegoats for society's failure to combat the disease more effectively.

Excessive demand for health or social services

A seemingly more compelling reason for excluding immigrants who test positive is economic. Canada's health-care systems and social service networks appear to be financially strapped and incapable of meeting the needs of everyone who lives in the country now. How, then, can immigration policies that could impose an additional strain on these services be justified?

The *Immigration Act* recognizes this concern, but the criteria it provides are not very helpful. Medical and social services for people with HIV/AIDS are available and accessible in Canada (albeit with varying degrees of difficulty, depending upon where one lives), so that is not an issue. What about preventing or delaying the provision of services? Given the familiar phenomena of crowded waiting rooms and waiting lists, *any* use of health-care services could reasonably be expected to delay provision of those services to Canadian citizens or permanent residents. Every time someone makes an appointment with a family doctor and waits patiently to be seen, that person is delaying the provision of services to everyone who has a subsequent booking. An immigrant also waiting to be seen by that family doctor would extend the delay. Does it thereby follow that admitting that immigrant causes an "excessive demand" on Canada's health-care system?

Part of the problem is that "excessive demand" has not been clearly defined in connection with medical inadmissibility, and perhaps cannot be defined with the requisite precision.[5] The *Medical Officer's Handbook* (Health and Welfare Canada 1992: 3-6) states that:

> The responsibility of the Medical Officer then is:
> (a) First, to identify and appraise those medical conditions which will now, or in the foreseeable future, place a substantial demand on medical services; and
> (b) Second, to arrive at a judgement as to whether or not that demand should be considered "*excessive*."
> (c) Again, this cannot be done on a precise, statistical basis. The Medical Officer's recommendation must rest on his knowledge of the natural history of the disease or disorder with and without treatment and in relation to age, sex and other aspects of the individual's physical and mental make-up.

Data about the utilization of health services by immigrants as a class do not exist, but even if they did, that information would not be sufficient for making assessments about "excessive demand," for two reasons.

First, the criteria for acceptance as an immigrant – and to some extent for acceptance as a refugee – are designed to ensure that the individuals admitted will make financial contributions to Canadian society through taxes and premiums, in addition to making claims on tax-supported services. Determinations of "excessive demand" therefore require a comparison of potential benefits and costs. Moreover – and this is the second reason – that comparative judgment must be made on an individual, not a class, basis. The relevant issue is whether *this particular* immigrant would contribute more than he or she would cost. Somerville picks up on this point:

> [W]ould an immigrant whose net contribution to the gross national product has outweighed any health care cost that that person engendered constitute an excessive cost to the Canadian health care system? An immigrant, who may be more productive than the average person, could contribute more in 5 years of work within Canada than that person could cost, even if he or she were to become ill and die of HIV-related disease. Would this net benefit to the Canadian economy mean that such a person should not be considered an excessive cost to the health care system? Therefore, should people with at least a 5-year life expectancy not be regarded as inadmissible as immigrants on medical grounds? (1989: 891)

Because any judgment about "excessive demand" would have to be comparative and individualized, that criterion could not justify the automatic exclusion of a prospective immigrant who tested positive.

Moreover, making "excessive demand" judgments on a comparative, individualized basis raises worries about the fairness of those judgments. The criterion assumes that there is some projected cost for the use of health-care services that is acceptable, ie, not "excessive," and that applicants who are likely to exceed that acceptable level may be excluded. Would that criterion be applied neutrally?

> Presumably, this [test] applies whether the potential candidate is a Nobel laureate, a construction worker, or a billionaire; an open question is whether a rich person who could create tax revenues in excess of projected health costs should be more welcome than the Nobel laureate or the construction worker....[6]

The problem is exacerbated by the sweeping discretion accorded medical officers and visa officers. Without standardized procedures to assess medical inadmissibility and determinate criteria to appraise "excessive demands," their decisions will inevitably be inconsistent and thus inequitable. And prospective immigrants will have no redress.

Although the financial pressures being exerted on Canada's health-care systems make every avenue for controlling costs appealing, it is not clear how or whether those pressures would be eased by barring prospective immigrants who are HIV-positive. Precise data are difficult to obtain, and estimates depend upon a host of assumptions. A cost–benefit analysis of immigrants to Canada in 1988 calculated the net benefits of testing in the decade after immigration to be between $1.7 and $13.7 million (Zowall et al 1990). That estimate must be put in context, however. The overall demand for health-care services in Canada is driven by much bigger and more powerful forces, including: the aging of the population; the ever-expanding array of expensive pharmaceutical and technological interventions; the failure of health promotion efforts to have significant impacts on behaviour such as smoking; and the expectations of public and health-care professionals. Genuine attempts to address the perceived health-care crisis should be directed at those forces, and not deflected by worries about the "excessive demand" that immigrants might impose on health-care services.

Conclusions

Being HIV-positive is not in itself a threat to public health: the spread of HIV is a result of the joint behaviour of the person from whom HIV is transmitted and the person to whom HIV is transmitted. For that reason, prospective immigrants who are HIV-positive should not be automatically excluded on the ground that they represent a danger to public health.

The notion of "excessive demand" is deceptively simple and deceptively plausible. Attempts to give it specific content and to apply it to decisions about the medical admissibility of prospective immigrants reveal, however, that it is rife with ethical problems. In the absence of compelling evidence about the contribution of HIV-positive immigrants collectively to the costs of health and social services and the likely cost of caring for individual immigrants who are HIV-positive, and in the absence of clearly defined procedures and criteria for assessing "excessive demand," prospective immigrants who are HIV-positive should not be automatically excluded on this ground.

Against Testing

Stigmatization

Widely accepted principles of law and bioethics require that HIV testing in Canada be conducted entirely on a voluntary basis, that is, only with the specific voluntary and informed consent of the person being tested (see, eg, Jürgens 1998a). To institute mandatory testing for immigrants would be to single them out and treat them differently, and that special treatment would stigmatize them as people who are particularly dangerous, particularly irresponsible, or both. Treating them differently could play into and exacerbate existing prejudices and fears:

> Sweden's ombudsman on ethnic discrimination found that citizens opposed to immigrants in general usually cloaked their prejudice by expressing it as a fear that immigrants might have some terrible, unknown disease that would be passed on to the citizens' children. AIDS has given an identifiable substance to these fears, but such prejudices should not be encouraged or given symbolic confirmation through implementation of mandatory HIV antibody testing (Somerville 1989: 893).

Moreover, that stigmatization could spread. As Galloway (1994: 161) points out in discussing the impacts of Canadian immigration law on Canadian residents: "The official exercise of prejudice against those who share the same personal characteristic will have indirect repercussions for those who, while not being subject to the specific law, are subject to the authority of the same lawmaker." Given that people with HIV/AIDS continue to suffer stigmatization and discrimination that are debilitating to them and those around them, there is no reason to invite a backlash.

> "It is inequitable ... to use cost as a reason to exclude people infected with HIV, for there are no similar exclusionary policies for those with other costly chronic diseases, such as heart disease or cancer"

Potential harm to applicants

HIV testing done in foreign countries to provide the medical documentation necessary to support an application for landing might not meet the standards required in Canada. The tests may not be as accurate, and counseling about the nature of the testing and the implications of the results could be absent or inadequate. Those being tested might not be told about the possibility of false positive results. Subsequent tests to confirm preliminary positive results might even be unavailable. In these circumstances, not only would some uninfected persons be unfairly denied entry without any means of rectifying such a serious error (Gostin et al 1990: 1745); they also could end up living with, and making decisions on the basis of, the false belief that they are HIV-positive.

In addition, people who lived in countries with harsh, coercive, or punitive policies on HIV/AIDS and who wanted to come to Canada would have to make a difficult decision. They "would be forced to choose between losing any opportunity to do this and taking a risk of what could happen to them in their country of origin if they were rejected as immigrants on the basis of HIV antibody positivity" (Somerville 1989: 893). They could pay a high price in their countries of origin for their dream of a better life in Canada.

Conclusions

In the absence of specific voluntary and informed consent to testing, high standards of accuracy and quality in testing, and adequate counseling before and after testing, HIV testing in Canada would not be ethically or legally acceptable. To subject potential immigrants to testing of a caliber lower than that required in Canada would deny their moral equality and expose them to risks and harms that are unacceptable and certainly not justified in terms of protecting this country's public purse.

Against Automatic Exclusion of Persons Who Test Positive

Parity with other diseases

With respect to the criterion of "excessive demand" on health or social services, how different is HIV-positive status from other medical conditions? This is an important question to ask, but apparently only one attempt has been made to answer it rigorously (Zowall et al 1992). The objective of this study was to compare the direct health-care costs of illnesses associated with HIV and coronary heart disease (CHD) in immigrants to Canada. As the authors of the study note, the potential economic burden of a disease on the health-care system cannot be determined by examining that disease in isolation. Rather, the economic burden of the disease "must be compared with that of other prevalent diseases (for which immigrants may or may not be currently screened) to develop a policy that is rational, practical and fair" (Zowall et al 1992: 1164). This comparison of HIV and CHD concluded that

> there are some economic savings to the health care system associated with mandatory HIV antibody screening of immigrants to Canada. However, HIV infection is not the only condition that imposes a financial burden. The impact of CHD, in terms of both the number of people affected and the associated health care costs, would be at least equal to the impact of HIV infection (Zowall et al 1992: 1170).

The list of potentially costly medical conditions and risk factors for future illness, such as tobacco consumption (Angus 1992: 1132) and over-use of alcohol, could easily be extended. Consistency and fairness demand that they be treated in the same way: "It is inequitable ... to use cost as a reason to exclude people infected with HIV, for there are no similar exclusionary policies for those with other costly chronic diseases, such as heart disease or cancer" (Gostin et al 1990: 1746). Jürgens (1998a: 207), going further still, asks:

> Should we hold persons of over 50 years of age medically inadmissible because they are unlikely to contribute significantly to Canadian society in monetary terms, but are likely to need costly health care relatively soon after immigrating to Canada? Should we screen for genetic disorders?

Such questions are not mere rhetorical devices; ethics, law, and public policy must take them seriously.

A slippery slope to genetic testing

If mandatory HIV testing of immigrants were introduced, and if parity with other diseases were accepted, the slide down an ethically problematic slippery slope could be impossible to stop. The internationally funded and conducted Human Genome Project, which will map the entire human genome, is well ahead of schedule. One outcome of all the genetic information being produced will be the equally rapid development of an extensive set of genetic screening tools. The ability of medical science to identify individuals who are more likely than the population as a whole to develop serious or lethal diseases will be enormously enhanced. It is already possible to identify carriers of a limited number of hereditary conditions, to determine the probability of transmission to offspring, and (in a much smaller number of cases) to screen for individual susceptibility. Testing for Huntington's disease is an example of the latter category. The recent commercialization of a test for the BRCA1 mutation, which confers high hereditary susceptibility to breast cancer, is almost certainly a harbinger of a much broader range of genetic tests.

Would the "excessive demand" criterion justify expanding the medical screening of immigrants to include such tests? How might that criterion be interpreted as more and more tests become readily available? What apprehensions about the medical costs of treating the offspring of prospective immigrants who are carriers of a particular condition might lead to blanket exclusions? Are we comfortable with a future in which, for example, prospective immigrants at high hereditary risk for breast cancer would be excluded based on the "excessive demand" criterion? After all, prospective immigrants are not our compatriots, and it is easy to imagine the subtle and covert introduction of "biological fitness" as a de facto test for admission to Canada.

Objectification

Somerville and Wilson (1998: 831; see also Somerville 1989: 891) note that applying the "excessive demand" criterion for exclusion might

> indicate an unacceptable attitude toward migrants as persons – in that it views them only in terms of the economic benefit they offer. In addition, it places only a monetary value on their worth – in that it states that they do not merit the cost they would present to society.

The eighteenth-century philosopher Immanuel Kant (1949[1785]: 51) emphasized that the moral status of persons gives them dignity, not value: "Whatever has a value can be replaced by something else which is *equivalent*; whatever, on the other hand, is above all value, and therefore admits of no equivalent, has a dignity" [emphasis in original]. Kant (1949[1785]: 50) argues that persons are rational beings, and that means that they must always treat themselves and others "*never merely as means*, but in every case *at the same time as ends in themselves*" [emphasis in original]. And for Kant (1949[1785]: 51), possessing intrinsic worth, or dignity, is "the condition under which alone anything can be an end in itself...." In this view, regarding prospective immigrants solely in economic terms and therefore as potentially substitutable (eg, an applicant with a medical condition that could be expensive to manage can be replaced by a more cost-effective one who does not have such a condition) denies them their inherent moral dignity and status as persons.

Conclusions

These concerns and dangers strengthen the ethical case against mandatory HIV screening of prospective immigrants, and the automatic exclusion of those who test positive. But they also point to a deeper, more insidious conflict. People can be readily regarded as means and as having value because ethics always has trouble competing with economics. Money and what it can buy are real, tangible, and immediate. Ethical values, in contrast, can appear diffuse, intangible, and remote. The contest hardly seems fair.

For that reason, it is particularly important to identify the presumptions, both about the way the world works and the way it should work, that frame public policies and are embedded in them, often without being explicitly recognized (Schrecker & Somerville, 1998: 120-122). What conceptual commitments lie behind standards, rules, policies, and operational procedures? On what grounds are they justified? With reference to what basic values and priorities? And what rules are defined by the exceptions?

Such questions are crucial to the recognition and defence of emerging international norms incorporating human rights. With respect to immigrants, most nations begin with "a general presumption of exclusion, unless certain conditions are met" (Somerville & Wilson, 1998: 825). Somerville, though, makes a case for the ethical values that a policy of not testing immigrants would promote:

> Canada could provide an important, indeed critical, example to the rest of the world if it is prepared to state that the potential costs, in economic terms, to care for people admitted as immigrants who later develop HIV-related illness are more than compensated for by the values – humaneness, humanitarian concern and respect for human rights – that we wish to uphold in *choosing* not to test asymptomatic prospective immigrants for HIV antibodies (1989: 894).

Somerville's exhortation does exactly what morality is supposed to do: get people to go beyond self-interest. One may reject the call to think in more than dollars and cents, but that rejection should be seen for what it is – a dismissal of the very claims of morality.

Conclusions and Recommendations

Restrictions on immigration for reasons of medical inadmissibility must be carefully identified and solidly justified, and the evidence for them must be clear and compelling. It is too easy, in the absence of convincing arguments and firm data, to inflate fears and exaggerate dangers. The burden of proof, therefore, is on those who want automatically to exclude immigrants who test HIV-positive in the interest of either public health or public economy.

With respect to public health, it has been accepted in Canada that that burden cannot be met. Because this position is ethically sound, we make the following recommendations.

1. The policy and practice of not deeming prospective immigrants who test HIV-positive medically inadmissible on the grounds that they represent a danger to public health should continue in Canada.

   With respect to public economy, the burden of proof might be seen to be met: providing health and social services to immigrants who are HIV-positive could be perceived as so costly as to warrant exclusion. Given the preceding analysis, this possibility must be circumscribed and developed along the lines set out in the following three recommendations.

2. The criteria for determining medical inadmissibility must not be formulated with respect to any single disease or condition:

   > [W]hat is ultimately required is *not* a discrete approach to HIV/AIDS or any other disease. This would be a step backward. What is required is a set of criteria that can be applied consistently to all dangerous, communicable diseases (Employment and Immigration Canada 1991: 46; emphasis in original).

   Policies that appear to treat people with HIV/AIDS more favourably than people with similarly serious diseases inevitably encounter the charge of "AIDS exceptionalism" (Burris 1994; Slater 2000). A policy that treated people with HIV/AIDS less favourably than similarly serious diseases would be a reverse form of AIDS exceptionalism. The motivation for the kinds of policies that initially attracted this charge was to ensure that people with HIV/AIDS were treated humanely and were not discriminated against. That approach should also prevail with respect to immigration.

   The United Nations International Guidelines on HIV/AIDS and Human Rights note:

   > Where states prohibit people living with HIV/AIDS from longer-term residency due to concerns about economic costs, States should not single out HIV/AIDS, as opposed to comparable conditions, for such treatment and should establish that such costs would indeed be incurred in the case of the individual alien seeking residency. In considering entry applications, humanitarian concerns, such as family reunification and the need for asylum, should outweigh economic considerations (UNHCHR/UNAIDS, 1998: para 106).

   Excluding prospective immigrants who are HIV-positive for economic reasons is not defensible unless analogous requirements are in place for other conditions such as cardiovascular disease, and unless anticipated future costs are assessed in a comparable way and on a comparably individualized basis.

3. Decisions about the medical inadmissibility of applicants for immigrant status should be made on an individualized, contextualized basis. Decision-making procedures that are equitable, flexible, and sensitive to changing medical and social conditions display the moral concern and respect that is owed to everyone.

4. Were the two preceding recommendations to be implemented, determinations of medical inadmissibility could in principle be made on economic grounds. The "excessive demands" criterion is, however, too conceptually thin and too ethically problematic to be the basis of such determinations. It would need to be replaced with an approach that rigorously measures the economic impact of the medical disease or condition in question, that provides substantive guidance to medical officers and visa officers, and that operates neutrally and consistently for all prospective immigrants.

– Barry Hoffmaster
and Ted Schrecker

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[1] Letter by David A Dodge, Deputy Minister, Health Canada to Janice Cochrane, Deputy Minister, Citizenship and Immigration Canada, dated 10 August 2000 (on file).

[2] This is pointed out by Watney 1990 and Sabatier 1996, among many others.

[3] Section 19.

[4] For one physician, it also entails paternalistic state action: "We have an obligation to protect the weaker people in our society who are not sufficiently prudent or conscientious to follow guidelines to protect themselves" (Green 1993).

[5] Draft regulations once tried to clarify the notion of "excessive demands" by directing Medical Officers to "bear in mind that excessive demands are caused when the total costs of health and any required prescribed social services, in the five years immediately following assessment, exceed by more than five times the average per capita expenditures for health and social services in Canada" (*Canada Gazette*, Part I, Vol 127, no 33 at 2561). For a critical assessment of this proposal, see Wilson 1994.

[6] This quotation comes from the submission of the Canadian Liver Foundation and the Canadian Association for the Study of the Liver to the Medical Inadmissibility Review. Employment and Immigration Canada, "Summaries of Submissions Received from Non-Governmental Organizations," 1991: 20.

Draft Discussion Paper on HIV/AIDS and Immigration Released

In October 2000, the Canadian HIV/AIDS Legal Network released a 57-page draft discussion paper on HIV/AIDS and immigration,[1] reacting to the announcement that HIV testing may become mandatory for all prospective immigrants to Canada. A final version of the paper will be released in early 2001.

Why a Project on HIV/AIDS and Immigration?

On 20 September 2000, Canadian newspapers reported that Health Canada recommended to Citizenship and Immigration Canada that testing all prospective immigrants for HIV, and excluding those testing positive, is the "best public health option." Subsequently, the Minister of Citizenship and Immigration, Elinor Caplan, stated that her department is indeed considering implementing mandatory HIV testing for all prospective immigrants to Canada, and excluding all those testing positive (with the exception of refugees and family-class sponsored immigrants) from immigrating to Canada on both public health and "excessive cost" grounds.

Even before these recent announcements, there was discussion and debate in Canada about the issues raised by HIV/AIDS in the context of immigration. In June 2000, the over 150 members of the Canadian HIV/AIDS Legal Network, various national HIV/AIDS organizations, and Health Canada were asked to identify which new and/or pressing issue the Legal Network should address in its current work plan. A majority of respondents asked the Legal Network to analyze legal and ethical issues related to HIV/AIDS and immigration.

What Are the Issues?

An analysis of immigration policy in the context of HIV/AIDS must consider the following questions:

1. Should visitors with HIV ever be restricted from coming into Canada?
2. Should there be mandatory HIV testing of all prospective immigrants?
3. Should persons with HIV seeking to immigrate to Canada be prevented from becoming permanent residents?
4. Should there be mandatory testing of refugees?
5. Should refugees with HIV ever be barred from entering Canada?
6. Should there be any restrictions imposed on immigrants and/or refugees with HIV who are admitted once they arrive in the country?

Activities Undertaken

In 1998, the Legal Network, as part of its joint project with the Canadian AIDS Society, provided a short analysis of the issue of whether immigrants should be mandatorily tested for HIV in its final report on *HIV Testing and Confidentiality*.[2] In 2000, the Network published an info sheet on HIV testing of immigrants in its series of info sheets on HIV testing.[3]

In June 2000, the Network started undertaking comprehensive research on the legal issues raised by immigration and HIV/AIDS. As part of this research, it conducted interviews with many key informants, and organized a workshop at the Legal Network's 2000 Annual General Meeting.

What Does the Draft Discussion Paper Contain?

The draft paper:

- describes the general trends in approaches taken to disease and migration both internationally and in Canada;
- describes Canada's current policies regarding HIV/AIDS and immigration;
- describes some of the proposed changes in immigration legislation and policy that may affect visitors, immigrants, and refugees with HIV/AIDS;
- evaluates Canada's current and proposed policies regarding immigration and HIV; and
- presents a set of **recommendations** to the federal and provincial governments for the future direction of their policies on immigration and HIV.

The draft paper does not contain an ethical analysis of the issues related to immigration and HIV/AIDS. Such an analysis can be found in another recently published paper, prepared by Barry Hoffmaster and Ted Schrecker, entitled "An ethical analysis of the mandatory exclusion of refugees and immigrants who test HIV-positive" (for a short version of the paper, see page 1 of this issue; a longer version is available at http://www.aidslaw.ca/Maincontent/issues/immigration.htm). The paper also does not contain a detailed analysis of other countries' approaches to dealing with the issue of HIV/AIDS and immigration. The Legal Network is collecting this information, and will include it into the final version of this paper.

What Are the Goals of the Project?

The goal is to contribute to a process of informed and rigorous discussion concerning the many issues related to HIV/AIDS and immigration in Canada, and to ensure that decisions about whether prospective immigrants should be mandatorily tested for HIV, and excluded from immigrating if HIV-positive, will be based on a careful analysis of the legal, ethical, and policy issues involved.

What Does the Draft Discussion Paper Conclude?

The paper concludes that:

- Canada's policy of neither testing nor excluding **visitors** with HIV (except in some rare circumstances) is satisfactory and should be maintained;
- the possible benefits of mandatory **testing** of immigrants are outweighed by its potential harms;
- any **exclusion** of a prospective immigrant with HIV on **public health grounds** is discriminatory and inconsistent with current, commonly-accepted public health practice;
- Canada's current policy of **automatic exclusion** of all persons known to have HIV on the ground that they will pose an **excessive burden** on health or social services is unwarranted, as it singles out HIV when there are other diseases

and conditions that might place greater demands on the public purse, and does not allow for a case-by-case assessment;
- prospective immigrants with HIV who have compelling compassionate and humanitarian reasons for being in Canada should be granted permanent resident status, rather than being issued Minister's Permits, which afford them no access to medical care and which may be revoked at any time; and
- all medical barriers to admission of refugees should be removed.

Next Steps

The draft paper has been widely distributed for comment and input. In particular, individuals and organizations, including federal and provincial ministries, HIV/AIDS and immigrants organizations, members of the Legal Network, and many others have been asked to let the Legal Network know whether they agree with the conclusions and recommendations in the paper; whether relevant information is missing; and whether certain areas in the paper should be expanded. A final report on HIV/AIDS and immigration will be released in early 2001, taking into account the comments and input received. The final report will be submitted to Health Canada and to Citizenship and Immigration Canada, as well as to all those to whom recommendations in the report will be directed. As usual, the Legal Network will then undertake a variety of follow-up activities aimed at ensuring that the recommendations will be implemented.

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[1] Klein A. *HIV/AIDS and Immigration: A Draft Discussion Paper*. Montréal: Canadian HIV/AIDS Legal Network, 2000. Available at http://www.aidslaw.ca/Maincontent/issues/Immigration/immigrationdraft-presentation.htm.

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[3] Immigrants and HIV Testing. Available at http://www.aidslaw.ca/Maincontent/issues/testing/e-info-ta16.htm.

DURBAN 2000: LAW, ETHICS, AND HUMAN RIGHTS

Joint United Nations Programme on HIV/AIDS
UNAIDS
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In this special section of the *HIV/AIDS Policy & Law Review*, made possible by funding received from the Joint United Nations Programme on HIV/AIDS (UNAIDS), we publish a summary and highlights of the one-day satellite conference on legal, ethical, and human rights issues related to HIV/AIDS organized by the Canadian HIV/AIDS Legal Network and the AIDS Law Project, South Africa, and co-hosted by UNAIDS. This conference was held on 7 July 2000, just prior to the XIII International AIDS Conference in Durban.

In addition, as we did in 1998 with Geneva98,[1] we reproduce the most relevant presentations on legal, ethical, and human rights issues related to HIV/AIDS given at the Durban2000 conference itself, as well as selected abstracts. With funding from UNAIDS, this issue will be mailed to over 500 people and organizations with an interest in HIV/AIDS and human rights, particularly in developing countries, in addition to the regular distribution list. The goal is to increase access to materials on human rights, legal, and ethical issues related to HIV/AIDS, for individuals and organizations worldwide; facilitate networking among individuals and groups active in the area; and promote policy and legal responses to HIV/AIDS that respect human rights.

Putting Third First: Critical Legal Issues and HIV/AIDS

On 7 July 2000, before the XIII International AIDS Conference, the Canadian HIV/AIDS Legal Network and the AIDS Law Project, South Africa held a one-day satellite meeting on legal, ethical, and human rights issues in Durban, South Africa. Entitled *Putting Third First – Critical Legal Issues and HIV/AIDS*, the satellite focused on legal strategies to advance the human rights of those most vulnerable to HIV/AIDS and to discrimination: people in the developing world, and people who, although they live in the industrialized world, suffer from poverty and marginalization and are at high risk of contracting HIV. The satellite grew out of the ongoing partnership between the Canadian HIV/AIDS Legal Network and the AIDS Law Project, South Africa, and was co-hosted by UNAIDS.

The full-day meeting gave participants from both developing and industrialized countries the chance to discuss a limited number of concrete issues in substantial depth. This opportunity does not usually occur at international AIDS conferences with abstract-driven sessions based on short presentations on many different topics. Four critical issues were identified by the organizers for discussion: access to treatment; criminal law and HIV/AIDS; legal and ethical issues relating to vaccine research; and the vulnerability of women and the role of the law. Discussion papers on these issues were briefly presented in plenary, and then discussed in greater depth in concurrent workshops. Roughly 140 people took part, including activists, lawyers, academics, policymakers, and those working in community-based service organizations.

Opening Remarks

Mark Heywood (Head of the AIDS Law Project, South Africa) and Lori Stoltz (President of the Canadian HIV/AIDS Legal Network) welcomed the participants. Dr Peter Piot (Executive Director, UNAIDS) outlined the scope of the tragedy in the developing world. His remarks are published below. The Honourable Maria Minna (Canadian Minister for International Cooperation) called on pharmaceutical companies to make drugs affordable and accessible. Dr Paul De Lay (HIV/AIDS Division Chief, United States Agency for International Development [USAID]) highlighted the global inequities that persist in access to basic medicines, and the trade pressures brought to bear on countries seeking to make drugs affordable.

In her opening address, Justice Yvonne Mokgoro of the Constitutional Court of South Africa shared the moving personal story of a family from her community, illustrating how stigma and discrimination exact a terrible human toll and frustrate both prevention and care efforts. Stigma operates as a powerful barrier to disclosing HIV infection, even to partners placed at risk, a burden that falls particularly heavily on women in their intimate relationships. The lack of access to prophylaxis to prevent perinatal transmission means yet more children born with HIV, and a greater burden on caregivers. Breaches of confidentiality, including by health-care workers, can lead to loss of job and family; fear of discrimination leads many to avoid medical care. Justice Mokgoro also highlighted the need for education of both lawyers and judges in order to advance the human rights of people with HIV/AIDS, but reminded participants that litigation is only one strategy among many in pursuit of social change. “There is no longer room for the ordinary,” she urged. “We have to take drastic steps.”

The Issues

The authors of the four discussion papers each summarized their papers briefly, highlighting issues for further discussion in smaller workshops.

Access to Treatment

Zackie Achmat, an activist with the Treatment Action Campaign in South Africa, presented a number of key principles that should guide legal and political strategies for access to HIV/AIDS treatment. He highlighted the link between preventing HIV and access to treatment. Treatment can prevent both disease progression and transmission. Access to treatment will give people hope, and a greater willingness to get tested and to disclose, thereby helping to overcome the fear and stigma that lead to human rights abuses and hinder prevention efforts. The deepest violation of a person’s dignity is the denial of equal access to social services and resources that would allow that person to live or die with dignity; treatment literacy and activism promote the rights to dignity and autonomy. Successful litigation strategies, particularly regarding socio-economic rights, will require political coalitions with broader social movements. Finally, an internationally coordinated strategy must develop and advance “a global moral consensus that a holocaust against the poor based on the lack of access to essential medicines is unacceptable.” A short version of the paper on access to treatment will be published in the next issue of the *Canadian HIV/AIDS Policy & Law Review*.

Criminal Law and HIV/AIDS

Richard Elliott, a lawyer with the Canadian HIV/AIDS Legal Network, addressed the issue of criminalizing conduct that risks transmitting HIV. A number of basic principles should guide any such use of the law, including: respect for human rights; using the best available medical evidence; and opting for the “least intrusive, most effective”approach. The traditional functions of criminalization only justify a limited use of criminal sanctions, and other considerations militate against their overuse, including the detriment to public health initiatives (eg, possibly deterring testing, breaching confidentiality for criminal prosecutions) and the implications for HIV-positive women of criminal penalties for not disclosing HIV infection to a sexual partner. Where feasible, public health officials could intervene in individual cases of conduct posing a “significant risk” of infecting others instead of having immediate resort to criminal sanctions. Such proactive measures offer greater flexibility, preserve confidentiality, and yet can still achieve the most important objective (ie, preventing transmission). A number of strategic questions must be considered: Are criminal prosecutions or public health approaches to risky conduct preferable? Shall we use traditional criminal offences or create new, HIV-specific criminal legislation? How can we avoid the misuse of the state’s coercive power? A short version of Richard Elliott’s paper is published in this issue (see infra, “Criminal Law and HIV/AIDS: Strategic Considerations”).

Vulnerability of Women and HIV/AIDS

Cathi Albertyn, Head of the Gender Research Project at the Centre for Applied Legal Studies (University of the Witwatersrand), stressed that addressing the HIV/AIDS epidemic effectively requires that we address gender inequality. She identified a number of areas in which the gender inequality that makes women vulnerable to HIV/AIDS is entrenched in the law. Using South Africa as a case study, she examined whether, and how, the presence or absence of a framework of basic human rights can advance gender equality and reduce HIV vulnerability. Engaging with the law can amount not only to “rule-making” (eg, equalizing the status of women and men in customary marriages) but also to “culture-breaking” (ie, challenging the dominant social norms). But in either case, a range of additional legal and non-legal strategies will be required to effect the social transformation necessary to reduce women’s vulnerability to HIV/AIDS. In tackling issues such as sexual autonomy, cultural and economic equality, and access to health care, housing, and basic necessities, the lessons learned from the South African context include: democratizing the state, building relationships with political parties, establishing partnerships with civil-society NGOs, and developing the expertise to participate in policy and law reform processes. A short version of Cathi Albertyn’s paper is published in this issue (see infra, “Using Rights and the Law to Reduce Women’s Vulnerability to HIV”).

Legal and Ethical Issues Related to Vaccine Research

David Patterson, a human rights lawyer and co-chair of the International AIDS Conference’s new track on rights and action, discussed the legal and ethical challenges of conducting HIV preventive vaccine research in developing countries. These fall into three principal areas: the rights and protection of research subjects and communities; the issue of equity in research and access to the benefits of vaccine research; and, finally, the need to establish local ethical review mechanisms and monitor research on an ongoing basis. Patterson reviewed both states’ obligations under international law, and the moral obligations on individual researchers and institutions under international codes of ethics. Noting that universal ethical standards in clinical research are being challenged, Patterson canvassed issues such as informed consent, undue inducement, the potential for discrimination against research participants, the potential disproportionate impact on women and girls, the standard of care for those infected during the course of the trial, and the necessity of guaranteeing that research subjects receive the benefits of any successful vaccine developed. Recommendations presented included: creating an independent, international body to advise on legal and ethical issues related to HIV vaccines; creating an international treaty on access to vaccines; insisting that industrialized countries’ obligations to promote the right to health include supporting HIV vaccine research and distribution; reforming national legislation to facilitate vaccine research while prohibiting unethical experimentation; and developing a bill of rights for vaccine trial volunteers. A short version of David Patterson’s paper is published in this issue (see infra, “Resolving Legal, Ethical, and Human Rights Challenges in HIV Vaccine Research”).

Closing Comments

Participants heard a videotaped address from Justice Michael Kirby of the High Court of Australia on the need for political leadership in protecting the rights of those infected and affected by HIV/AIDS in order to save lives. Following a summary report from each workshop, Justice Edwin Cameron closed the meeting with his eloquent comments on the theme of stigma, discrimination, and human rights running through each of the issues discussed during the day. A judge of the High Court of South Africa, and an openly HIV-positive gay man, Justice Cameron condemned the global inequity in access to medicines that meant he could attend the meeting: “I can purchase my life.” He reminded the participants that not only do we need the right concepts and actions in responding to the epidemic, as highlighted by Justice Kirby, but we also need the right feelings – our outrage, grief, and compassion must move us to action.

Sponsors and Acknowledgements

Financial support for the satellite was provided by: Canadian International Development Agency; Correctional Service Canada; Health Canada, HIV/AIDS Programs Policy & Coordination Division and the International Affairs Directorate; Joint United Nations Programme on HIV/AIDS, Liberty Life Foundation; National Institutes of Health, Office of AIDS Research; Open Society Initiative for Southern Africa, Swedish International Development Cooperation Agency; The United States Agency for International Development (USAID), through the POLICY Project, implemented by The Futures Group International in collaboration with Research Triangle Institute and The Centre for Development and Population Activities.

The organizers also wish to acknowledge the contribution of the Program Advisory Committee: Judith Auerbach, National Institutes of Health, Office of AIDS Research; Reeta Bhatia, Health Canada; Edgar Carrasco, Acción Ciudadana Contra el SIDA; Sofia Gruskin, François-Xavier Bagnoud Center; Mark Heywood, AIDS Law Project, South Africa; Florian Hübner, Groupe sida Genève; Ralf Jürgens, Canadian HIV/AIDS Legal Network; Miriam Maluwa, UNAIDS; Lane Porter, The Futures Group International/POLICY Project and USAID; M. Puravalen, Asia/Pacific Council of AIDS Service Organizations; Lauri Watson, Swedish International Development Cooperation Agency.

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[1] Geneva98: Law, Ethics, and Human Rights. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(2/3): 78-117; available at http://www.aidslaw.ca/Maincontent/otherdocs/Newsletter/spring99/geneva98.htm.

Putting Third First: Opening Statement

We reprint here the opening statement made by Dr Peter Piot, Executive Director, UNAIDS, at the opening of "Putting Third First: Critical Legal Issues and HIV/AIDS" in Durban on 7 July 2000.

Honourable Minister,
Honourable Justices,
Ladies and Gentlemen,

From its very beginnings, UNAIDS has recognized that respect for human rights is central to turning the tide of this epidemic, and we have urged that all of our work be based on such respect. As a Programme born of partnership, we are also acutely aware of the limitations of each of us working alone, and the power of all of us working together.

I am therefore extremely pleased that UNAIDS is joining with all those with whom we work regularly and closely.

Human rights, ethics, and law must be at the forefront of our multisectoral response. Simply put, AIDS is one of the most serious human rights challenges of our time. It has brought in its wake widespread discrimination and other human rights abuses, set back the right to development, and in the hardest-hit countries it threatens the very essence of human security.

The success of HIV interventions depends upon promoting and protecting human rights. I would like to raise three main points.

My first point is that respect for human rights (including civil and political, as well as economic, social, and cultural rights) is intricately linked to reducing vulnerability to HIV infection. There are many aspects – just three I feel are often neglected:

(1) Governments have a particular responsibility toward ensuring that those most vulnerable such as women, prisoners, military personnel, men who have sex with men, and sex workers are legally protected. People must be able to fulfill their rights to associate freely and have access to information if they are to organize themselves and their communities against this epidemic.

(2) In the area of economic, social, and cultural rights, we must admit that this has been a neglected area. Even in countries with limited resources, States must advance toward the realization of the highest attainable standard of

health, including through ensuring access to essential care and treatment services and commodities.

(3) The right of all people to benefit from scientific progress is often overlooked. Rules concerning intellectual property rights, while critical to the development of new HIV-related medicines, and hopefully one day a vaccine and cure, must be crafted with sufficient flexibility so that intellectual property law supports, rather than impedes, greater access. Reducing the prices of HIV drugs is essential, and we are working on this along a number of avenues. But sustainable financing for procurement is also needed, along with strengthened health infrastructures that can deliver the goods however cheaply they may be procured.

My second point is that the impact of HIV infection and AIDS is worse when other rights are not respected.

When human rights are not respected, people suffer double jeopardy. Over and above having to deal with a serious health condition, the difficulties of people with HIV are compounded by the consequent loss of other rights in many different walks of life: *the right to employment, the right to marry, and the right to privacy.* In the area of *freedom of movement*, alone, for example, far too many States impose HIV-related entry restrictions. Some States require that nationals returning to their country submit themselves to HIV testing. People with HIV have been expelled or threatened with deportation from their country of residence and separation from their families solely because of their HIV-positive status.

So where does this leave us? All this signifies a lot of misery and suffering of millions of people. In the face of this suffering, people ask: What is the worth of human rights instruments?

Above all, we must act!

But the gap between human rights aspirations and human rights realities in people's lives is not a reason to turn away from our work in this area: to the contrary, we must redouble our efforts to narrow the gap and make human rights more of a reality.

We must also frequently remind ourselves that the law can work in support of a rights-based approach, but it can also work against it. You will be discussing today a number of important aspects of the law, including criminalization of the spread of HIV infection. Such approaches, which may seem politically attractive at first glance as they give the impression that something is being done, do little to stop the epidemic and may even make it worse. Such measures lead to fear and discrimination. Fear and discrimination discourage people from getting tested and being open about their status, and from seeking out preventive and care services. Such laws are often overbroad: they make no sense from the perspective of human rights and do not represent sound public health practice.

My third point is that human rights are essential to our collective response to the epidemic.

For a long time we have known that the role of the community sector is particularly important in responding to AIDS, as it is often better placed to work with marginalized groups than government service providers.

Countries that protect human rights have a vibrant, organized community sector, free to engage in a constructive dialogue with governments over the direction and priorities of the national response. Protection and enjoyment of human rights are, therefore, essential for an effective and expanded response to the epidemic.

Above all, we must act! ***Action must be based on good science, sound public health, and universal human rights*****, if we are to limit the spread and impact of AIDS.** Let me conclude, chairperson, with four messages to individuals, governments, civil society, and the international community.

1. **To those communities already engaged in the struggle against HIV based on the respect for human rights, I say: stay your course!** We have good evidence that what you are doing works and we now need to go on to expand local and community responses in a sustainable way to increase our coverage and impact. Advocacy partnerships are the way ahead here: building strategic alliances between groups who understand

the epidemic and those who understand human rights and are more engaged in advocacy, bringing urgent issues to the attention of governments, the private sector, and the international community. Communities are the building blocks of societies, where our understanding of the epidemic must begin, be enhanced and supported, and where our best efforts must finally lead us.

2. **Governments have a responsibility to create and maintain a legal framework that protects human rights and an environment in which the rest of the community can play its part.** In the last couple of years we have seen a number of good examples, such as the Philippines' *AIDS Prevention and Control Act*. This law prohibits compulsory testing and discrimination, while protecting confidentiality and promoting AIDS education. We need more such laws and these laws need to be enforced. UNAIDS and other relevant agencies such as the Office of the High Commissioner for Human Rights have been developing and disseminating guidelines to assist States to develop such legislation.

3. **Sustainable human development and the protection and promotion of human rights, not maximizing profits, should be our collective goals in addressing an emergency of this magnitude.** There is a strong correlation between exclusion from the global economy and increased rates of HIV infection: the gap between the most privileged and the poorest nations and communities is growing, not shrinking. AIDS is both a cause and a consequence of this disparity.

4. **My final message is that each and every one of us has the opportunity to demonstrate "personal political commitment" in our families, our communities, and our countries.**

As the Universal Declaration of Human Rights states: "Everyone has duties to the community in which alone the free and full development of his [or her] personality is possible." I believe the community referred to in the Universal Declaration of Human Rights ranges from the smallest spheres of friendship and family to the largest global community, and each of us has a corresponding duty to inform himself or herself, to reflect, and then to act within all of our communities.

We have no choice but to seize this opportunity. As the UN Secretary-General, Kofi Annan, recently stressed, "AIDS is a threat to an entire generation – indeed, a threat to human civilization as a whole." In the face of such a threat, failure is not an option.

I wish you the best for today and the coming week, with all the opportunities it will offer you for learning, reflection, and commitment through action.

Resolving Legal, Ethical, and Human Rights Challenges in HIV Vaccine Research

In the absence of a cure for AIDS, attention has turned to the possibility of developing a preventive vaccine for HIV infection. Yet many scientific, ethical, legal, and economic obstacles remain.[1] At the current rate, the development and production of an effective vaccine could take 15 to 20 years or longer. If tens of millions more HIV infections and deaths are to be avoided in the coming decades, vaccine research needs to be greatly expedited. Furthermore, it must be undertaken ethically, and the products of this research must benefit people in developing countries.

This article, an edited and updated version of a paper presented at "Putting Third First," addresses challenges arising in HIV preventive vaccine research in developing countries. It does not address clinical research in developing countries relating to treatments or therapeutic vaccines.[2] Nor does it address legal and ethical issues relating to HIV vaccine research in industrialized countries, although similar issues arise in both contexts.[3] The article concludes that while ethical codes are silent on the obligation to undertake research and development, international law provides strong legal obligations – particularly with regard to industrialized states – that should be invoked to accelerate HIV vaccine development, and distribution.

Relevant Legal, Ethical, and Human Rights Principles

In the last fifty years, international laws and ethical guidelines have been developed that set out the rights and responsibilities of researchers and research subjects before, during, and after clinical research, as well as the duties of states to make the benefits of that research available nationally and internationally.[4] The following principles are drawn from two sources: public international law, and internationally recognized codes of ethics. International law and codes of ethics address both the rights of individual participants in human trials of HIV vaccines, and broader issues of equity and access affecting whole populations.[5]

International Human Rights Instruments

The Universal Declaration and the two International Covenants contain principles relevant to health, scientific progress, and international cooperation. The UN General Assembly has also addressed these issues, notably in the UN Declaration on Social Progress and Development (1969) and the UN Declaration on the Right to Development (1986). There is thus a legal basis for the moral and ethical obligations on industrialized states to promote the health, not only of their own citizens, but of people in developing countries. This includes promoting research into diseases (and HIV subtypes) specific to developing countries.[6]

International Guidelines on HIV/AIDS and Human Rights, 1998

The International Guidelines on HIV/AIDS and Human Rights provide a framework for a multi-sectoral response, including national law and policy reform, and community and private-sector involvement, based on the rights and obligations contained in international human rights treaties.[7] In particular, Guideline 6 sets out that states should enact legislation to provide for the regulation of HIV-related goods, services, and information regarding, for example, the safety and efficacy of HIV vaccines.

The Nuremberg Code, 1947

The Nuremberg Code identifies informed consent as an absolute precondition for the conduct of research involving human subjects. Its usefulness today is limited, other than to remind us of the dangers of unchecked medical experimentation.

Declaration of Helsinki, 1964 (last amended 1996)

The Declaration of Helsinki provides basic principles for the conduct of medical research on human subjects. The principles in the Declaration are reviewed and revised from time to time. In 2000, a working group prepared amendments that provided: "In any medical study, every patient – including those of a control group, if any – should be assured of proven effective prophylactic, diagnostic, and therapeutic methods."[8]

Ethical Principles and Guidelines for the Protection of Human Subjects in Research (the Belmont Report), 1979

The Belmont Report was prepared by the US National Commission for the

Protection of Human Subjects of Biomedical and Behavioral Research. Because of its clarity and authority, the Belmont Report is a standard reference on ethics in research involving human subjects. The Report sets out three basic ethical principles to guide research: respect for persons, beneficence, and justice.[9]

International Ethical Guidelines for Biomedical Research Involving Human Subjects (the CIOMS Guidelines), 1982 (last amended 1992)

These Guidelines are published by the Council for International Organizations of Medical Sciences.[10] They expand and extend the ethical principles embodied in the Declaration of Helsinki, particularly to research in developing countries. The CIOMS Guidelines were revised in 1992, in part to address specific concerns about HIV/AIDS research, and are again under revision. A preliminary consultation was held in March 2000. Background papers will be published later in 2000, and a further conference on the issues may be held in 2001.[11]

Ethical Considerations in HIV Preventive Vaccine Research: UNAIDS guidance document, 2000

In 1998, UNAIDS conducted a series of regional and international consultations to try to achieve a global consensus on key ethical issues in HIV preventive vaccine research.[12] The UNAIDS guidance document sets out UNAIDS' policy in 18 guidance points that address a wide range of issues, including: international response, access, capacity development, community representation, benefits, harms, consent, and care and treatment.[13]

An international code of ethics for business: The Global Compact

The Global Compact challenges individual corporations and representative business associations to support nine key principles relating to human rights, labour, and the environment, "which emanate from universally agreed standards found in United Nations documents."[14] The application of the Global Compact to HIV vaccine research and development has yet to be explored.

Major Legal, Ethical, and Human Rights Challenges

Discrimination

Trial participants may face discrimination. If a candidate vaccine generates HIV antibodies to certain envelope proteins in an uninfected research participant, this may result in a false-positive HIV test (eg, for matters such as insurance and employment) when an ELISA or similarly sensitive but not highly specific test is used. In this case, a Western blot or other specific test that can distinguish a "vaccine-positive" result could be used. However, such tests are substantially more expensive than the simpler screening tests, and in developing countries it may not be feasible to propose that a more expensive test be used routinely to distinguish vaccine-positive from HIV-positive results.

Discrimination may also be encountered due to mere enrolment in a vaccine trial, especially where trial participants are identified as being at increased risk of HIV infection (eg, injection drug users in the VaxGen trial in Thailand). On the other hand, given that preventive vaccine trials only enrol HIV-negative volunteers, known exclusion from a trial might also lead to stigma and discrimination. Confidentiality is key, and there is a need to share experiences of ways in which confidentiality can be preserved in such circumstances. Social harm should be monitored throughout the trial with the same vigilance as physical harm.[15]

Impact on preventive behaviour

Vaccine trials may have a positive or negative impact on preventive behaviour. A trial could result in a net increase in HIV incidence if people took more risks as a result of their participation. In practice, these fears have not been substantiated by results obtained in the US and Thailand.[16] Vaccine trial protocols must stress the need for education and counseling of all trial participants (active vaccine and placebo recipients) to ensure safer sexual practices and a reduction in harm related to injection drug use.

Impact on women and girls

Vaccine trials may result in a disproportionate impact on women and girls. Women and girls are often at greater risk of HIV infection than same-aged male counterparts for a range of biological, social, cultural, economic, and legal reasons. Particular concerns arise in the context of preventive vaccine trials. For example, consent may be coerced, or as a result of enrolling in the trial a woman may be under more pressure from her partner to have unprotected sexual intercourse. There are also concerns about the participation of women of child-bearing age in trials, owing to undetermined risks to the fetus.

Informed consent

Informed consent is crucial. There is a heavy burden on researchers to ensure that trial subjects fully understand and consent freely to their participation. UNAIDS Guidance Point 12 notes the need for consultation between community representatives and researchers to design an effective informed-consent strategy. Fears that people in developing countries cannot understand the necessary concepts may be exaggerated. For example, Richter et al have developed a practical guide for obtaining consent in the South African context.[17]

Undue inducement

Undue inducement would render trials unethical. Undue inducement is a function of both the benefits offered and the material circumstances of the individuals and community from which the research subjects are drawn. UNAIDS Guidance Point 10 identifies the benefits participants should receive. Although participation is altruistic, it is still fair to assume that volunteers will expect that the benefits of the research will somehow and sometime flow to their communities. If there is no credible plan at the outset to distribute the successful products of the research in the community where the research is undertaken, can researchers maintain consent was freely given?[18]

Participation of children

The participation of children in vaccine trials raises particular concerns. Children will also be potential HIV vaccine trial participants, and require particular arrangements for obtaining informed consent from them and/or their parents/guardians.

HIV-positive volunteers

Volunteers who test positive for HIV infection on applying to join the trial must receive attention. Only those volunteers who are initially HIV-negative can participate in the trial. As with all nominal testing, the initial screening must be accompanied by pre-and post-test counseling. It is not clear what further obligations are owed to volunteers who test HIV-positive at this stage. On the one hand, their willingness to take part in the trial should be acknowledged. On the other, special treatment (eg, medical care above the local available standard) would encourage people in the community who know or suspect they may be HIV-positive to volunteer, and the resulting financial burden might threaten the viability of the trial itself.

Treatment and care issues

Treatment and care issues for participants infected during the trial must be addressed. In spite of counseling, some trial participants will contract HIV infection through sexual contact or injection drug use during the trial. In industrialized countries, these people would usually receive a standard of care that, although it varies, now includes highly active antiretroviral therapy (HAART). Some argue that this standard should also apply to trial participants in developing countries, irrespective of local conditions.

The contrary view is that this is an unrealistic standard in many developing countries because of the cost of these drugs, and because the sophisticated medical monitoring that should accompany antiretroviral therapy is often not available. The UNAIDS Guidance Document proposes "a level of care and treatment that approaches the best proven care and treatment that are attainable in the potential host country." (Guidance Point 16)

There is a strong argument that the Declaration of Helsinki requirement that "the best proven diagnostic and therapeutic method" be afforded to trial participants does not apply to HIV preventive vaccine trials. The Declaration notes that "a fundamental distinction must be recognised between medical research in which the aim is essentially diagnostic or therapeutic for a patient, and medical research the essential object of which is purely scientific and without implying direct diagnostic or therapeutic value to the person subjected to the research." Nor does the Declaration specify whether this standard refers to the best therapy anywhere in the world, or to that which prevails in the country in which the trials are being conducted.[19]

Phase I and II vaccine trials have no intended benefit for the trial participant and hence this provision would not apply. Phase III trials may benefit the trial participant (if, of course, they receive an effective candidate vaccine and not a placebo), yet such trials do not involve the treatment of sick persons. The Commentary accompanying the CIOMS Guidelines notes that "Phase III vaccine trials do not conform to either of the categories defined in the Declaration of Helsinki."[20] On the other hand, it can be argued that there is a grey area between research that is of direct benefit and that which is of no direct benefit.

Access

Access to an effective vaccine must be assured. The principle of justice demands that those persons who are the subjects of research should also benefit from that research. The UNAIDS Guidance Document states that: "Plans should be developed at the initial stages of HIV vaccine development to ensure such availability." (Guidance Point 2)

Proposals to oblige pharmaceutical companies to provide a successful vaccine at low cost or no cost to the communities or countries where the research was undertaken may backfire within the present commercial framework, as such up-front requirements may diminish commercial interest in investing in vaccine development. This is particularly true if the research is specific to HIV subtypes found only in developing countries.

The International AIDS Vaccine Initiative (IAVI), the Global Alliance for Vaccines and Immunization (GAVI), and the World Bank have each developed proposals to promote access to vaccines in developing countries.

Provisions also exist under international intellectual property law for the issuing of compulsory licences for the local manufacture of pharmaceutical products, including vaccines, or their import in competition with the patent holder.[21] The adoption of such measures might also reduce incentives for further private-sector vaccine research and development, and hence reduce access to new vaccines from this source in the longer term.

Negotiation of social benefits

Other social benefits should be negotiated. It may take many years after a Phase III trial for a successful vaccine to be licensed, manufactured in bulk, and made available to the community where the original research took place. What other benefits, such as the development of infrastructure and training, might be negotiated as part of the agreement to participate in the trials?

> AIDS poses an unprecedented challenge to human rights and development. A preventive vaccine for HIV infection and AIDS offers a potential solution, but there are many obstacles to research, development, and distribution.

Review boards in the host country

Competent mechanisms in the host country must ensure that proposed research will be legal and ethical, monitor trials, and ensure follow-up of promised support. But which standards should apply? How will the community be represented? How can we guarantee independence from the commercial interests that fund much of the research? The pool of available expertise in some countries may be limited and there may be a real risk of conflicts of interest between persons in their review capacity and as researchers in their own right.

Even with a place on an ethics review board, community representatives may find themselves overwhelmed by the science and language of clinical research. How can we ensure community interests are defended? What opportunities are there for sharing experience between communities and countries?

An Evolving Discourse

Universal ethical standards in clinical research are being challenged. The urgent need for an HIV vaccine has led some people to question whether universal ethical standards should be maintained, given the differences in research contexts between industrialized and developing countries. HIV vaccine research is arguably different, again, from other biomedical research in developing countries. The UNAIDS Guidance Document is a response to an exceptional case, rather than an erosion of standards of clinical research in developing countries more generally.

Developing countries and communities now expect to have substantive input into the design and implementation of research. Ethical approval should not only be obtained from the appropriate body in the sponsor country, but from a competent and independent review committee in the host country as well.

Yet because of disparities in wealth, scientific experience, and technical capacity, developing countries are still vulnerable to undue influence and exploitation. Indeed, the very concept of "community" requires care.[22] Community understanding and expertise in negotiation will increase as more trials are planned and the necessary training and institutional development is undertaken.

While some basic science in vaccine research may be publicly funded, most applied research and development is increasingly undertaken by the private sector. In spite of the demonstrated need for an HIV vaccine in the developing world, the limited demand (in economic terms, and the ability and willingness of governments and individuals to pay) is a major reason why the private sector is reluctant to invest more in the development of an HIV vaccine. While an estimated $2 billion annually is spent worldwide on research for AIDS treatments, in 1999 privately funded research and development on HIV vaccines was in the range of $50-$124 million per year, with fewer than 200 scientists worldwide in the private sector dedicated to HIV vaccine–related work.[23] In the same year, total global research and development for HIV vaccines in both the public and private sectors was about $300 million. Of this amount, IAVI estimates that only $5-$10 million a year was spent on vaccines designed specifically for use in developing countries.

Further, although the economies of industrialized nations are presently fairly buoyant, and hence research funds are more readily available, a downturn in the global economy in the next few years could see much tighter constraints on public and private sector research funding.

As the scale of the disaster becomes more apparent, there will be a shift in the discourse from ethics to international law and human rights. In January 2000, the HIV/AIDS epidemic was the subject of a full day's discussion at the UN Security Council. Also in early 2000, the US government identified the global spread of AIDS as a threat to US national security and global stability.[24] As the epidemic also threatens the very stability of some states, it is increasingly appropriate and urgent to respond at the international political level.

Creative proposals to use international law to address the public health needs of developing countries include the suggestion of an international vaccine treaty. The treaty would mobilize nations to contribute to a global vaccine fund and bind signatories to minimum national levels of vaccination, thus stimulating further production, research and development.[25]

There are clear legal and moral obligations on industrialized states, and other actors, to provide the necessary technical and financial assistance to developing countries to address the HIV epidemic, including through the development of HIV preventive vaccines.

There will be increasing scrutiny and questioning of the role and responsibilities of the private sector, transnational corporations, and related multilateral organizations. Pharmaceutical research and development based on a mixed model of government and private sector–sponsored research, commercial marketing, and access to (state or private) health insurance, has had some success in developing and delivering treatments for people with HIV and AIDS in industrialized countries. However, this model has largely failed the 95 percent of the world's population with HIV who live in developing countries.

Reflecting increasing concern about the impact of globalization, the civil society declaration of the Millennium Forum, adopted in May 2000, called on the United Nations "to reform and democratize all levels of decision making in the Bretton Woods institutions and the World Trade Organization (WTO) and integrate them fully into the United Nations system, making these institutions accountable to the Economic and Social Council."[26]

The Global Compact, noted above, offers a potential framework for addressing global corporate responsibility in the context of HIV/AIDS, but the lack of any binding force has led to calls for binding international rules for transnational corporation activities, so far only in the areas of labour standards, fair trade, and environmental protection.[27] Much work remains to be done in the application of The Global Compact (and other mechanisms of influence on transnational corporations) to health, and specifically HIV/AIDS.

Conclusion and Recommendations

AIDS poses an unprecedented challenge to human rights and development. A preventive vaccine for HIV infection and AIDS offers a potential solution, but there are many obstacles to research, development, and distribution. One of the major challenges is to encourage investment in HIV vaccine research and development, particularly in relation to HIV subtypes prevalent in developing countries.

Existing international ethical standards are designed to protect research subjects and to ensure equitable access to the products of research. These ethical standards are living documents, and should be adapted as required, following consultation with stakeholders. National legislation should be reformed to make these standards legally binding.

These international ethical standards are, however, silent on the obligation to develop HIV preventive vaccines. International human rights law imposes obligations on states to safeguard and promote the health not only of their own citizens and people within their borders, but of all people. There are clear legal and moral obligations on industrialized states, and other actors, to provide the necessary technical and financial assistance to developing countries to address the HIV epidemic, including through the development of HIV preventive vaccines.

States should take measures to encourage ethical private-sector HIV vaccine and development. If the private sector cannot or will not undertake appropriate HIV vaccine research, the obligation falls on governments, particularly governments of industrialized countries, to direct and fund this research. At the same time, adequate funding should be made available for existing prevention, care, and treatment programs. HIV preventive vaccine research should not be seen as a "back door" to treatments for HIV/AIDS.

The focus on HIV vaccine must not divert attention from difficult questions relating to sexuality and drug use.[28] Greater attention also needs to be paid to the present global economic (dis)order and North–South disparities.[29]

Above all, we must acknowledge that the development and distribution of an HIV preventive vaccine in developing countries will take many years, perhaps decades – or we may never have an effective vaccine for HIV/AIDS. We must strengthen, not relax, other prevention efforts. Finally, we must remain aware that AIDS is an expression of gross global inequity, and that solutions such as vaccines are at best an intermediate step to addressing this overarching issue.

– David Patterson

David Patterson is a human rights consultant based in Geneva, Switzerland. He can be reached at david.patterson@attglobal.net. The full text of this paper, including a list of related articles, reports, and other documents on the issue of HIV/AIDS vaccines, can be found on the website of the Canadian HIV/AIDS Legal Network (http://www.aidslaw.ca/durban2000/e-durban-vacc.htm). The full text of the paper also provides a list of key resources containing information on this issue.

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[1] For a succinct summary, see AIDS Vaccines in the Developing World, Fact Sheet, Interagency Coalition on AIDS and Development, 1999 (www.icad-cisd.com), reprinted in the *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(4): 41-43 (also available at http://www.aidslaw.ca/Maincontent/otherdocs/Newsletter/summer99/vaccines.htm).

[2] See generally: The ethics of clinical research in developing countries. Nuffield Council on Bioethics, 1999 (www.nuffieldfoundation.org).

[3] The Canadian HIV/AIDS Legal Network, in partnership with the Centre for Bioethics of the Clinical Research Institute of Montréal, will be publishing a paper in early 2001 on the legal, ethical, and human rights issues raised by the development and eventual availability of a vaccine for HIV/AIDS. See also Kerns A. *Ethical Issues in HIV Vaccine Trials.* New York: St Martin's Press, 1997; Grady C. *The Search for an AIDS Vaccine*. Bloomington: Indiana University Press, 1995.

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[14] The Global Compact (www.unglobalcompact.org).

[15] Sheon A et al. Preventing discrimination against volunteers in prophylactic HIV vaccine trials: lessons from a Phase II trial. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology* 1998; 19(5): 519-526 at 524.

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[21] *Globalization and Access to Drugs: Perspectives on the WTO/TRIPS Agreement*. Health Economics and Drugs, DAP Series No 7, Geneva: World Health Organization, 1997, 2nd ed. Contact: Documentation Centre, Essential Drugs and Other Medicines, World Health Organization, 1211 Geneva 27, Switzerland (email: darec@who.ch). See also: Compulsory licensing and parallel importing: what do they mean? Will they improve access to essential drugs for people living with HIV/AIDS? ICASO background paper, 1999 (www.icaso.org).

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Criminal Law and HIV/AIDS: Strategic Considerations

Richard Elliott's paper on criminal law and HIV/AIDS, an edited and updated version of his presentation at "Putting Third First," sets out five guiding principles for criminal law policy and HIV/AIDS; briefly outlines the rationales for criminalization; discusses three strategic legal questions regarding the criminalization of HIV transmission/exposure; and offers a number of recommendations for consideration of those needing to articulate a well-considered perspective on the ethical, legal, human rights, and public health dimensions of the criminalization of HIV transmission/exposure.

Introduction

In numerous jurisdictions, criminal sanctions have been invoked against HIV-positive people for conduct that transmits, or risks transmitting, the virus. But calls for criminalization or other coercive state measures have often appealed to prejudice and fear. Generally absent is any critical reflection as to the appropriate role of such policies in responding to HIV/AIDS. The result is not only criminalization, but an ill-considered overreaction that overextends the criminal law.

To date, prosecutions for HIV transmission/exposure have been reported primarily in developed countries, but the criminalization of HIV transmission/exposure has recently begun to receive increased attention in developing countries and countries in transition. Court cases and proposed laws have focused primarily on two kinds of conduct by HIV-positive people. First, even though such conduct is already criminal, regardless of a person's HIV status, assaults such as biting or spraying of bodily fluids (often at police, prison guards, or paramedics) have often led to more serious criminal charges (and sentences) when committed by an HIV-positive person. Second, HIV-positive individuals who conceal their status from, or do not disclose it to, their sexual partners have been charged with a variety of criminal offences (sometimes under specific laws that make this an offence).

At some point, every jurisdiction will likely have to deal with a case of an HIV-positive person who, aware of their infection, engages in conduct that causes or risks transmission. Public health authorities, police, prosecutors, the judiciary, and legislators will be confronted with the difficult questions raised by proposals for criminalizing such conduct. People with HIV/AIDS, community-based organizations, and other service providers, as well as advocates and human rights activists, will need to respond to the inevitable proposals for criminalization. How to do so will depend upon the political landscape of the jurisdiction, the existing legislation that may be applicable or relevant, the manner in which the issue has been placed on the policy agenda, the state of development of a community-based HIV/AIDS movement, and its capacity to articulate important points that need to be heard in this debate.

Sound public policy in this area is necessary to prevent the misuse of coercive measures, minimize the harm to people with HIV/AIDS and vulnerable communities, and minimize the negative effects on HIV prevention efforts and on access to care, treatment, and support. Presented here is an overview of the factors that should be taken into account by policymakers, activists, lawyers and other advocates, and people with HIV/AIDS, when analyzing the issue of criminalizing HIV transmission/exposure. The following sections

- set out five guiding principles for policy development;
- outline the functions of criminal law and a number of other policy considerations;
- identify three strategic questions regarding criminal law and HIV/AIDS; and
- offer a number of recommendations for discussion.

Guiding Principles for Criminal Law Policy and HIV/AIDS

To ensure that state policy is sound, a number of principles should guide state policy regarding the use of criminal sanctions or coercive public health measures, and any discussion of strategies.

- First, states should *respect and promote human rights*, as set out in the HIV/AIDS and Human Rights International Guidelines.[1]
- Second, *if* resort is had to the criminal law, then *preventing HIV transmission must be the single most important objective* of doing so. HIV prevention should not be sacrificed in pursuit of other criminal law policy goals (such as retribution).
- Third, decisions regarding the scope of the criminal law's application must be based on *the best available evidence* regarding modes of transmission and levels of risk. Irrational, overbroad uses of the law are unjust and endanger the public health by communicating misinformation about how HIV is transmitted.
- Fourth, *coercive measures are of limited utility* in responding to HIV transmission. They will be inapplicable or ineffective with respect to most instances of HIV transmission or exposure, and may undermine more effective initiatives to prevent the spread of HIV and provide care to those living with the disease.
- Fifth, coercive measures should be used sparingly and as a last resort, on the principle that the *least intrusive measures possible* to achieve the demonstrably justified objective is always to be preferred, so as to minimally impair valuable rights and interests.

Keeping these guiding principles in mind helps in assessing the strength of arguments for and against various coercive measures, and in answering specific questions about how, and to what extent, the criminal law should be applied.

Criminalization: Pros and Cons

To determine the justifiable parameters of the criminal law with respect to HIV transmission or exposure, we must consider both the rationales for criminalization and other policy considerations that suggest a restrictive approach to its use.

Functions of criminal law

There are four primary arguments for invoking criminal law, but they offer at best a limited justification for criminalization in the context of HIV transmission. First, the *incapacitation* argument – that imprisonment prevents a person from harming others – is weak. Prisons are environments in which high-risk activities (unprotected sex, sharing needles) are common and even likely, and some prisoners in some countries also receive conjugal visits. Most prisoners are eventually released, meaning HIV transmission inside prisons affects the health of the public outside.

Second, it is said that criminalization will bring about *rehabilitation* – in the sense of preventing risk behaviour in future. This claim is dubious, given the nature of sexual activity and drug use (which account for most cases of HIV transmission). Rehabilitation is a complicated matter. It seems more likely that other interventions (eg, counseling, addressing underlying drug use or poverty, etc) will lead to long-term changes in risk behaviour, preventing further transmission.

Third, the goal of imposing *retribution* can only justify criminal sanctions in cases where the conduct is so morally wrong that it deserves punishment by the state through the use of its harshest measure. Where there is no "guilty mind," and hence no moral culpability, criminal penalties cannot be justified. Furthermore, not every morally wrong act should also be defined as a crime, so only a small subset of cases of HIV transmission/exposure could justifiably be criminalized on the basis that such harsh punishment is deserved.

Fourth, the argument that criminalization will *deter* people from conduct that risks transmitting HIV may hold some theoretical attraction, but is of questionable practical value.

The law could only have any appreciable effect in cases where a person (a) knows they are HIV-positive, (b) considers the potential for criminal penalties, and (c) as a result, modifies their conduct by avoiding or reducing activities that risk transmission and/or by disclosing their status to the other person. It would be dangerous to the public health to overestimate the deterrent value of the crude tool of criminal prohibitions on such complex, intimate, deeply ingrained human behaviour as sex or drug use, often not motivated by fully rational assessments of risks and benefits. Any deterrent effect would also be undermined when a person's ability to disclose their HIV-positive status or to avoid or reduce risk is impaired (eg, by stigma and discrimination, possibility of violence, poverty, addiction, etc). Similarly, social, economic, and legal realities often undermine any deterrent effect of criminal prohibitions (eg, already widespread impunity for men who harm women or children, or place them at risk of harm).

Policy considerations suggesting restraint

There are also a number of other reasons why criminal law is limited as an HIV prevention tool and why its application to HIV/AIDS should be restricted.

First, there are *difficulties with proof* on a number of fronts, including uncertainty as to what physical and mental elements it should be necessary to prove for a conviction. It would be unjust to prosecute and imprison a person who did not even know they were HIV-positive. But should a conviction also require that the person knew their conduct posed a risk of transmission? What level of mental culpability (*mens rea*) should be required for criminal liability: intention to harm or to risk harm? recklessness about whether harm occurs? mere negligence? Furthermore, in most cases, only the participants in an activity that usually takes place in private will be able to give evidence as to what was disclosed or not, or what acts took place. The credibility of the HIV-positive accused, or of a complainant, could determine their criminal liability in such a case.

> The same gender inequality factors that increase many women's vulnerability to HIV infection will also hinder their ability to avoid or reduce the risk of transmission to husband or other male partner. Criminalization does not address these.

Second, criminalization could *damage important public health initiatives* in a number of ways, particularly if overextended or misused. The media coverage of court cases or new legislation inevitably contributes to the stigma surrounding HIV disease and people with HIV/AIDS as "potential criminals." Any effect in deterring risk activity could ultimately be outweighed by deterring people from getting tested for HIV, so as to avoid possible criminal liability for not disclosing (although the significance of this potential effect is hard to gauge). If the confidentiality of counseling sessions will be breached by search warrants or subpoenas in pursuit of evidence for a criminal prosecution, this undermines access to support for people with HIV/AIDS that may in fact assist in changing risk behaviours. Creating a category of "other" people who are the sole focus of criminal sanctions may create a false sense of security among people who are (or think they are) HIV-negative, encouraging risky behaviour on their part. Finally, the overextension of the criminal law, particularly when accompanied by sensational media reporting, undermines efforts to educate the public about how HIV is, and is not, transmitted.

Third, criminalization may, in practice, amount to *selective prosecution* of those who are socially and/or economically marginal and are associated in the public mind as the "guilty" people with HIV/AIDS. The singling out of HIV, and people living with HIV, for criminalization is also a form of selective prosecution. As the AIDS Law Project South Africa has pointed out,

> the intensity of the demand for criminalisation of HIV transmission may itself be a reflection of the prejudices surrounding the HIV epidemic, because no comparable demand has arisen in response to transmission of other sexually transmitted diseases which, although less serious in their medical consequences, are in fact more easily transmitted than HIV and nonetheless result in physical and emotional harm to the person infected.[2]

Fourth, while we may understand the desire to protect women at risk of HIV infection from male partners by invoking the criminal law for risk activities, a concern about *gender inequality* means we must also consider the effect of criminalization on women – particularly women with

HIV/AIDS. Some women exposed to HIV or infected by their partners may not benefit from the prosecution and incarceration of their partner if this means a loss of economic support for them or their children.[3] Criminalization may be "tainted by gender bias"[4] if it fails to account for differing levels of risk: all else being equal, the risk of female-to-male transmission is lower than male-to-female transmission (although this difference may not be great enough that a court would consider it legally significant). Also, the same gender inequality factors that increase many women's vulnerability to HIV infection will also hinder their ability to avoid or reduce the risk of transmission to husband or other male partner. Criminalization does not address these. For example, research reveals physical violence against people with HIV/AIDS following disclosure,[5] including HIV-positive women at the hands of male partners.[6] In such circumstances, criminalizing non-disclosure and/or unsafe sex does not protect those who are vulnerable; it compounds the dual burden of vulnerability and HIV.

Finally, consider the *intrusion into privacy* that criminal prosecutions would entail for both the accused HIV-positive person and the complainant, whose sexual histories and "confidential" records kept by health professionals or counselors would become evidence in the courts. Court orders suppressing media reporting of a person's identity are a partial solution at best.

Strategic Questions

Three strategic legal questions regarding the criminalization of HIV transmission/exposure are briefly discussed here.

Criminal prosecutions or public health interventions?

"One reason people tend to accept uncritically criminalization of HIV is that they do not compare it to other possible methods of dealing with the problem."[7] Most jurisdictions grant powers to authorities to protect the public health, which could be used to intervene in cases of conduct that risks transmitting HIV. In addition to education, counseling, and support, the law may also authorize more coercive measures, such as compelling a medical exam, orders to refrain from certain kinds of conduct, and detention for breach of a public health order or if otherwise necessary.

Positive attributes of public health interventions

A number of factors suggest that the exercise of public health powers may be preferable to criminal prosecutions.

- First, they offer greater flexibility. Tailoring an intervention to an individual's specific circumstances (including addressing underlying causes of risk behaviour) is likely to be more effective in changing behaviour.
- Second, they are proactive measures aimed at preventing risk activity, rather than solely reactive to events that have already occurred.
- Third, they are more private interactions, preserving confidentiality better and avoiding further stigmatization associated with HIV.
- Fourth, for these reasons, public health interventions achieve the most important goals as well as, or better than, criminalization. While the criminal law is certainly better suited for *retribution*, this cannot be the prime determinant of public policy. Public health interventions are more likely to achieve *rehabilitation* (ie, behaviour change). If ultimately necessary, they offer a more effective means of *incapacitation* (detention in a health setting rather than a prison). Absent additional research, we can only speculate whether criminal sanctions or public health interventions will have a greater effect in *deterring* risky behaviour, the key consideration. But experience suggests the activities accounting for most HIV transmission (sex and injection drug use) are highly resistant to change, persisting in the face of criminal prohibitions. An individualized approach, addressing the causes of risk activity, may be more effective.

Other considerations

Two other factors must also be considered in deciding whether criminal prosecutions or public health interventions are the preferable route.

- First, public health laws may not always offer the same degree of (at least theoretical) protection against deprivations of liberty as the criminal law, and interventions may frequently be directed at marginalized individuals already subject to governmental surveillance as "clients" of the mental health, criminal justice, disability, or drug/alcohol systems.[8] But the same rights and interests are engaged, so substantially equivalent protections should be incorporated. "Due process protection" in the application of public health or criminal laws to restrict the rights to liberty and security of the person is required as a matter of human rights.[9] This suggests that there is a need for reform to public health laws, not that criminalization is a preferable policy response.

- Second, public health interventions may not represent as viable or credible an alternative to criminalization if lack of resources undermines their feasibility. The resources needed to staff and sustain a public health system, and accompanying services to address issues such as drug addiction, domestic violence, intellectual disability, mental illness, or poverty, may simply be unavailable in many developing countries (and stretched in wealthier countries). But rather than necessarily suggesting a greater role for the criminal law, this highlights the need for adequate resources for more effective measures to prevent HIV transmission.

Existing offences or new HIV-specific laws?

If criminal prosecutions are to be pursued, should this take the form of applying traditional offences or should new criminal legislation specific to HIV be enacted? The answer depends in part on the existing state of the law in a given jurisdiction.

When clearly applicable provisions already exist (eg, an offence of knowingly spreading disease), there is no need for any HIV-specific legislation (although the existing laws may be poorly drafted or misused). Where no such provisions exist, the criminal law's application to HIV transmission/exposure will be shaped by prosecutorial initiative and judicial interpretation of other traditional criminal offences (eg, assault) in response to specific complaints. In some cases, this has led to legislators' proposals for legislation against certain acts that transmit or may transmit HIV, often in response to particular cases and political pressure.

Enacting "criminal HIV exposure" laws may mean greater certainty as to what is prohibited, and a carefully drafted statute could minimize the likelihood of judicial waywardness that overextends the law in interpreting generic criminal offences. But there is no guarantee that the highly politicized legislative process will necessarily provide a considered, measured approach either. Indeed, there are good reasons why the International Guidelines on HIV/AIDS and Human Rights recommend against HIV-specific legislation.[10]

- First, such statutes will be unnecessary in many cases because existing laws may be adequate, without singling out HIV/AIDS.
- Second, creating a new offence could compound the problem of criminalization: the benefit of careful legislative drafting to prevent misuse of the criminal law would be squandered unless it also expressly ousted the applicability of other offences.
- Third, an HIV-specific statute would be unlikely to have any additional deterrent effect over and above the deterrent effect (such as it may be) of criminal prosecution under traditional criminal offences.
- Fourth, and most significantly, the legislative process would further stigmatize HIV/AIDS, deterring HIV testing, undermining education efforts, and impeding access to counseling and support services that will assist behaviour changes.

How to prevent misuse of coercive powers?

Attempts to prevent the misuse of criminal or coercive public health laws could involve a number of complementary strategies.

- First, the *proactive educational strategies* that best advance sound public policy are not those that invite the debate on criminalization, but rather those that focus on eliminating HIV/AIDS-related stigma and discrimination. This may reduce the degree to which prejudice, misinformation, and fear drive demands for harsh overreactions. Targeted educational initiatives could educate the primary parties responsible for shaping the law in this area.
- Second, people with HIV/AIDS and community-based organizations will need to *respond to proposed legislation* or make submissions to advisory bodies studying the issue of criminal law and HIV.
- Third, if proceedings are underway that may establish or clarify the parameters of the law, careful consideration should be given to *intervening in legal proceedings*, in an attempt to influence the outcome through submissions on the policy considerations.
- Fourth, community-based organizations may review existing "soft law" such as regulations, guidelines, policies, and protocols governing criminal prosecutors and public health authorities, measuring them against the provisions of domestic and international human rights law, as well as the guiding principles identified above and in the International Guidelines on HIV/AIDS and Human Rights.

Recommendations

The following recommendations are offered for consideration by those needing to articulate a well-considered perspective on the ethical, legal, human rights, and public health dimensions of the criminalization of HIV transmission/exposure:

1. Lobby for strong, accessible, and enforceable legislation protecting confidentiality and freedom for discrimination for people with HIV/AIDS and vulnerable groups. Lobby for access to prevention information and materials, as well as care, treatment, and support for those who may be exposed to the risk of infection.
2. Undertake educational campaigns on HIV/AIDS, including how it is and is not transmitted, including for public health authorities, police, prosecutors, lawyers, the judiciary, and legislators and other policymakers. Stress the need for a reasoned approach in the face of political pressure for a "get tough" response, and the importance of proven public health strategies for fighting the epidemic.
3. Prepare an analysis or position statement on the criminalization of conduct that causes or risks HIV transmission, through community discussion and consultation, including people with HIV/AIDS and members of communities vulnerable to both HIV and discrimination.
4. Articulate that analysis, when necessary, to: government officials responsible for justice, health, and prison portfolios; legislative committees or law commissions examining the issue; community-based HIV/AIDS organizations and other service providers; public health authorities and workers; and lawyers and other advocates and human rights activists.

> If criminalization "serves to undermine our overall public health response to the HIV epidemic, then we must seriously question whether the gains from criminalization are worth it."

5. Respond to cases of criminal or public health prosecutions, should they arise, both by addressing the general public through a media strategy and by making submissions (if possible) to judicial bodies holding legal proceedings, in cooperation with other community-based organizations sharing similar policy concerns.
6. Engage in dialogue with police, prosecutors, and public health in developing guidelines or protocols for handling cases in which an HIV-positive person may engage in conduct that risks transmission. Through this process, develop guidelines for the use of public health powers and a graduated approach to the use of coercive measures.

Conclusion

"Each of the usual rationales for the criminal law – retribution, incapacitation, and deterrence – appear ill-suited to deal with a disease epidemic."[11] At the same time, a number of public policy considerations suggest that invoking the criminal law should only be done with restraint. Overall, we must consider whether criminalizing risky conduct will protect and promote public health. If criminalization "serves to undermine our overall public health response to the HIV epidemic, then we must seriously question whether the gains from criminalization are worth it."[12]

– Richard Elliott

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The full text of this paper, including a list of related articles, reports, and other documents on the issue of criminal law and HIV/AIDS, can be found on the website of the Canadian HIV/AIDS Legal Network at http://www.aidslaw.ca/durban2000/e-durban-crimlaw.htm. The full text of the paper also provides a list of key newsletters and journals publishing information on this issue, as well as websites containing such information.

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[1] Office of the United Nations High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS. HIV/AIDS and Human Rights: International Guidelines. New York and Geneva: United Nations, 1998, paras 10 & 72.

[2] AIDS Law Project South Africa (H Axam et al) Response Paper to the SA Law Commission's Discussion Paper, 1999 (http://www.hri.ca/partners/alp), at endnote 72.

[3] Comment at workshop from F Hassan, staff attorney, AIDS Law Project South Africa, 7 July 2000.

[4] Bobinski MA. Women and HIV: a gender-based analysis of a disease and its legal regulation. *Texas Journal of Women and the Law* 1994; 3: 7.

[5] Zierler S et al. Violence victimization after HIV infection in a US probability sample of adult patients in primary care. *American Journal of Public Health* 2000; 90: 208-215.

[6] North RL, Rothenberg KH. Partner notification and the threat of domestic violence against women with HIV infection. *New England Journal of Medicine* 1993; 329: 1194-1996; Rothenberg KH et al. Domestic violence and partner notification: implications for treatment and counseling of women with HIV. *Journal of the American Medical Women's Association* 1995; 50: 87-93; Rothenberg KH, Paskey S. The risk of domestic violence and women with HIV infection: implications for partner notification, public policy, and the law. *American Journal of Public Health* 1995; 85: 1569-1576.

[7] Bobinski MA, in ML Closen et al. Criminalization of an epidemic: HIV/AIDS and criminal exposure laws. *Arkansas Law Review* 1999; 46: 921 at 969.

[8] Gibson S. "Knowingly and recklessly": the policy and practice of managing people who place others at risk of HIV infection. *HIV/AIDS Legal Link* 1997; 8(3): 6-9 at 7.

[9] International Guidelines, supra, note 1 at para 112.

[10] International Guidelines, supra, note 1, Guideline 4, para 29(a).

[11] Gostin L. The politics of AIDS: compulsory state powers, public health, and civil liberties. *Ohio State Law Journal* 1989; 49: 1017 at 1056.

[12] Dalton HL. Criminal Law. In: S Burris et al. *AIDS Law Today: A New Guide for the Public*. New Haven: Yale University Press, 1993, at 255.

Using Rights and the Law to Reduce Women's Vulnerability to HIV

Cathi Albertyn's paper, an edited and updated version of her presentation at "Putting Third First," argues that both human rights and the law can play an important, if limited, role within a wider set of national and international strategies to reduce women's vulnerability to HIV. It analyzes the nature of women's vulnerability to HIV/AIDS, and highlights some of the issues and lessons in using rights and the law to advance gender equality and reduce women's vulnerability to HIV/AIDS.

Introduction

Of the 34.3 million people living with HIV/AIDS at the end of 1999, an estimated 24.5 million (71 percent) were in sub-Saharan Africa and about one in six (5.6 million) in South and Southeast Asia. Women represent 55 percent of all people with HIV/AIDS in Africa, and in Africa and South and Southeast Asia, women and girls (15-24 years) experience the highest rates of infection.[1] Indeed, it is women and girls who are increasingly bearing the brunt of the HIV/AIDS epidemic. Underlying this is the fact of women's and girls' inequality that shapes their increased vulnerability to HIV infection and their disproportionately high responsibilities as caregivers for the sick and dying as well as for the living. Thus, while physiology affects women's greater risk of HIV transmission, it is women's and girl's lack of power over their bodies and their sexual lives, supported and reinforced by their social and economic inequality, that make them such a vulnerable group in contracting, and living with, HIV/AIDS.[2]

The concentration of HIV/AIDS not only within the developing world, but also within the more vulnerable groups within that world, suggests that the extent of the epidemic is directly related to global and national social and economic inequalities. It also means that strategies for dealing with the epidemic must have at their core a comprehension of these inequalities. It is therefore a fundamental assumption of this paper that (a) if we agree that changing sexual behaviour is at the core of reducing HIV infection, and that (b) if efforts to change sexual behaviour require changes in the social and economic power relations in society, then our ability to address the HIV/AIDS epidemic is inextricably linked to our ability to address gender inequality at all levels.

The HIV/AIDS epidemic therefore involves greater attention to changing gender and global inequality, including poverty. This long-term task of transforming gender and economic relations can be accompanied by more short-term legal and rights-based strategies to address HIV/AIDS. These relate to (a) the need to insert gender and gender equality concerns into laws, policies, and programs that address HIV/AIDS (in relation to prevention, treatment, and care) and to (b) the related need to address the status of women and girls more generally. Within this broad context, we need to identify where, and how, rights and legal strategies can make a difference in various national contexts.

Women's Vulnerability to HIV/AIDS

The claim of a causal connection between HIV/AIDS and gender inequality is a deceptively simple one. The reality is much more complex where unequal gender relations necessitate an understanding of men's relative power and women's relative powerlessness in a way that does not deny male vulnerability to HIV/AIDS, but seeks to understand how and why women are relatively more at risk.

Although women are more vulnerable than men, statistics suggest that not all women are equally vulnerable to being infected and affected by HIV/AIDS, because women are not all equal. Not only is women's vulnerability to HIV/AIDS rooted in their sexual, social, and economic inequality, but this gender inequality is further fragmented by factors such as race, class, urban/rural location, sexual orientation, religion, and culture. Understanding the differing vulnerability of specific groups of women is crucial, not only for (a) identifying the complex causes of women's vulnerability, but also for (b) finding effective solutions that address the many causes and manifestations of this inequality.

Demographic portrayals of the epidemic in South Africa, for example, suggest that it is the women who are most unequal in social and economic terms who are most at risk of infection. People with HIV/AIDS are not only more likely to be women; they are more likely to be poor, African women. Young African women and girls are increasingly at risk. However, infection rates are also particularly high among monogamous married women. Vulnerable groups also include sex workers, migrants, and refugees.

Research suggests that for African women, HIV vulnerability emerges from an intersection of poverty with culture, since African women are more likely to be subject to social and cultural norms that result in their having no say over sexual relations. It is widely held that men have the right to make all decisions regarding sexual relations. Klugman writes that "[i]f a husband initiates sex, his wife may not refuse him; the same applies in relationships outside of marriage. This makes it impossible for women to protect themselves from HIV/AIDS by initiating non-penetrative sex … or insisting on fidelity or condom use. Women are … also products of this culture and may themselves have internalized ideas of manhood that make it appropriate for men to have many partners and to manage sexual relations while they accept their partner's dominance and remain faithful."[3] Violence against women and girls also plays a major role in the spread of HIV. Often, violence is so pervasive that men and women come to accept coercive, even violent, sex as "normal."[4]

> We all know that gender is about power. In terms of power, the woman is the subordinate partner.

The intersection of poverty (or economic inequality), culture (or social inequality), and gender in increasing vulnerability to HIV is illustrated by the reality that poor women may resort to bartering sex for survival. This not only occurs in the form of commercial sex work, but also in other forms of "bartering" behaviour that are not seen as "sex work." Here women form sexual relationships to ensure food and maintenance for themselves and their families. Thus, in many societies, men provide women with desired goods in return for sexual access on a one-off, or short- or long-term basis. Sex may also be traded for a job, permit, or promotion in the employment sphere, and for marks or fees in the educational sphere. Most of this sex is unsafe because women risk loss of economic support from men by insisting on safer sex.[5]

While it seems that African women are more vulnerable because of their greater inequality, not enough is known about the pattern of the epidemic to understand how the varied and complex interplay of economic status, sociocultural norms, and the ability (or lack thereof) to negotiate sexual relationships plays out in all communities here and across the world.[6] It is only from a clear understanding of this within discrete national and cultural contexts that effective strategies for prevention, treatment, and care can be developed. At the same time, more needs to be known about men and masculinity in different cultural and national settings.

Gender-specific roles combined with poverty and sociocultural attitudes toward women and girls mean that they bear the burden of caring for the sick.[7] Research has also found that HIV-positive women face discrimination in health care, education, and legal rights. They are also more likely to be blamed, stigmatized, and even abandoned by their families. Rural women are particularly at risk. [8]

It is this intersection of different aspects of gender inequality with HIV vulnerability that has prompted the call for a more integrated and holistic approach to HIV prevention and care.[9] This involves a focus both on risk reduction and the removal of social, cultural, and economic barriers to effective prevention behaviour.

It also means addressing the health, social, and economic needs of those who are HIV-positive or living with AIDS, as well as protecting people with HIV/AIDS from discrimination and stigma. Easing the burden of care through a variety of measures is also critical. Importantly, one has to move beyond questions of health and science to address critical questions of poverty, development, and human rights. Given the multiple levels of inequality that converge to shape women's particular vulnerability to HIV/AIDS, these issues can be categorized according to "levels of gender inequality" rather than the more conventional division of prevention, treatment, and care. This model could serve as a basis for a more extensive comprehension and audit of gender equality and its relationship to HIV/AIDS within particular national settings. It is set out very briefly here, together with some indication of the legal and human rights issues involved.

Women's personal autonomy

This refers to women's actual autonomy over her "self" – physical, mental, and moral. It not only relates to (and is measured by) decisions and choices about reproduction and sexuality, but also to moral autonomy more broadly and to freedom from physical or emotional violence. It relates directly to women's ability to protect themselves from HIV infection in sexual relationships, and includes the ability to decide when and whether to have sex, to engage in certain sexual practices, and to use contraception. It implies good reproductive health and the ability to make reproductive choices. Importantly, it means that women should be free of violence and coercive sex. This area is particularly, but not exclusively, addressed by a range of rights and laws encompassed in reproductive and sexual rights and violence against women.

Clearly, the development of rights campaigns under the "umbrella" of sexual or reproductive rights, the right to be free from violence, or the right to equality are all highly relevant to the question of HIV/AIDS. Such campaigns would bring together legal and non-legal strategies and could include the following critical gender areas:

- access to female condoms and microbicides;
- a focus on male practices and attitudes;
- access to information about safe-sex practices and reproductive health services;
- access to prevention of parent-to-child transmission; and
- access to post-exposure prophylaxis for rape survivors.

While these issues can be framed in terms of rights and can form the basis of advocacy, research, educational, and other strategies; they are less likely to be the subject of legal strategies such as law reform or litigation. An exception to this is in legal contexts where it is possible to advocate for law reform or litigate on the basis of socioeconomic rights, such as the right to health care (see below). Law reform and litigation initiatives could be targeted at the following issues:

- ensuring a legal framework for protection against violence, and effective enforcement of the law;
- ensuring an appropriate legal framework for sex work (decriminalization, but without punitive measures);
- ensuring the right to choice, both in terms of termination of pregnancy and in terms of the rights of HIV-positive women to have children;
- developing regulations for, and enforcement of, a right for rape survivors to be informed by the police/district surgeon about the need to access antiretroviral drugs to prevent possible HIV transmission;
- undertaking legal action to obtain drugs to reduce parent-to-child transmission if it is possible in a national context to rely on the right to reproductive choice or the right of access to health care.

Women in relationships and the family

In many countries, women still do not enjoy equal rights within relationships, including marriage, and the family. Some women are still subject to forced, arranged marriages, often at an early age. Women may also be denied equal rights to marital property and may lack the authority or equal ability to initiate or oppose divorce. Inequality within the family emerges from and is reinforced by stereotypes of women as subordinate that render them vulnerable to violence and coercive sex within marriage. Such inequality reinforces women's powerlessness in sexual relationships and their economic dependence on men.

In India, the legal status of women in practically all spheres of law – eg, consent to sex, marriage, divorce, maintenance, and inheritance – is subordinate to that of men, on the basis of profound gender discrimination. A woman's ability to protect herself from unsafe, forcible sex depends on the balance of power in the relationship with her partner. We all know that gender is about power. In terms of power, the woman is the subordinate partner.[10] This pattern is reflected in different settings across the world.

Women's position within the family or household also shapes their burden of caring for the sick and the stigmatization (or abandonment) they suffer as a result of their HIV status.

Some of the legal issues include ensuring a legal framework of equal rights within the family, in marriage, divorce, guardianship and custody of children; and protecting the rights of HIV-positive women within relationships or the family, especially in relation to abuse, abandonment, and discrimination.

Cultural inequality

Many cultural and social attitudes and practices undermine and negate women's equality, and directly or indirectly increase women's vulnerability to HIV/AIDS. These vary from country to country. In South Africa, the practice of bridewealth or lobola has been linked not only to patriarchal attitudes of "ownership" of women, but also to increased violence (and hence vulnerability to HIV/AIDS).[11]

In Africa there is an increasing concern to develop sociocultural institutions to support women and families living with HIV/AIDS. This may involve legal activism within customary law, but the degree of cultural variation means that the strategies will be very specific to particular contexts. Some legal issues include:

- ensuring access to resources through inheritance in customary law;
- providing access to land; and
- providing equal status and rights within the family.

Socioeconomic inequality

Women's economic inequality, coupled with their sexual inequality, shapes their vulnerability to HIV/AIDS. Contracting and living with HIV/AIDS or caring for the sick also deepens women's poverty and their need for basic services from the state. This category encompasses a broad range of issues that relate to meeting women's basic needs and empowering them economically. There are numerous areas of legal and non-legal interventions here to reduce women's economic dependence on men and to ensure equitable access to services to meet their basic needs.

Women's capacity for economic empowerment is linked to the extent to which their basic needs are met, including access to education, health care, food, security, housing, etc. Access to these basic needs becomes even more critical where women have HIV or AIDS (often in addition to caring for other sick family members).

Many of these issues relate to women's social and economic rights. Here opportunities should be sought to participate in the development of policy frameworks, laws and regulations that shape women's access to, and enjoyment of, these rights. It is often difficult to litigate issues that involve choices about policies or the allocation of resources by the state. For this reason, some argue that social and economic rights are not justiciable. Despite this, there are many examples of the innovative and creative use of the law to hold governments accountable for these rights.

For example, if an antidiscrimination law is in place, it could be used or extended to address discrimination in access to these rights, such as discriminatory treatment of HIV-positive women by the health system. One could also think about using a *mandamus*, ie. an order requiring the state to perform its functions. This kind of legal procedure may be useful to compel proper delivery of social welfare grants. The removal of an existing service could also found a legal case, if socioeconomic rights are entrenched in some form in the legal system. It is, however, perhaps most difficult to use the law to enforce the provision of services that do not exist and require additional resources. Some countries have sought to rely on the notion of a basic minimum content of these rights, while others have sought to develop mechanisms to engage the state in a dialogue over the delivery of such rights.

Access to health care

Health-care needs in relation to prevention are for the most part listed under the section on personal autonomy above. People with HIV/AIDS need access to proper health care for opportunistic infections and to obtain access to drugs that are currently unaffordable to them. This right also touches on the needs of women who care for those who are sick, such as access to gloves and equipment.

Campaigns on socioeconomic rights relating to treatment and health care are central to all women's needs. Here direct legal action is possible, although difficult. It is partly dependent on the extent to which the country permits legal action on the basis of socioeconomic rights. However, there are positive international frameworks on health rights in both the Cairo Platform for Action[12] and the Outcomes Document of the Beijing+5 review[13] that can be used by advocates in this area.

Access to nutrition, clean water, and sanitation

Clean water and sanitation and adequate nutrition are necessary for people with HIV/AIDS to maintain their health status and for effective home-based care.[14]

Access to social security

Women engaged in home-based care have an urgent need for resources.[15] Where countries can afford social welfare systems, legal activities can be devised to ensure that the right to social grants caters to the needs of this group of women, for example, that there is a child maintenance grant that is payable to a surviving cousin or aunt, or a special cash grant to those involved in home-based care. Legal action can also help to ensure the efficient delivery of these grants. However, these legal activities would have to be accompanied by broader advocacy and monitoring work to ensure rights and effective payments. Legal rules could also be developed to provide rights and protections for those involved in home-based care.

Access to housing

Shelter and housing for women who lose their housing upon becoming sick (because it is tied to work, often her husband's work, or her husband's family throws her out of her home) is also a critical need. Legal action has proved effective here. For example, in Kenya, court action forced a husband to accept his ill wife back into the home.[16] In South Africa, in a slightly different context, a woman was permitted to stay in the house attached to the work that both she and her husband did on a farm, after her husband had been dismissed.[17]

Access to education

Girl children have often been removed from school to carry out household work or care for the sick. The AIDS epidemic has increased this trend, with girls being taken out of school to help care for sick people with HIV/AIDS. This has critical consequences for development, in view of the positive returns on an investment in the education of girls.

Access to resources through inheritance

In Africa, women's access to resources through inheritance is also critical, and the removal of legal barriers to this should be a priority. In customary law, women have no right to inherit from their husbands and fathers but are entitled to maintenance from the (male) heir. However, the customary protection of widows and children via such maintenance obligations of the heir has largely broken down and many women and their families are left destitute after the death of a father or husband. This has devastating consequences for women who are living with HIV/AIDS or caring for those who are sick. In addition, the economic vulnerability of widows makes them particularly susceptible to sexual demands by male relatives, thereby increasing their vulnerability to HIV.

This is a key area of legal action. Litigation and law reform have proved successful in different contexts.[18]

Reducing women's economic dependence on men

Given the intersection of poverty and vulnerability, there is a need to ensure a proper legal framework to reduce the economic dependence of women on men. There are a variety of areas for legal intervention here, ranging from greater legal protection for women in the informal sector and vulnerable categories of workers in the formal sector to the laws affecting access to credit and the establishment of small and medium enterprises.

- Women need access to resources for economic advancement, including jobs, land, property, and credit. They also require this to cope with their increased burden of care arising from HIV/AIDS. The law can be an effective tool in these areas.
- Women's actual predominance in the lower levels of the economy and the informal sector increases their economic vulnerability. Legal reform and other measures that target these sectors, including the informal sector and small and medium enterprises, are critical to women's greater empowerment.
- Antidiscrimination measures in the workplace must protect against discrimination on the basis of gender and HIV status.
- Within the formal sector, economic policies are increasing women's vulnerability as atypical workers (falling outside traditional labour law protection) and as migrant workers (increasing their vulnerability to exploitative work conditions and sexual risks).[19] Increased legal protection is critical.

Women's political equality, equal status, and citizenship

This is a general category that can be used to identify and assess the extent to which women are accepted as equal to men within a particular society and nation, as well as its laws, policies, and programs.

It includes the extent to which women and men are equally protected by human rights and the law in a society generally, and particularly with reference to the areas set out above. Important here is the extent to which there is an enabling legal framework of principles and rights that affirms gender equality. The extent to which gender equality is recognized as a principle and a right within a political context can influence the opportunities for effective political and legal advocacy to advance women.

A second aspect is the extent to which gender is integrated into a government's policies and programs. In other words, is the commitment to gender equality translated into effective policies and programs with (i) a sufficient allocation of resources and (ii) a system of monitoring and evaluation to ensure that the gendered objectives of the particular policy or program are met? This measures women's programmatic vulnerability.

The Role of the Law and Human Rights in Different National Contexts

Given (a) the fact that HIV/AIDS occurs in differing political, economic, and social contexts for women across the developing world and at the margins of the First World, and (b) the many ways in which gender inequality impacts on HIV/AIDS; there can be no uniform set of priorities or strategies across all countries and even for all women within a particular country. Domestic strategies have to be tailored to the needs of diverse groups of women within any country and mindful of the opportunities offered by that country's political culture, economic policies, legal system, and cultural and religious values. This final section highlights some of the issues and lessons in using law and rights to advance gender equality and reduce women's vulnerability to HIV/AIDS.[20]

> Law reform on abortion in South Africa was accompanied by a shift in the dominant public discourse on abortion from that of immorality and crime to that of women's rights.

The role of rights struggles

Human rights have played an important role in global and national struggles for gender equality, both as an important political resource for mobilizing groups and in providing an enabling framework for the task of advancing gender equality. Rights struggles are more likely to be successful (based at least on the South African experience) when they are pursued by a broad alliance of organizations committed to clear goals and engaged in a variety of legal and non-legal strategies. These presume a vibrant civil society and include alliance building, research, media, law reform and litigation, educational lobbying, etc. The objectives should also be framed by a "rights message" that resonates with the community for whom it speaks. Importantly, the value of human rights lies as much in our capacity to use them strategically as it does in the norms and values that they espouse.

There are several rights that could potentially be used to mobilize people, groups, and communities on HIV/AIDS issues. A range of first-generation rights (equality, dignity, privacy, security of the person) can be used as part of a broader call for reproductive or sexual rights or the right to be free from violence. Here the campaign could focus specifically on women and HIV/AIDS, or on women more generally. A particular campaign targeted at the reproductive health of HIV-positive women could include a wide range of issues relating to pregnancy, birth, and freedom from discrimination in health care. Sexual and reproductive rights could frame campaigns for increased access to female condoms and research and development of microbicides.

Legal strategies

Improving the legal status of women through the establishment of a basic threshold of legal rights is a necessary, but not a sufficient, step in addressing gender inequality (and hence reducing women's vulnerability to HIV/AIDS). Legal strategies (whether targeted at law reform or litigation) also have to worry about implementation and enforcement of the rights enshrined in the law. This has been a major obstacle to women's rights worldwide. The effective implementation of rights often depends upon factors such as the institutional capacity of the state, available human, financial, and technical resources, and economic policy frameworks. Overcoming these barriers requires creative legal and nonlegal strategies to hold governments accountable to women.

At the same time, there may be value in securing a law or a right in the absence of immediate opportunities for implementation, even if this is largely symbolic. Strategic engagement with the law in a manner that is clear about objectives and works within the constraints of the particular political and legal national context can have significant results. Importantly, this can achieve not only "rule-making" but also "culture-breaking" results.[21] "Culture-breaking" law reform can challenge and shift dominant norms and values. For example, law reform on abortion in South Africa was accompanied by a shift in the dominant public discourse on abortion from that of immorality and crime to that of women's rights (although many in society remained opposed to abortion). What is significant here is that legal strategies for changing the law took place within a broad human rights context and were accompanied by a range of non-legal (political, educational, media) strategies targeted at the same objective. This was critical, as legal change does not in and of itself change the public understanding of an issue, let alone attitudes within society.[22]

Building alliances across borders, sectors, and issues

Successful rights struggles and law reform initiatives emerge from broad alliances and an active civil society. National and international women's organizations have a rich history and experience of effective activism and successful rights struggles. In recognizing the links between gender inequality and HIV/AIDS, it is important to build bridges between organizations working on "gender" and on "HIV/AIDS." These new partnerships may focus on process (how to go forward) or substance (what issues?) to enrich the work of both partners.

Although there is some recognition in the international arena of the links between HIV/AIDS and gender equality (most noticeably in the UNAIDS program),[23] HIV/AIDS has remained largely ghettoized within health.[24] This expresses an ongoing dissonance between the activities clustered around "gender" and "HIV/AIDS" that is unfortunate at a time when the partnership needs to be deepened and extended. Importantly, it needs to move beyond issues of women's health and sexual and reproductive rights to include broader developmental and human (especially socioeconomic) rights concerns. Inherent in this is a greater emphasis on the experiences and context of women (and men) in the developing world who live directly in the shadow of the epidemic, and who are often most dependent upon international norms for leverage back home.

Rights and legal strategies – organized at the community, national, or international level – can help to reduce gender inequality and women's vulnerability to HIV/AIDS. The challenge is to find the correct strategic partnerships and interventions within a particular national or international context.

– Cathi Albertyn

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[1] All international figures are from the UNAIDS *Report on the Global HIV/AIDS Epidemic*, June 2000.

[2] Rao Gupta G, Weiss E. *Women and Aids: Developing a New Health Strategy* Washington: International Centre for Research on Women, 1996.

[3] Klugman B. Sexual rights in Southern Africa: A Beijing discourse or a strategic necessity. *Health and Human Rights* 2000; 4:2: 145 at 146-147. See also McFadden P. Sex, Sexuality and the Problem of AIDS in Africa. In: R Meena (ed). *Gender in Southern Africa: Conceptual and Theoretical Issues*. Harare: Sape Books, 1992.

[4] Recent research in Gauteng, South Africa, found that nearly one-third of women and men surveyed agreed that forcing sex on someone you know is never sexual violence. A study of the Southern Metropolitan Local Council of Johannesburg and CIETafrica, reported, inter alia, in *Sunday Times* 25 June 2000. See also Pendry B. The links between gender violence and HIV/AIDS. *Agenda* 1998; 39: 30; and Watts C, Garcia-Moreno C. Violence against women: its importance for HIV/AIDS prevention and care. *Women's Health News* May 2000, no 34 (Women's Health Project, Johannesburg).

[5] See for example, Weiss E, Rao Gupta G. *Bridging the Gap. Addressing Gender and Sexuality in HIV Prevention*. ICRW, 1998; and Gender-Related Vulnerability and Obstacles to Prevention and Coping, prepared by the Royal Tropical Institute (KIT) and the Southern Africa Aids Information Dissemination Service (1995/6).

[6] Although South Africa is used as an example, this seems to be true across many developing countries. See, for example, the recent report commissioned by UNIFEM: Gender Related Socio-Economic Impact of HIV/AIDS in Zimbabwe. Harare, April 2000. See also the references in the previous footnote.

[7] The Zimbabwean study found that 76 percent of children who left school to care for sick people were girls.

[8] UNIFEM, supra, note 6.

[9] See, for example, Rao Gupta & Weiss, supra, note 2; and Abdool Karim Q. Women and AIDS – the imperative for a gendered prognosis and prevention policy. *Agenda* 1998; 39: 15.

[10] Dhaliwal M. Creation of an enabling and gender-just legal environment as a prevention strategy for HIV/AIDS among women in India. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(2/3): 86 at 88.

[11] White C. Close to home in Johannesburg – gender oppression in township households. *Women's Studies International Forum* 1993; 16(2): 149. See also Mthembu P. A positive view. *Agenda* 1998; 39: 26. More generally, see

Pieterse M. The Impact of Customary Laws and Practices on HIV/AIDS. Occasional paper for the Aids Law Project, Centre for Applied Legal Studies, University of the Witwatersrand, 1999.

[12] The Cairo Programme of Action of the International Conference on Population Development, 1994.

[13] See the unedited final outcome document of Beijing +5, June 2000 (available at http://www.un.org/womenwatch/daw/followup/beijing+5.htm).

[14] See, for example, ibid, paras 9 and 107d.

[15] UNIFEM, supra, note 6.

[16] Reported in *Sunday Independent* 6 August 2000.

[17] See the decision of the South African Land Claims in *Conradie* v *Hanekom* LCC/8R/99 (22/04/99).

[18] In South Africa, a process of law reform will, hopefully, see women access property through inheritance. See the discussion paper of the South African Law Commission (available at http://www.law.wits.ac.za/salc/salc.html).

[19] I am grateful to Geeta Rao Gupta for this point.

[20] These are largely lessons drawn from the South African experience. Some of them are documented in Albertyn C et al. *Engendering the Political Agenda. A South African Case Study.* Centre for Applied Legal Studies, University of the Witwatersrand. Soon to be published by the UN Institute for Research and Training for the Advancement of Women.

[21] Stoddard T. Bleeding heart: reflections on using the law to make social change. *New York University Law Review* 1997; 72(5): 267.

[22] See: Reproductive heath and the right to choose – policy and law reform on abortion. In: Albertyn et al, supra, note 20.

[23] The 1996 HIV/AIDS and Human Rights International Guidelines identify women as a vulnerable group (Guideline 8). The program of the 1999 International Partnership Against HIV/AIDS in Africa goes further, to call specifically for the strengthening of the status of women through legal and other means to reduce their vulnerability (policy area 10).

[24] Unfortunately, the central place accorded to the relationship between HIV/AIDS and gender in the work of UNAIDS and within the African region did not find its way into the final document of Beijing +5. While the language on health included positive and progressive statements on HIV/AIDS, areas relating to poverty, development, and human rights were disappointingly silent.

The Deafening Silence of AIDS

For most of those attending the XIII International AIDS Conference in Durban, the Jonathan Mann Memorial Lecture delivered by Justice Edwin Cameron on Monday, 10 July 2000, was one of the highlights of the conference. The presentation is a passionate and compelling appeal to make medical care and treatment accessible and affordable to the more than 30 million people in resource-poor countries who face death from AIDS.

It is a great honour to be asked to deliver the first Jonathan Mann Memorial Lecture. It is fitting that this remembrance should have been created to honour Mann's memory and legacy. He more than any other individual must be credited with first conceiving and constructing a global response to the AIDS epidemic. This he did not only as founding director of the World Health Organization's Global Programme on AIDS between 1986 and 1990 but also, after he left the WHO, in his theoretical and advocacy work within the discipline of public health.

It is particularly fitting that the lecture series should be initiated at the start of the first international conference on AIDS to take place on African soil. Jonathan Mann's earliest experience of the epidemic was in Africa, where from March 1984 to June 1986 he was director of the Zaire AIDS Research Programme. It was here that Mann first confronted the social complexities and the dire implications of the disease.

Mann's work in Central Africa included epidemiological, clinical, and laboratory components. In retrospect it is clear that it was on this continent that the motive forces impelling his insights into the epidemic were formed.[1] He published early research indicating that HIV transmission occurs only rarely in the home or health-care setting.[2] His work in Zaire subjected him to an arduous schooling in all aspects of HIV: surveillance and epidemiology, issues of testing in a developing country, case definition, condom usage, and exposure among commercial sex workers.[3] It alerted him from the outset to the fearful twinned menace of HIV and tuberculosis.[4] His time in Africa also attuned him to questions involving children and pediatric AIDS, and he published pioneering work on what has perhaps become the epidemic's most poignant issue in Africa – transmission of the virus from mother to child.[5]

But it was not only with regard to the details of the epidemiology and management of HIV that Mann's years in Africa yielded insights that later proved critical. His work among Africa's at-risk communities, with Africans living with HIV and with those dying from AIDS, with health-care personnel, mothers, sex workers, and government bureaucrats in Africa formed the basis of an insight he later termed a "very intense, emotional, and personal" discovery.[6] This was his realization during the 1980s that there are empirical and theoretical links between human rights abuses and vulnerability to HIV/AIDS. In each society, Mann later wrote, "those people who were marginalized, stigmatized and discriminated against – before HIV/AIDS arrived – have become over time those at highest risk of HIV infection."[7]

Mann's statement cannot be accepted without nuance, since in some African countries it is precisely mobility and relative affluence that have placed people at risk of exposure to HIV. But Mann's analysis here had led him to a more fundamental and general insight, one that formed the focus of his future work and advocacy: his realization that health and human rights are not opposing, but rather complementary, approaches to what he called "the central problem of defining and advancing human well-being."[8]

In relation to AIDS, Justice Michael Kirby of the High Court of Australia – one of the world's most eloquent voices for truth and fairness – has termed this insight "the HIV paradox": that sound reasons rooted not only in respect for human dignity, but in effective public health planning, necessitate a just and nondiscriminatory response to AIDS, and that recognition of and respect for individual human rights does not impede prevention and containment of HIV, but actually enhances it.[9]

In this perception Jonathan Mann located the core of his remaining lifework. And his commitment to advancing its practical realization constitutes his most profound contribution to securing a humane worldwide response to the AIDS epidemic.[10] Amid the grievous facts of the epidemic, the one redemptive gleam is the fact that nowhere have the doctrines of public health overtly countenanced repression and stigma, discrimination and isolation, as legitimate governmental responses to AIDS.[11]

That there has been discrimination and stigma against persons with AIDS and HIV, on an enormous and debilitating scale, is beyond question. The death by stabbing and stoning of Gugu Dhlamini in December 1998, not 20 kilometres from here, provides a brutal testament of hatred and ignorance.[12] But these practices have not been supported – at least officially, or in any large measure – by the institutional power of the world's public health systems. The fact that public policy at a national and international level has weighed against them constitutes a significant portion of the legacy of Jonathan Mann.

But this by no means exhausts the significance of his work. In the 14 years since Mann left Zaire for Geneva in 1986, the epidemic has manifested momentous changes. The two most considerable are these:

- the demographics of its spread; and
- the medical–scientific resources available to counter it.

In its demographics HIV has altered from an epidemic whose primary toll seemed to be within the gay communities of North America and Western Europe to one that, overwhelmingly, burdens the heterosexual populations of Africa and the developing world. The data are so dismaying that reciting the statistics of HIV prevalence and of AIDS morbidity and mortality – the infection rates, the anticipated deaths, the numbers of orphans, the health-care costs, the economic impact – threatens to drive off, rather than encourage, sympathetic engagement.[13] Our imagination shrinks from the thought that these figures can represent real lives, real people, and real suffering.[14]

Amid the welter of disheartening data, two facts, well-recited though they are, obtrude with overwhelming force:

- nine-tenths of all people with HIV/AIDS are in poor countries; and
- two-thirds of the total are in sub-Saharan Africa.

Meanwhile, the demography of HIV has been overlaid by a shift even more momentous. Over the last five years, various aggregations of drug types, some old and some new, have been shown, when taken in combination, to quell the replication of the virus within the body. The result has been life-altering and near-revolutionary. For most of those with access to the new drug combinations, immune system decline has not only halted, but been reversed.

In most of Europe, North America, and Australasia, illness and death from AIDS have dropped dramatically. In these regions, hundreds of thousands of people who a few years ago faced imminent and painful death have been restored to living. Opportunistic infections have receded, and suffering, pain, and bereavement from AIDS have greatly diminished.

Beneficent social effects have come with the medical breakthrough. The social meaning of the new drugs is that the equation between AIDS and disease and death is no longer inevitable. AIDS can now be compared with other chronic conditions that, with appropriate treatment and proper care, can in the long term be subjected to successful medical management. Among the public at large, fear, prejudice, and stigma associated with AIDS have lessened. And people living with HIV/AIDS have suffered less within themselves and in their working and social environments.

In short, the new combination drug treatments are not a miracle. But in their physiological and social consequences they come very close to being miraculous.

This near miracle, however, has not touched the lives of the majority of those who most desperately need it. For Africans and others in resource-poor countries with AIDS and HIV, these drugs are out of reach. For them, the implications of the epidemic remain as fearsome as ever. In their lives, the prospect of debility and death, and the effects of discrimination and societal prejudice, loom as large as they did for the gay men of North America and Western Europe a decade and a half ago.

This is not because the drugs are prohibitively expensive to produce. They are not. Recent experience in India, Thailand, and Brazil has shown that most of the critical drugs can be produced at a cost that puts them realistically within reach of the resource-poor world.[15] The primary reason why the drugs are inaccessible to the developing world is twofold. On the one hand, drug-pricing structures imposed by the manufacturers make the drugs unaffordably expensive. On the other, the international patent and trade regime at present seeks to choke off any large-scale attempt to produce and market the drugs at affordable levels.[16]

With characteristic prescience, in his address at the XI International AIDS Conference in Vancouver in 1996, Mann foresaw the significance of the treatment issue.[17] He said that of all the walls dividing people in the AIDS epidemic, “the gap between the rich and the poor is most pervasive and pernicious.”

It is this divide that, 14 years after Mann left Africa, threatens to swallow up 25 million lives in Africa.

I speak of the gap not as an observer or as a commentator, but with intimate personal knowledge. I am an African. I am living with AIDS. I therefore count as one among the forbidding statistics of AIDS in Africa. I form part of nearly five million South Africans who have the virus.

I speak also of the dread effects of AIDS with direct experience. Nearly three years ago, more than twelve years after I became infected, I fell severely ill with symptomatic effects of HIV. Fortunately for me, I had access to good medical care. My doctor first treated the opportunistic infections that were making me feel sick unto death. Then he started me on combination therapy. Since then, with relatively minor adjustments, I have been privileged to lead a vigorous, healthy, and productive life. I am able to do so because, twice a day, I take two tablets – one containing a combination of AZT (zidovudine) and 3TC, the other containing nevirapine (Viramune). I can take these tablets because, on the salary of a judge, I am able to afford their cost.

If, without combination therapy, the mean survival time for a healthy male in his mid forties after onset of full AIDS is from 30 to 36 months, I should be dead by about now. Instead, I am healthier, more vigorous, more energetic, and more full of purposeful joy than at any time in my life.

In this I exist as a living embodiment of the iniquity of drug availability and access in Africa. This is not because, in an epidemic in which the heaviest burdens of infection and disease are borne by women, I am male; or because, on a continent in which the vectors of infection have overwhelmingly been heterosexual, I am proudly gay; or even because, in a history fraught with racial injustice, I was born white. My presence here embodies the injustices of AIDS in Africa because, on a continent in which 290 million Africans survive on less than one US dollar a day, I can afford monthly medication costs of about US$400 per month. Amid the poverty of Africa, I stand before you because I am able to purchase health and vigour. I am here because I can afford to pay for life itself.[18]

Amid the poverty of Africa, I stand before you because I am able to purchase health and vigour. I am here because I can afford to pay for life itself.

To me this seems an iniquity of very considerable proportions that, simply because of relative affluence, I should be living when others have died; that I should remain fit and healthy when illness and death beset millions of others.

Given the epidemic’s two most signal changes, in demographics and in medical science, surely the most urgent challenge it offers us is to find constructive ways of bringing these life-saving drugs to the millions of people whose lives and well-being can be secured by them. Instead of continuing to accept what has become a palpable untruth (that AIDS is of necessity a disease of debility and death), our overriding and immediate commitment should be to find ways to make accessible for the poor what is within reach of the affluent.

If this is the imperative that our circumstances impose upon us, one would have expected the four years since Mann spoke at Vancouver to have been filled with actions directed to its attainment by those with power to change the course and the force of the epidemic. Instead, from every side, those millions living with AIDS in resource-poor countries have been disappointed. International agencies, national governments, and especially those who have primary power to remedy the iniquity – the international drug companies – have failed us in the quest for accessible treatment.

In my own country, a government that in its commitment to human rights and democracy has been a shining example to Africa and the world has at almost every conceivable turn mismanaged the epidemic.[19] So grievous has governmental ineptitude been that, since 1998, South Africa has had the fastest-growing HIV epidemic in the world. It currently has one of the world's highest prevalences. Nor has there been silence about AIDS from our government, as the title of my lecture suggests. Indeed, there has been a cacophony of task groups, workshops, committees, councils, policies, drafts, proposals, statements, and pledges. But all have thus far signified piteously little.

A basic and affordable measure would be a national program to limit mother-to-child transmission of HIV through administration of short courses of antiretroviral medication. Research has shown this will be cost-effective in South Africa.[20] Such a program, if implemented, would have signaled our government's appreciation of the larger problem, and its resolve to address it. To the millions of South Africans living with HIV, it would have created a ray of light. It would have promised the possibility of increasingly constructive interventions for all with HIV, including enhanced access to drug therapies. To our shame, our country has not yet committed itself to implementing even this limited program. The result is that many thousands of babies are born every month, unnecessarily and avoidably, with HIV. They will experience preventable infections, preventable suffering, and preventable deaths. If none of that is persuasive, then from the point of view of the nation's economic self-interest, their HIV infections entail preventable expense. Yet we have done nothing.

> Lower drug prices are not just one of a range of adjunct conditions. They are an indispensable precondition to creating just and practicable access to care and treatment.

In our national struggle to come to grips with the epidemic, perhaps the most intractably puzzling episode has been President Mbeki's flirtation with those who in the face of all reason and evidence have sought to dispute the etiology of AIDS.[21] This has shaken almost everyone responsible for addressing the epidemic. It has created an air of disbelief among scientists, confusion among those at risk of HIV, and consternation among AIDS workers.

To my regret, I cannot believe that President Mbeki's speech at the official opening of this conference last night has done enough to counter these adverse conditions. I personally yearned for an unequivocal assertion from our president that HIV is a virally specific condition that is sexually transmitted, which if uncontained precipitates debility and death but for which antiretroviral treatments now exist that can effectively and affordably be applied. To my grief, the speech was bereft of this.

One of the continent's foremost intellectuals, Dr Mamphela Rampele, has described the official sanction given to skepticism about the cause of AIDS as "irresponsibility that borders on criminality."[22] If this aberrant and distressing interlude has delayed the implementation of life-saving measures to halt the spread of HIV and to curtail its effects, then history will not judge this comment excessive.

At the international level, too, there has been largely frustration and disappointment. At the launch of the International Partnership against AIDS in Africa in December 1999, UN Secretary-General Kofi Annan made the important acknowledgment that "[o]ur response so far has failed Africa." The scale of the crisis, he said, required "a comprehensive and coordinated strategy" between governments, intergovernmental bodies, community groups, science, and private corporations.[23] That was seven long months ago. In those seven months, there have been more than 200 days – days in which people have fallen sick and others have died; days on each of which, in South Africa, approximately 1700 people have become newly infected with HIV.

In that time, the World Bank, to its credit, has made the search for an AIDS vaccine one of its priorities.[24] President Clinton, to his credit, in an effort "to promote access to essential medicines," has issued an executive order that loosens the patent and trade throttles around the necks of African governments.[25] And UNAIDS, to its credit, "has begun" what it describes as "a new dialogue" with five of the biggest pharmaceutical companies. The purpose is “to find ways to broaden access to care and treatment, while ensuring rational, affordable, safe and effective use of drugs for HIV/AIDS-related illnesses.”[26] All these efforts are indisputably commendable. But, taken individually or together, they fail to muster the urgency and sense of purpose appropriate to an emergency room where a patient is dying. In fact, the analogy is understated, since the patients who are dying number in the tens of millions. And for all their families and loved ones, the emergency is dire and immediate. What is more, the treatment that can save them exists. What is needed is only that it be made accessible to them.

Bedeviling much of the debate about the options for practical action is the pivotal question of drug pricing. No one denies that drug prices are “only one among many obstacles to access” in poor countries.[27] But there are many, many people in the resource-poor world for whom prices on their own are, right now, the sole impediment to health and well-being. A significant number of Africans have access to health care and could pay modest amounts for the drugs now. In any scenario, therefore, lowering drug prices immediately is necessary. It should therefore be an immediate and overriding priority.

In fact, lower drug prices are not just one of a range of adjunct conditions. They are an indispensable precondition to creating just and practicable access to care and treatment, for a number of reasons. First, the debate about drug pricing has diverted attention and energy from other vital challenges, such as creating the institutional infrastructure for delivery and monitoring in poor countries. Second, and more crucially, it has sadly provided some governments with a justification for delaying implementation of programs to prevent mother-to-child transmission of the virus.[28] It has also delayed consideration of more ambitious alternatives in antiretroviral therapy.

This situation has led the corporations and governments into a sort of collusive paralysis, in which reciprocal blaming continues to provide each side with an excuse for inaction. Amid all of this, it is hard to avoid the impression that the drug companies are shadow-boxing with the issues.[29] In this country people with AIDS have felt devastated by the lack of immediate follow-through to the announcement eight weeks ago that five of the largest drug companies had undertaken to “explore” ways to reduce their prices.

In this context, it is also hard to avoid the conclusion that UNAIDS – whose program leader, Dr Peter Piot, is a perceptive man of principle who worked with Jonathan Mann in Africa – has failed to muster its institutional power with sufficient resourcefulness, sufficient creativity, and sufficient force.[30]

Amid this disappointment, it is quite wrong to speak, as the title of my lecture does, of “the deafening silence of AIDS.” Gugu Dhlamini was not silent. She paid with her life for speaking out about her HIV status. But she was not silent. And her death has failed to silence many other South Africans with AIDS, black and white, male and female – most of whom are less protected by privilege than I – who have spoken out for dignity and justice in the epidemic.

In the supposed silence, the trumpet of principled activism has also been sounded. In America, brave activists changed the course of presidential politics by challenging Vice-President Gore’s stand on drug pricing and trade protection. Their actions paved the way for subsequent revisions of President Clinton’s approach to the drug pricing issue.[31] In my own country, a small and under-funded group of activists in the Treatment Action Campaign, under the leadership of Zackie Achmat, has emerged. In the face of considerable isolation and hostility, they have succeeded in reordering our national debate about AIDS. And they have focused national attention on the imperative issues of poverty, collective action, and drug access. In doing so they have energized a dispirited PWA movement with the dignity of self-assertion, and renewed within it the faith that by action we can secure justice.

> That is the true challenge to this conference: to make the future different. Drugs are available to make AIDS a chronically manageable disease for most people with the virus. But unless we intervene in the present with immediate urgency, that will not happen.

In the last years of his life, Jonathan Mann began speaking with increasing passion about the moral imperatives to action that challenge us all.[32] He well understood that this involves confronting vested interests: “Preventing preventable illness, disability and premature death, like preventing human rights abuses and genocide, to the extent that it involves protecting the vulnerable, must be understood as a challenge to the political and societal status quo."[33] Mann's last work also underscored the fundamental significance of human dignity in the debate about health and human rights and foreshadowed the transition of the debate about human rights and the "HIV paradox" to a conception of a full human entitlement to medical care, where the means for it are available.[34]

Ten months before his death, in November 1997, Mann called on an audience to place themselves "squarely on the side of those who intervene in the present, because they believe that the future can be different."[35] That is the true challenge to this conference: to make the future different. Drugs are available to make AIDS a chronically manageable disease for most people with the virus. But unless we intervene in the present with immediate urgency, that will not happen.

We gather here in Durban as an international grouping of influential and knowledgeable people concerned about alleviating the effects of this epidemic. By our mere presence here, we identify ourselves as the 11,000 best-resourced and most powerful people in the epidemic. By our action and resolutions and collective will, we can make the future different for many millions of people with AIDS and HIV for whom the present offers only illness and death.

This gathering can address the drug companies. It can demand urgent and immediate price reductions for resource-poor countries. It can challenge the companies to permit without delay parallel imports and the manufacture under licence of drugs for which they hold the patents. Corporately and individually we can address the governments and intergovernmental organizations of the world, demanding a plan of crisis intervention that will see treatments provided under managed conditions to those who need them. The Vancouver conference four years ago was a turning point in the announcement of the existence of successful drug therapies. This conference can be a turning point in the creation of an international impetus to secure equitable access to these drugs for all people with AIDS in the world.

Moral dilemmas are all too easy to analyze in retrospect. It is often a source of puzzled reflection how ordinary Germans could have tolerated the moral iniquity that was Nazism, or how white South Africans could have countenanced the evils that apartheid inflicted, to their benefit, on the majority of their fellows.[36] Yet the position of people with AIDS or HIV in Africa and other resource-poor regions poses a comparable moral dilemma for the developed world today. The inequities of drug access, pricing, and distribution mirror the inequities of a world trade system that weighs the poor with debt while privileging the wealthy with inexpensive raw materials and labor. Those of us who live affluent lives, well attended to by medical care and treatment, should not ask how Germans or white South Africans could tolerate living in proximity to moral evil. We do so ourselves today, in proximity to the impending illness and death of many millions of people with AIDS. This will happen unless we change the present. It will happen because available treatments are denied to those who need them for the sake of aggregating corporate wealth for shareholders who by African standards are already unimaginably affluent.[37]

That cannot be right, and it cannot be allowed to happen. No more than Germans in the Nazi era, no more than white South Africans during apartheid, can we at this conference say that we bear no responsibility for more than 30 million people in resource-poor countries who face death from AIDS unless medical care and treatment is made accessible and available to them. The world has become a single sphere, in which communication, finance, trade, and travel occur within a single entity. How we live our lives affects how others live theirs. We cannot wall off the plight of those whose lives are proximate to our own. That is Mann's legacy to the world of AIDS policy, and it is the challenge of his memory to this conference today.

– Edwin Cameron

Mr Justice Edwin Cameron is a Justice of the High Court of South Africa, Johannesburg. This is an edited version of the first Jonathan Mann Memorial Lecture, given by Justice Cameron at the XIII International AIDS Conference, Durban, South Africa, on 10 July 2000. Please address correspondence to Mr Justice Edwin Cameron, Judges' Chambers, High Court of South Africa, Cr Pritchard & Kruis Streets, Private Bag X7, 0001 Johannesburg, South Africa.

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[1] Almost a third of the items on Mann's formidable list of 169 publications appear to stem from his 27 months in Africa.

[2] JM Mann et al. Prevalence of HTLV-III/LAV in household contacts of patients with confirmed AIDS and controls in Kinshasa, Zaire. *Journal of the American Medical Association* 1986; 256; 721-724; JM Mann et al. HIV seroprevalence among hospital workers in Kinshasa, Zaire: lack of association with occupational exposure. *Journal of the American Medical Association* 1986; 256: 3099-3102; JM Mann et al.

HIV sero-incidence in a hospital worker population: Kinshasa, Zaire. *Annales de la Société Belge de Médecine Tropicale* 1986; 66(3): 245-250; JM Mann et al. Zaire: non-sexual household transmission of AIDS. *Journal of the American Medical Association* 1986; 256: 3091-3092; and B Ngaly, RW Ryder, K Dila, K Mwandagalirwa, JM Mann et al. Human immunodeficiency virus infection among employees in an African hospital. *New England Journal of Medicine* 1988; 319: 1123-1127. See also R Marcus, K Kay, JM Mann. Transmission of human immunodeficiency virus (HIV) in healthcare settings world-wide. *Bulletin of the World Health Organization* 1989, 67(5): 577-582. This work both confirmed earlier studies to which it referred and anticipated the later conclusive studies in North America: JL Gerberding et al. Risk of exposure of surgical personnel to patients' blood during surgery at San Francisco General Hospital. *New England Journal of Medicine* 1990; 322: 1788-1793; RM Gershon, D Vlahov. HIV infection risk to health-care workers. *American Industrial Hygiene Association Journal* 1990; 51: A-802–A-806; J Jagger et al. Rates of needle-stick injury caused by various devices in a university hospital. *New England Journal of Medicine* 1988; 319: 284-288; R Marcus et al. Surveillance of health care workers exposed to blood from patients infected with the human immunodeficiency virus. *New England Journal of Medicine* 1988; 319: 1118-1123; and JM Orient. Assessing the risk of occupational acquisition of the human immunodeficiency virus: implications for hospital policy. *Southern Medical Journal* 1990; 83: 1121-1127.

[3] JM Mann et al. Surveillance for AIDS in a central African city: Kinshasa, Zaire. *Journal of the American Medical Association* 1986; 255: 3255-3259; TC Quinn, JM Mann, P Piot, JW Curran. AIDS in Africa: an epidemiological paradigm. *Science* 1986; 234: 955-963; JM Mann. The epidemiology of LAV/HTLV-III in Africa. *Annals of the Institute Pasteur/Virology* 1987; 138: 113-118; JM Mann et al. ELISA readers and HIV antibody testing in developing countries. *Lancet* 1986; i: 1504; H Francis, JM Mann et al. Serodiagnosis of the acquired immunodeficiency syndrome by enzyme-linked immunosorbent assay compared to cellular immunologic parameters in African AIDS patients and controls. *American Journal of Tropical Medicine & Hygiene* 1988; 38: 641-646; K Kayembe, JM Mann et al. Prevalence of anti-HIV antibodies in patients without AIDS or AIDS-related syndrome in Kinshasa, Zaire. *Annales de la Société Belge de Médecine Tropicale* 1986; 66: 343-347; R Colebunders, JM Mann et al. Evaluation of a clinical case definition of acquired immunodeficiency syndrome in Africa. *Lancet* 1987; i: 492-494; R Colebunders, H Francis, JM Mann et al. Persistent diarrhea, strongly associated with HIV infection in Kinshasa, Zaire. *American Journal of Gastroenterology* 1987; 82: 859-864; R Colebunders, JM Mann et al. Slow progression of illness occasionally occurs in HIV infected Africans. *AIDS* 1987; 1: 65-66; JM Mann et al. Condom use and HIV infection among prostitutes in Zaire. *New England Journal of Medicine* 1987; 316: 345; JM Mann et al. Human immunodeficiency viral infection and associated risk factors in female prostitutes in Kinshasa, Zaire. *AIDS* 1988; 2: 249-254; and SZ Wiktor, JM Mann et al. Human T-cell lymphotropic virus type 1 (HTLV-1) among female prostitutes in Kinshasa, Zaire. *Journal of Infectious Diseases* 1990; 161: 1073-1076.

[4] JM Mann et al. Association between HTLV-III/LAV infection and tuberculosis in Zaire. *Journal of the American Medical Association* 1986; 256: 346; G Slutkin, J Leowski, JM Mann et al. The Effects of the AIDS Epidemic on the Tuberculosis Problem and Tuberculosis Programmes. In: AF Fleming, M Carballo, DW Fitzsimons (eds.). *The Global Impact of AIDS* (London: Alan R Liss, Inc, 1988), at 21-25; and G Slutkin, J Leowski, JM Mann. Tuberculosis and AIDS. *Bulletin of the International Union against Tuberculosis and Lung Disease* 1988; 63: 21-24 [noting the increased rate of progression from asymptomatic to overt TB for people co-infected with HIV].

[5] JM Mann et al. HIV seroprevalence in pediatric patients 2-14 years of age at Mama Yemo Hospital, Kinshasa, Zaire. *Pediatrics* 1986; 78: 673-677; JM Mann et al. Risk factors for human immunodeficiency virus seropositivity among children 1-24 months old in Kinshasa, Zaire. *Lancet* 1986; i: 654-657; CF von Reyn, CJ Clements, JM Mann. Human immunodeficiency virus infection and routine childhood immunization. *Lancet* 1987; ii: 669-672; P Nguyen-Dinh, AE Greenberg, JM Mann et al. Absence of association between plasmodium falciparum malaria and human immunodeficiency virus infection in children in Kinshasa, Zaire. *Bulletin of the World Health Organization* 1987; 65: 607-613; CF von Reyn, JM Mann et al. HIV infection and routine childhood immunization: a review. *Bulletin of the World Health Organization* 1987; 65: 905-911; AE Greenberg, P Nguyen-Dinh, JM Mann et al. The association between malaria, blood transfusions and HIV seropositivity in a pediatric population in Kinshasa, Zaire. *Journal of the American Medical Association* 1988; 259: 545-549; J Chin, G Sankran, JM Mann. Mother-to-Infant Transmission of HIV: An Increasing Global Problem. In: E Kessel, SK Awan (eds). *Maternal and Child Care in Developing Countries.* Thun, Switzerland: Ott, 1989, at 299–306; and RW Ryder, W Nsa, SE Hassig, JM Mann et al. Perinatal transmission of the human immunodeficiency virus in 482 infants born to seropositive women in two hospitals in Zaire. *New England Journal of Medicine* 1989; 320: 1637-1642.

[6] L Gostin, V Lazzarini (eds). *Human Rights and Public Health in the AIDS Epidemic*. 1997, at 167.

[7] JM Mann, D Tarantola (eds). *AIDS in the World II*. New York: Oxford, 1996, at 464. See also J Mann. Health and human rights: if not now, when?" *Health and Human Rights* 1997; 2(3): 113-120.

[8] J Mann, L Gostin, S Gruskin et al. Health and human rights. *Health and Human Rights* 1994; 1(1): 19.

[9] M Kirby. AIDS and the Law. *South African Journal on Human Rights* 1993; 9(1): 1-21. In a moving tribute, Kirby credits Mann, among others, with inspiring his own realization in this regard: see M Kirby. The right to health fifty years on: still skeptical?" *Health and Human Rights* 1999; 4(1): 17.

[10] This recognition lies at the core of the most important international human rights policy response to HIV/AIDS the epidemic has yet produced: the International Guidelines on HIV/AIDS and Human Rights, produced at the Second International Consultation on HIV/AIDS and Human Rights, Geneva, 23–25 September 1996 (New York: United Nations, 1998). The Guidelines, formulated and issued under the aegis of UNAIDS and the Office of the High Commissioner for Human Rights, were adopted by the Commission on Human Rights on 20 January1997. They reflect the drafters' recognition that protection of human rights is essential not only to safeguard human dignity in the context of HIV/AIDS, but to ensure an effective, rights-based response to the epidemic. Most fundamentally, they embody the assertion that public health interests do not conflict with human rights ("Introduction" to the published Guidelines, para 15).

[11] This is not to discountenance the questions raised about "AIDS exceptionalism." See R Bayer. Public health policy and the AIDS epidemic: an end to AIDS exceptionalism? *New England Journal of Medicine* 1991; 324: 1500, answered by S Burris. Public health, AIDS exceptionalism and the law. *John Marshall Law Review* 1994; 27: 251. That debate, however, is ancillary because Bayer's approach does not seem intended to suggest, and does not unavoidably entail, human rights curtailments.

[12] Gugu Dhlamini was a young activist living with HIV in a township near Durban who on World AIDS Day 1998 publicly announced her HIV status. Three weeks later a group of fellow residents attacked and killed her, partly, it is believed, as a result of her statement. An inquest into her death is still pending.

[13] UNAIDS released updated statistics on 27 June 2000, available from UNAIDS (http://www.unaids.org).

[14] For South Africa, see *The Impending Catastrophe: A Resource Book on the Emerging HIV/AIDS Epidemic in South Africa*. Menlo Park, CA: Henry J Kaiser Family Foundation, 2000.

[15] See Médecins Sans Frontières. HIV/AIDS Medicines Pricing Report. Setting Objectives: Is There a Political Will? MSF, 2000 (available from Médecins Sans Frontières at www.accessmed-msf.org).

[16] For a general critique, see M Angell. The pharmaceutical industry: to whom is it accountable? [editorial] *New England Journal of Medicine* 2000; 342 (25).

[17] An audio clip of the speech is available from *The Village Voice* (http://www.villagevoice.com/issues/9837/schoofs-mann.ram). In 1992, Mann and others commented on AZT and drug development to deal with the AIDS crisis: "A logical outcome of the successes of AIDS activism in the industrialized world…will be to connect issues and struggles in the developing and industrialized countries…. [A]ccess to AZT, other antiretroviral agents and drugs to treat opportunistic infections [is] extremely limited or totally absent in the developing world." J Mann, DJM Tarantola, TW Netter (eds). *AIDS in the World: A Global Report*. Cambridge, MA: Harvard University Press, 1992, at 240.

[18] Mann called on physicians in America to make "a commitment to challenge the status quo of health as a purchasable privilege" in Healthcare and Human Rights, presented at the First International Conference on Healthcare Resource Allocation for HIV/AIDS and Other Life-Threatening Illnesses, Washington, DC, November 1997, available from IAPAC (http://www.iapac.org/humanrights/witness2.html).

[19] The evidence is critically overviewed in H Marais. *To the Edge: AIDS Review 2000*. University of Pretoria, 2000. See also my keynote address to a meeting of people living with AIDS, titled "Involvement of People Living with HIV/AIDS: How to Make It More Meaningful" and convened as a precursor to the XIII International AIDS Conference, Durban, South Africa, 9 March 2000.

[20] N Soderlund, K Zwi, A Kinghorn, G Gray. Preventing vertical transmission of HIV: a cost effectiveness analysis of options available in South Africa. *British Medical Journal* 1999; 318: 1650-1655.

[21] See President Thabo Mbeki, "Sitting Down with President Mbeki," interview by Joan Shenton, *Carte Blanche*, 16 April 2000, available from *Carte Blanche* (www.ktv.co.za/carteblanche/week/000416_mbeki.jhtml); President Mbeki to President Clinton and other leaders, published in *The Washington Post*, 19 April 2000. For comment, see R Bayer and M Susser. In South Africa, AIDS and a dangerous denial. *Washington Post* 20 April 2000; M Berger. Mbeki's AIDS letter defies belief. *Mail & Guardian* (Johannesburg) 28 April 2000; AC Bawa, D Herwitz, H Coovadia. Leave science to the scientists, Mr President. *Sunday Independent* (Johannesburg) 25 June 2000; and the following ministerial defence: M Tshabalala-Msimang, B Ngubane, E Pahad. Mbeki's stand on AIDS was dictated by African realities. *Sunday Independent* (Johannesburg) 2 July 2000.

[22] Dr Mamphela Rampele is a former vice-chancellor of the University of Cape Town; she is now a deputy president of the World Bank. She was quoted in M Schoofs. Flirting with pseudo-science. *Village Voice* 15 March 2000.

[23] United Nations Press Release SG/SM/7247, posted by UNAIDS on 9 December 1999 (www.unaids.un.org/news/press/docs/1999).

[24] J Burgess. AIDS measures top World Bank's agenda. *Washington Post* 13 April 2000.

[25] William J Clinton, Executive Order: Access to HIV/AIDS Drugs and IP/Trade Issues, 10 May 2000, available from HivNet.ch (www.hivnet.ch:8000/topics/treatment-access/viewR?816).

[26] UNAIDS. New Public/Private Sector Effort Initiated to Accelerate Access to HIV/AIDS CARE and Treatment in Developing Countries [press release], 11 May 2000, available from UNAIDS (http://www.unaids.org/whatsnew/press/eng/geneva110500.html).

[27] Glaxo Wellcome. Glaxo Wellcome with Four Other Pharmaceutical Companies Partner with United Nations Agencies in Public/Private Cooperation to Accelerate Access to HIV/AIDS Care and Treatment in Developing Countries [press release], 11 May 2000, available from HivNet.ch (http://www.hivnet.ch:8000/africa/af-aids/viewR?783).

[28] Mbeki, AIDS and the Intolerance of the Media [statement], 24 March 2000, accessed at

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www.woza.co.za/news/mar00/aidsmbeki24.htm. The statement reads in part, "Mbeki's dilemma is compounded by the fact that he does not have the option to dispense AZT to people because it is simply unaffordable. Not only is AZT not a cure for HIV/AIDS, but also it has been proven to be ineffective unless it is used together with other drugs." Contemporary news reports indicated that the statement was issued by Mr Parks Mankahlana, a spokesman in the Office of the Presidency; see: Mbeki hits at AIDS "intolerance." *Citizen* 24 March 2000.

[29] For stringent criticism of the arguments employed by drug companies to justify their pricing structures and their monopolies, see Angell, supra, note 16.

[30] See the perceptive analysis and critique by Dr Richard Stern. UNAIDS and HIV Drugs: A Call for Renewed Commitment to Advocacy. Posted to the Treatment-Access email list and available online (http://www.hivnet.ch:8000/topics/treatment-access/viewR?672).

[31] President Clinton changed his position during the November 1999 meeting of the World Trade Organization in Seattle and confirmed the change in an executive order of 10 May 2000 (see note 24).

[32] In his closing address at the 2nd International Conference on Health and Human Rights, Cambridge, MA, 5 October1996, he underscored the need to "move from concepts to action in health and human rights." Mann, supra, note 7 at 116.

[33] Mann, supra, note 7 at 117.

[34] J Mann. Dignity and health: the UDHR's revolutionary first article. *Health and Human Rights* 1998; 3(2): 30-38. In South Africa, Justice Arthur Chaskalson's Bram Fischer Memorial Lecture, "Dignity as an Underlying Value in the Constitution," delivered in Johannesburg on 18 May 2000, recently explored the conception of dignity as a value underlying other constitutional values.

[35] Mann, supra, note 18.

[36] On Nazi Germany, see G Sereny. *Albert Speer: His Battle with Truth* (New York: Knopf, 1995) and D Goldhagen. *Hitler's Willing Executioners: Ordinary Germans and the Holocaust* (New York: Knopf, 1996). On South Africa under apartheid, see Antjie Krog. *Country of My Skull: Guilt, Sorrow, and the Limits of Forgiveness in the New South Africa* (Johannesburg: Random House, 1999).

[37] A South African clergyman has tellingly translated the drug companies' arguments relying on research and development costs as follows: "In plain English it means: we cannot offer you the life-saving drugs now because we need profit to develop future life-saving drugs – those drugs will also be unaffordable!" The Very Revd Rowan Smith. "An ethical response to the AZT debate. *Cape Times* (Cape Town), 30 April 1999.

Gender, Sexuality, and HIV/AIDS: The What, the Why, and the How

The focus of Geeta Rao Gupta's plenary presentation of 12 July 2000 at the XIII International AIDS Conference is on the what, why, and how of gender, sexuality, and HIV/AIDS. Dr Rao Gupta discusses the factors associated with women's vulnerability to HIV; and the ways in which unequal power balance in gender relations increases not only women's, but also men's, vulnerability to HIV – despite, or rather because of, their greater power. She then addresses the question of how one is to overcome the seemingly insurmountable barriers of gender and sexual inequality. How can we change the cultural norms that create damaging, even fatal, gender disparities and roles? According to Dr Rao Gupta, an important first step is to recognize, understand, and publicly discuss the ways in which the power imbalance in gender and sexuality fuels the epidemic. She provides examples of sensitive, transformative, and empowering approaches to gender and sexuality and concludes that, in the final analysis, reducing the imbalance in power between women and men requires policies that are designed to empower women – policies that aim to decrease the gender gap in education, improve women's access to economic resources, increase women's political participation, and protect women from violence.

The focus of my talk, as the title suggests, is on the what, the why, and the how of gender, sexuality, and HIV/AIDS. I would like to thank my colleagues and friends, Ellen Weiss from the International Center for Research on Women (ICRW) and Purnima Mane of the Population Council, for helping me put this talk together. The talk is limited to issues related to the heterosexual transmission of HIV because that has been the focus of my work over the last decade. I recognize that heterosexual transmission is only one aspect of the epidemic, but it is by no means irrelevant since the most recent statistics show that heterosexual transmission of HIV remains by far the most common mode of transmission globally.

We have known for at least a decade that gender and sexuality are significant factors in the sexual transmission of HIV, and we now know that they also influence treatment, care, and support. Both terms, nevertheless, continue to remain misunderstood and are inappropriately used.

Gender is not a synonym for sex. It refers to the widely shared expectations and norms within a society about appropriate male and female behaviour, characteristics, and roles. It is a social and cultural construct that differentiates women from men and defines the ways in which women and men interact with each other.

Gender is a culture-specific construct – there are significant differences in what women and men can or cannot do in one culture as compared to another. But what is fairly consistent across cultures is that there is always a distinct difference between women's and men's roles, access to productive resources, and decision-making authority. Typically, men are seen as being responsible for the productive activities outside the home while women are expected to be responsible for reproductive and productive activities within the home. And we know from over twenty years of research on women's roles in development that women have less access over and control of productive resources than men – resources such as income, land, credit, and education. While the extent of this difference varies considerably from one culture to the next, it almost always persists (Sivard et al 1995; Buvinic 1995).

Sexuality is distinct from gender yet intimately linked to it. It is the social construction of a biological drive. An individual's sexuality is defined by whom one has sex with, in what ways, why, under what circumstances, and with what outcomes. It is more than sexual behaviour and is a multidimensional and dynamic concept. Explicit and implicit rules imposed by society, as defined by one's gender, age, economic status, ethnicity and other factors, influence an individual's sexuality (Zeidenstein and Moore 1996; Dixon Mueller 1993).

At the Center at which I work, we talk about the components of sexuality as the Ps of sexuality – practices, partners, pleasure/pressure/pain, and procreation. The first two refer to aspects of behaviour – how one has sex and with whom; while the others refer to the underlying motives. But we have learned through data gathered over many years that there is an additional P of sexuality that is the most important – power. The power underlying any sexual interaction, heterosexual or homosexual, determines how all the other Ps of sexuality are expressed and experienced. Power determines whose pleasure is given priority and when, how, and with whom sex takes place. Each component of sexuality is closely related to the other but the balance of power in a sexual interaction determines its outcome (Weiss and Rao Gupta 1998).

> We have known for at least a decade that gender and sexuality are significant factors in the sexual transmission of HIV, and we now know that they also influence treatment, care, and support. Both terms, nevertheless, continue to remain misunderstood and inappropriately used.

Power is fundamental to both sexuality and gender. The unequal power balance in gender relations that favours men, translates into an unequal power balance in heterosexual interactions, in which male pleasure supersedes female pleasure and men have greater control than women over when, where, and how sex takes place. An understanding of individual sexual behaviour, male or female, thus necessitates an understanding of gender and sexuality as constructed by a complex interplay of social, cultural, and economic forces that determine the distribution of power.

Research supported by ICRW and conducted by researchers worldwide has identified the different ways in which the imbalance in power between women and men in gender relations curtails women's sexual autonomy and expands male sexual freedom, thereby increasing women's *and* men's risk and vulnerability to HIV (Weiss and Rao Gupta 1998; de Bruyn et al 1995; Heise and Elias 1995). Let me first briefly go through the factors associated with women's vulnerability to HIV.

Women's Vulnerability

First, in many societies there is a culture of silence that surrounds sex that dictates that "good" women are expected to be ignorant about sex and passive in sexual interactions. This makes it difficult for women to be informed about risk reduction or, even when informed, makes it difficult for them to be proactive in negotiating safer sex (Carovano 1992).

Second, the traditional norm of virginity for unmarried girls that exists in many societies, paradoxically increases young women's risk of infection because it restricts their ability to ask for information about sex out of fear that they will be thought to be sexually active. Virginity also puts young girls at risk of rape and sexual coercion in high-prevalence countries because of the erroneous belief that sex with a virgin can cleanse a man of infection and because of the erotic imagery that surrounds the innocence and passivity associated with virginity. In addition, in cultures where virginity is highly valued, research has shown that some young women practise alternative sexual behaviours, such as anal sex, in order to preserve their virginity, although these behaviours may place them at increased risk of HIV (Weiss, Whelan, and Rao Gupta 2000).

Third, because of the strong norms of virginity and the culture of silence that surrounds sex, accessing treatment services for sexually transmitted diseases can be highly stigmatizing for adolescent and adult women (Weiss, Whelan, and Rao Gupta 2000; de Bruyn et al 1995).

Fourth, in many cultures, because motherhood, like virginity, is considered to be a feminine ideal, using barrier methods or non-penetrative sex as safer sex options presents a significant dilemma for women (Heise and Elias 1995; UNAIDS 1999).

Fifth, women's economic dependency increases their vulnerability to HIV. Research has shown that the economic vulnerability of women makes it more likely that they will exchange sex for money or favours, less likely that they will succeed in negotiating protection, and less likely that they will leave a relationship that they perceive to be risky (Heise and Elias 1995; Mane, Rao Gupta, and Weiss 1994; Weiss and Rao Gupta 1998).

And finally, the most disturbing form of male power, violence against women, contributes both directly and indirectly to women's vulnerability to HIV. In population-based studies conducted worldwide, anywhere from 10 to over 50 percent of women report physical assault by an intimate partner. And one-third to one-half of physically abused women also report sexual coercion (Heise, Ellsberg, and Gottemoeller 1999).

A review of literature on the relationship between violence, risky behaviour, and reproductive health, conducted by Heise and colleagues (1999) shows that individuals who have been sexually abused are more likely to engage in unprotected sex, have multiple partners, and trade sex for money or drugs. This relationship is also apparent in the findings from a study conducted in India. In this study men who had experienced extramarital sex were 6.2 times more likely to report wife abuse than those who had not. And men who reported STD symptoms were 2.4 times more likely to abuse their wives than those who did not (Martin et al 1999). And from other research we also know that physical violence, the threat of violence, and the fear of abandonment act as significant barriers for women who have to negotiate the use of a condom, discuss fidelity with their partners, or leave relationships that they perceive to be risky (Mane, Rao Gupta, and Weiss 1994; Weiss and Rao Gupta 1998).

An individual's sexuality is defined by whom one has sex with, in what ways, why, under what circumstances, and with what outcomes.

Additionally, data from a study conducted in Tanzania by Maman, Mbwambo, and colleagues (2000) suggest that for some women the experience of violence could be a strong predictor of HIV. In that study, of the women who sought services at a voluntary HIV counseling and testing center in Dar-es-Salaam, those who were HIV-positive were 2.6 times more likely to have experienced violence in an intimate relationship than those who were negative.

Men's Vulnerability

Let us move on now to the way in which the unequal power balance in gender relations increases men's vulnerability to HIV infection, despite, or rather because of, their greater power.

First, prevailing norms of masculinity that expect men to be more knowledgeable and experienced about sex, put men, particularly young men, at risk of infection because such norms prevent them from seeking information or admitting their lack of knowledge about sex or protection, and coerce them into experimenting with sex in unsafe ways, and at a young age, to prove their manhood (UNAIDS 1999).

Second, in many societies worldwide it is believed that variety in sexual partners is essential to men's nature as men and that men will seek multiple partners for sexual release – a hydraulic model of male sexuality that seriously challenges the effectiveness of prevention messages that call for fidelity in partnerships or a reduction in the number of sexual partners (Mane, Rao Gupta, and Weiss 1994; Heise and Elias 1995).

Third, notions of masculinity that emphasize sexual domination over women as a defining characteristic of maleness contribute to homophobia and the stigmatization of men who have sex with men. The stigma and fear that result forces men who have sex with men to keep their sexual behaviour secret and deny their sexual risk, thereby increasing their own risk as well as the risk of their partners, female or male (UNAIDS 1999).

Fourth, men in many societies are socialized to be self-reliant, not to show their emotions, and not to seek assistance in times of need or stress (WHO 1999). This expectation of invulnerability associated with being a man runs counter to the expectation that men should protect themselves from potential infection and encourages the denial of risk.

Overall, these manifestations of traditional notions of masculinity are strongly associated with a wide range of risk-taking behaviour. For example, a national survey of adolescent males aged 15 to 19 in the US found that young men who adhered to traditional views of manhood were more likely to report substance use, violence, delinquency, and unsafe sexual practices (Courtenay 1998).

Power Imbalance and HIV/AIDS

In addition to increasing the vulnerability of women and men to HIV, the power imbalance that defines gender relations and sexual interactions also affects women's access to and use of services and treatments. For example, the Tanzanian study conducted by Maman, Mbwambo, and colleagues (1999) found that there were gender differences in the decision-making that led to the use of HIV voluntary counseling and testing (VCT) services. While men made the decision to seek voluntary counseling and testing independent of others, women felt compelled to discuss testing with their partners before accessing the service, thereby creating a potential barrier to accessing VCT services.

Women's social and economic vulnerability and gender inequality also lie at the root of their painful experiences in coping with the stigma and discrimination associated with HIV infection. HIV-positive women bear a double burden: they are infected and they are women. In many societies being socially ostracized, marginalized, and even killed are very real potential consequences of exposing one's HIV status. Yet HIV testing is a critical ingredient for receiving treatment or for accessing drugs to prevent the transmission of HIV from a woman to her child.

In a recent study conducted by researchers in Botswana and Zambia in collaboration with researchers from ICRW, men and women expressed concern for women who test positive because they felt that men would be likely to abandon an HIV-positive partner. On the other hand, it was expected that women would initially get angry with an HIV-positive partner, but ultimately accept him (Nyblade and Field 2000).

Overcoming Inequality

How is one to overcome these seemingly insurmountable barriers of gender and sexual inequality? How can we change the cultural norms that create these damaging, even fatal, gender disparities and roles? An important first step is to recognize, understand, and publicly discuss the ways in which the power imbalance in gender and sexuality fuels the epidemic.

There has been a definite shift in the international public and political rhetoric on HIV/AIDS over the last two years. The dominant discourse now reflects an increased acknowledgment of the role that gender plays in fueling the epidemic. Unfortunately, aside from a few exceptions, such public discourse on sex and sexuality is still invisible. There is an urgent need to break that silence because we know that talking openly about sex is the first step to reducing denial and bringing about acceptance of our collective vulnerability.

In contrast, public health discourse, as seen in scientific journals and forums, reflects definite progress in understanding the importance of both gender and sexuality. But because this increased understanding is fueled in large part by the need to interpret the dynamics of the AIDS epidemic, the analysis of gender and sexuality is situated firmly within a framework of disease. Sexuality as seen through the public health prism, therefore, is still a potential determinant of ill health and little else. As a result, safer sex is the mainstream theme within this discourse, while sexual health, pleasure, and rights remain on the margins.

It is also important to note that the progress in the public health discourse on gender and sexuality is not matched by progress in action. There is a substantial gap between the talk and the walk. This is partly because it is easier now to explain the why and what with regard to gender, sexuality, and HIV/AIDS, but there is less known about the how – how to address these issues in a way that has an impact on the epidemic. It must be said, however, that this relatively little information on the how is not due to a lack of innovation and trying. Although there are still no clear-cut answers and there is very little data to establish the impact of the efforts that have been tried, it is possible to look back and identify clear-cut categories of approaches – approaches that fall at different points on a continuum from damaging to empowering.

To effectively address the intersection between HIV/AIDS and gender and sexuality requires that interventions should, at the very least, not reinforce damaging gender and sexual stereotypes. Many of our past and, unfortunately, some of our current efforts, have fostered a predatory, violent, irresponsible image of male sexuality and portrayed women as powerless victims or as repositories of infection. This poster, in which a sex worker is portrayed as a skeleton, bringing the risk of death to potential clients, is an example of the latter which, from experience we can predict, probably succeeded in doing little other than stigmatizing sex workers, thereby increasing their vulnerability to infection and violence. There are many other examples of such damaging educational materials. A particularly common type is one that exploits a macho image of men to sell condoms. No amount of data on the increase in condom sales is going to convince me that such images are not damaging in the long run. Any gains achieved by such efforts in the short term are unlikely to be sustainable because they erode the very foundation on which AIDS prevention is based – responsible, respectful, consensual, and mutually satisfying sex.

Approaches That Do No Harm

In comparison, gender-neutral programming is a step ahead on the continuum because such approaches at least do no harm. Examples include prevention education messages that are not targeted to any one sex, such as "be faithful" or "stick to one partner," or treatment and care services that make no distinction between the needs of women and men, not recognizing, for example, that women clients may need greater social support than men or that women might prefer female counselors and health-care providers to male providers. While such gender-neutral programs are better than nothing, they often are less than effective because they fail to respond to the gender-specific needs of individuals.

Gender-Sensitive Approaches

In contrast, gender-sensitive programming that recognizes and responds to the differential needs and constraints of individuals based on their gender and sexuality is another step forward on the continuum of progress. The defining characteristic of such interventions is that they meet the different needs of women and men. Providing women with a female condom or a microbicide is an example of such programming. It recognizes that the male condom is a male-controlled technology and it takes account of the imbalance in power in sexual interactions that makes it difficult for women to negotiate condom use by providing women with an alternate, woman-initiated technology. Efforts to integrate STD treatment services with family planning services to help women access such services without fear of social censure is another example of such an approach. We know that such pragmatic approaches to programming are useful and necessary because they respond to a felt need and often significantly improve women's access to protection, treatment, or care. But by themselves they do little to change the larger contextual issues that lie at the root of women's vulnerability to HIV. In other words, they are necessary, even essential, but not sufficient to fundamentally alter the balance of power in gender relations.

Transformative Approaches

Next on the continuum are approaches that seek to transform gender roles and create more gender-equitable relationships. The last few years have seen a burgeoning of such efforts. Two excellent examples of this type of intervention are the Men as Partners or MAP project being conducted by the Planned Parenthood Association of South Africa in collaboration with AVSC International and the Stepping Stones program. Both programs seek to foster constructive roles for men in sexual and reproductive health. The curricula for these programs use a wide range of activities – games, role plays, and group discussions – to facilitate an examination of gender and sexuality and its impact on male and female sexual health and relationships, as well as to reduce violence against women. What is novel about these programs is that they target men, particularly young men, and work with them and women to redefine gender norms and encourage healthy sexuality. These are just two of an increasing number of innovative efforts to work with men, women, and communities. There is an urgent need now to rigorously evaluate the impact of these and other creative curricula in the settings for which they were developed and to find ways to replicate their use on a larger scale.

There is also a need to find ways to intervene early to influence the socialization of young boys to foster gender-equitable attitudes and behaviours. Recent research conducted by Barker (forthcoming) in Brazil suggests that one way to do this is to study the many adolescent boys who do not conform to traditional expectations of masculinity. By studying these "positive deviants," Barker was able to identify a number of factors associated with gender-equitable attitudes among young adolescent males. These factors include:

acknowledgment of the costs of traditional masculinities, access to adults who do not conform to traditional gender roles, family intervention or rejection of domestic violence, and a gender-equitable male peer group. These factors underscore the importance of male role models, within the peer group and the family, who behave in gender-equitable ways. More such creative research on masculinity and its determinants is necessary in order to identify the best approaches to promote gender-equitable male attitudes and behaviours.

Other programs that seek to transform gender relations include efforts to work with couples as the unit of intervention, rather than with individual women or men. Couple counseling in HIV testing clinics to help couples deal with the results of their tests and in family planning programs that promote dual protection against both unwanted pregnancy and infection are recent examples of efforts that seek to reduce the negative impacts of the gender power imbalance by including both partners in the intervention. Some programs, however, have reported difficulty in being able to find and recruit couples who are willing to participate, although many couples who do participate describe couple counseling as a positive experience. Research is needed to identify ways to overcome the barriers to couple counseling and to test the effectiveness of this method in creating more gender-equitable relationships and in reducing vulnerability and stigma.

Approaches That Empower

Finally, at the other end of the continuum – far away from programs that foster damaging gender stereotypes – are programs that seek to empower women or free women and men from the impact of destructive gender and sexual norms. These are programs that empower women by improving their access to information, skills, services, and technologies, but also go further to encourage participation in decision-making and create a group identity that becomes a source of power – a group identity separate from that of the family because for many women the family is often the social institution that enforces strict adherence to existing gender norms. The Sonagachi sex worker project of West Bengal, India, is an excellent example of a project that sought to empower a community through participation and mobilization. What began as an HIV/AIDS peer education program was transformed into an empowering community organizing effort that put decision-making in the hands of the most disempowered – the sex workers (West Bengal Sexual Health Project 1996). How can we replicate Sonagachi in multiple sites worldwide? What are the ingredients that contributed to its success in mobilizing and organizing a disempowered community? Without the answers to these questions Sonagachi will remain the exception rather than the rule.

> The unequal power balance in gender relations increases men's vulnerability to HIV infection, despite, or rather because of, their greater power.

In the ultimate analysis, reducing the imbalance in power between women and men requires policies that are designed to empower women. Policies that aim to decrease the gender gap in education, improve women's access to economic resources, increase women's political participation, and protect women from violence are key to empowering women. We now have two international blueprints – the Cairo Agenda and the Beijing Platform for Action – that delineate the specific policy actions that are essential for assuring women's empowerment. Since governments worldwide have committed to these blueprints, it would be useful for the HIV/AIDS community to join hands with the international women's community to hold governments accountable for their promises by ensuring that the actions recommended in these documents are implemented. Creating a supportive policy and legislative context for women is crucial for containing the spread of the HIV/AIDS epidemic and mitigating its impact.

Moving Ahead

It is clear that the sensitive, transformative, and empowering approaches to gender and sexuality that I have just outlined are not mutually exclusive. They must occur simultaneously and efforts should be made to expand the portfolio of options within each category. In this, as in other AIDS programming, we need a multipronged approach. We must continue to address the differing needs and concerns of women and men, while we work on altering the status quo in gender relations, in minor and major ways.

As we look to the future, let us be alert to the potential impediments to our success. Let us ensure that new, promising HIV/AIDS biomedical technologies, such as vaccines, which have the potential for making a substantial dent in the epidemic, are not impeded by entrenched gender barriers. Let us acknowledge that no biomedical technology is ever gender-neutral. To ensure equal access for all, women and men, girls and boys, we must work hard now, way before these technologies are ready for use, to identify the potential gender-specific constraints to their use and find ways to overcome them.

And let us work together to fight against two commonly held beliefs that continue to stand in the way of our efforts. The first mistaken belief is that empowering women will disempower men. This is not true. Empowering women is not a zero-sum game. Power is not a finite concept. More power to one invariably, in the long term, means more power to all. Empowering women empowers households, communities, and entire nations.

The second is the fear that changing gender roles to equalize the gender power balance conflicts with the values of multiculturalism and diversity. In fact, by changing gender roles, what is being altered is not a society's culture but rather its customs and practices, which are typically based on an interpretation of culture. I believe that customs and practices that seek to subordinate women and trap men in damaging patterns of sexual behaviour are based on a biased interpretation of culture that serves narrow interests. We know that the customs and practices associated with male and female roles and sexuality in many societies today are compromising the rights and freedoms of individuals and promoting a cycle of illness and death. This must stop. There can be no more powerful reason for change; gender roles that disempower women and give men a false sense of power are killing our young and our women and men in their most productive years. This must change. That is the message that must be communicated – without any caveats, ifs, or buts.

> Empowering women empowers households, communities, and entire nations.

– Geeta Rao Gupta

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Human Rights and the AIDS Crisis: The Debate Over Resources

In his plenary presentation of 11 July 2000 at the XIII International AIDS Conference, Kenneth Roth, the Executive Director of Human Rights Watch, the largest US-based human rights organization, reflects on whether a human-rights perspective can help us confront the AIDS crisis. More specifically, he asks the question whether human rights can help us meet the urgent challenge of securing the vast resources we need for treatment and prevention. Mr Roth believes they can. He argues that human rights are a powerful tool for meeting basic human needs, but that their contribution to the fight against AIDS is not as simple or straightforward as many often assume. In his presentation, he explains why.

For well over a decade, the human-rights perspective has contributed to the evolving public-health understanding of how to address AIDS. We owe a particular debt of gratitude to the late Jonathan Mann. He, more than anyone, highlighted the synergistic relationship between health and human rights.

He helped us understand that respect for the rights of people who are infected or at risk of infection by HIV is essential for preventing and treating the disease. If we risk discrimination, coercion, or breach of confidentiality, we are less likely to be tested, to seek treatment, or to learn how to avoid infecting ourselves or others. He also showed us that combatting discrimination and social marginalization can help fight the vulnerability that handicaps many people, particularly women and girls, in their efforts to avoid infection.

Today, however, a new public-health challenge has come to the fore in the fight against AIDS. The issue is less what should be done to prevent or treat HIV infection than where we will find the enormous resources we need. Who should pay the cost of combatting AIDS? In particular, does the industrialized world have an obligation to help the people of the developing world, and if so, what precisely is owed? Should obligations arising out of the AIDS pandemic differ from obligations arising out of other public-health crises or from the general need for basic health care?

None of these life-and-death questions admits easy answers. But international human-rights standards can help point a useful direction. The relevant standards are not the ones of civil and political rights – the issues of discrimination and individual freedom that so far have played the largest role in fashioning a response to AIDS. Rather, the pertinent standards are found in the less familiar terrain of economic and social rights.

The leading human rights treaty in this area is the International Covenant on Economic, Social and Cultural Rights. Other human rights treaties are also relevant, but today I will limit my discussion to the Covenant. Adopted by the UN General Assembly in 1966, the Covenant has been ratified by 142 governments. I should note that, unfortunately, our host country, South Africa, as well as my own country, the United States, have signed the Covenant but not yet ratified it, evidently for fear of being bound by it.

The Covenant requires governments to respect the right to the basic necessities of human life – the right to such things as work, education, food, clothing, and housing. The most important right for our purposes is set out in Article 12, which proclaims the right of everyone to enjoy *the highest attainable standard of physical and mental health.* Among other steps, this right requires governments to prevent, treat, and control diseases, and to assure medical care and attention to everyone in the event of illness.

A new public-health challenge has come to the fore in the fight against AIDS. The issue is less what should be done to prevent or treat HIV infection than where we will find the enormous resources we need.

As you can see, if this right were fully respected, we would be well on our way to solving the AIDS crisis. Treatment would be available to everyone, and effective prevention strategies could be widely implemented. Yet, obviously, we are far from that moment. Indeed, when it comes to AIDS, it seems almost a cruel joke even to assert the right to health because governments seem to accord it so little weight.

Why is this? Why do rights-based arguments seem so ineffective in convincing governments to provide the resources needed to fight AIDS? The difficulty is best illustrated by contrast with a more classic rights-based appeal – say, a demand to stop torture. Even in countries that practise torture, torture is shameful. By exposing a government's use of torture, we can shame the government into curtailing this inhumane practice. So why can't similar public shaming be used to force governments to devote the resources needed to fight AIDS? It can, but the process is not nearly as straightforward. Let me explain why, and how we might proceed.

The difficulty with invoking economic and social rights is that the duty to respect them is far more qualified than the duty to respect civil and political rights. Governments are expected to uphold civil and political rights immediately. Moreover, responsibility for doing so is assigned almost exclusively to the national government of the country in question; there is no opportunity to pass the burden on to others. By contrast, the economic and social rights treaty allows its rights to be fulfilled gradually, over time. Each government is asked only to *take steps* to secure these rights, and to do so only *to the maximum of its available resources, with a view to achieving progressively [their] full realization.* Moreover, the treaty assigns responsibility for compliance more broadly – not only to the immediate national government, but also to the international community as a whole, through the duty to provide *international assistance*.

This gradualism and shared responsibility make it much more difficult to shame a particular national government for its poor state of health care or, for that matter, its inadequate education or housing. Governments can deflect criticism by blaming others. There is no easy way to move beyond this finger-pointing. Or governments can simply assert that their current contributions, stingy as they might be, are all they owe to meet the AIDS challenge. Again, there are no clear benchmarks by which to rebut these claims.

So how, given these qualified, divided responsibilities, might we enforce economic and social rights? Or, more specifically for our purposes, how might we uphold a right to adequate AIDS health care? How do we move beyond the finger-pointing and evasions to hold particular governments responsible?

The answer begins with the observation that shared responsibility for upholding the right to health does not mean no responsibility. The mere fact that many governments have a duty to assist in fighting AIDS does not mean that any one of them can shirk its responsibility for acting.

In my view, the treaty's requirement that governments *take steps* to secure economic and social rights should mean, at a minimum, that they take the following three steps. First, each government should be required to adopt a plan that is reasonably designed to achieve the right in question – in our case, the right to adequate AIDS health care. Second, governments should be required to establish a timetable for implementing the plan, so that implementation is not perpetually put off for the future. Third, governments should demonstrate progress toward fulfilling the plan – actual movement toward the goal of providing an adequate response to the AIDS epidemic.

Straightforward as these three steps are, many governments will strenuously resist taking them. Why? Because governments know that once they adopt a plan and timetable to fulfill economic and social rights, they set benchmarks by which to measure their compliance. Governments instinctively resist such accountability because it limits their ability to pursue less essential, though perhaps more self-serving, goals.

To establish this accountability is precisely why it is so important for us to insist that every government, rich or poor, devise its own individual plan and timetable for meeting the AIDS crisis. If a government resists, we should make that failure itself a focal point for public shaming, since a government can hardly be said to be serious about confronting AIDS if it won't even adopt an official plan for doing so.

Once a government does adopt a plan and timetable, our advocacy of the right to health becomes much easier. If the plan and timetable are inadequate, or if the government devotes insufficient resources to implementation, it becomes easier to ask why the government is doing so little to address AIDS, or why combatting the disease is accorded such a low priority. If a government pleads poverty, that invites us to scrutinize other expenditures that are said to deserve higher priority. This often brings up such difficult but essential questions as whether a military build-up or a prestigious government project is really more important than greater investment in public health. Even when a government invests in health or other development needs, its plan and timetable would allow us to ask whether the investment has been made with the interests of the most needy foremost in mind, or whether other, less fundamental interests are driving priorities.

Still, important questions remain. When speaking to governments, particularly those of the industrialized world, how do we make sure that every government contributes its share? How do we avoid buck-passing, stingy responses, or the free-rider syndrome, in which one country shirks its responsibilities on the assumption, usually false, that another country will foot the bill? The key is to insist on a plan and timetable for meeting the AIDS crisis that are adopted not only by individual governments, acting one by one. Instead, for each country in need, we must have a plan and timetable adopted globally, by all the governments of the world acting together. For each needy country, we must demand a *World Conference of Governments* to confront that country's AIDS crisis.

We must insist that each such World Conference of Governments not be yet another talking shop. We need a series of World Conferences in which all industrialized governments convene to consider a country in need, the doors are locked, and no one leaves the room until the finger-pointing and evasions stop, no one goes home until the resources are finally committed that are adequate to the emergency at hand. If industrialized governments still fail to do what is right, the setting of a World Conference would make it far easier for us to marshal the public condemnation we need to spur action. It ensures that any governmental failure occurs under the harshest possible spotlight. In this way, we can give the imprecise requirements of the treaty on economic and social rights sufficient precision and bite that enforcement through public shaming becomes feasible.

Our needs are enormous but not beyond fulfilment. Far more is spent routinely on far less urgent problems. If, as UNAIDS now reports, 50 percent of people age 15 and older will die of AIDS-related illnesses in some southern African countries, we cannot afford to allow half-hearted responses any more. If the industrialized governments plead poverty, we should remind them of the wide and growing income gap between the richest and poorest countries. According to the UN Development Program, the income gap between the fifth of the world's population living in the richest countries and the fifth in the poorest was 74 to 1 in 1997, well more than double the gap of 30 to 1 in 1960. There is no excuse, in light of this worsening trend, for the industrialized world to say that funds are not available.

But the duty of the industrialized world should be understood not only in terms of international assistance to needy nations – essential as that is. For better or worse, the industrialized world is also the principal source of funds to develop AIDS medicines and, eventually, we hope, an AIDS vaccine. A global AIDS plan, to be complete, must include funds for investment in research and development. It should also include a reasonable delivery program to provide global access to essential drugs or vaccines that are developed. And it should ensure that research for drugs and vaccines focuses on the virus as it appears in all parts of the world, not just the West.

When essential drugs or vaccines are developed, it is not reasonable to insist on selective compliance with the international legal protocol for protecting patents – the so-called TRIPS Agreement of the WTO. It is wrong to reap the benefits of patent protection under TRIPS while fighting tooth and nail to discourage developing countries from invoking parallel provisions in that same protocol for providing cheaper access to drugs in the case of a health emergency like the AIDS crisis. Governments and corporations should not seek to enjoy the rights of an international trade regime without also accepting the caveats inherent in the definition of those rights that permit compulsory licensing and parallel importing in the event of a health emergency. In other words, an industrialized government cannot be said to be *taking steps* to *progressively realize* the right to health when it defends excessive corporate profits over the right of access to essential, life-saving medicine in cheap or generic form.

Does the industrialized world have an obligation to help the people of the developing world, and if so, what precisely is owed?

Of course, to make this point is not to reject the corporate argument that profits are needed to justify the risks and expenses of research and development. Failure to provide reasonable profits would be counterproductive if it led to abandonment of the quest for a vaccine or better drugs. But a government that is conscious of its duty to uphold the right to health would defend only the level of corporate profits needed to provide basic incentives, not corporate windfalls. To the extent that the necessary corporate incentives cannot be paid by patients who can afford the full price of medication, the cost should be paid in government subsidies, not in the lives of impoverished AIDS victims.

The duty to establish a plan and timetable to address the AIDS epidemic applies not only to relatively wealthy states. Even governments of developing countries have a duty to devise a plan and timetable for applying whatever resources they have to meeting such basic needs as adequate health care. In most if not all cases, these needs will exceed resources. But the adoption of a plan and timetable for spending whatever funds are available will provide the transparency needed for the public to scrutinize government expenditures and priorities and, where necessary, to demand adjustments and reallocations.

Such transparency also permits the public to participate in the difficult process of setting priorities among competing fundamental needs. To begin with, decisions must be made for allocating funds among those infected by, affected by, and vulnerable to HIV/AIDS. Then priorities must be set between addressing the AIDS crisis and addressing other maladies such as malaria, tuberculosis, and diarrheal diseases, or providing basic health care. Finally, funds must be allocated between these broad health needs and other basic needs in such areas as education, housing, or nutrition, many of which also affect health. Human rights standards provide no simple road map for setting these difficult priorities. But if human rights are understood to require at the very least a transparent public plan and timetable for addressing these basic needs, they will facilitate the public debate and participation that is most likely to secure government policies that are sensitive to these needs.

The requirement of a governmental plan and timetable for meeting the AIDS crisis also has a key non-economic dimension. Sometimes the most important thing a government can do to combat AIDS is to provide public leadership. We see examples of such leadership in Uganda, Thailand, and Senegal. Funding is certainly helpful for spreading the word through public education, but funding alone will not compensate for the lack of a clear message. Governments have a duty, regardless of their economic circumstances, to convey the best available scientific knowledge about how to treat AIDS and avoid infection.

That means governments must not mislead the public with wild and scientifically refuted messages about the origin of AIDS. That means governments must not scare the public with exaggerated stories about the dangers of the best available drugs for stemming the spread of HIV from mother to child. That means governments must not discourage testing for fear of prompting demands for treatment. That means governments must abandon regional, national, or personal pride if it stands in the way of saving lives. A government's message about preventing HIV infection is not only a matter of resources; it is also a matter of political choice, courage, and will. We should be unsparing in our criticism of governments, like our host government, that shirk that duty, because they violate any pretense of progressively realizing the right to health in the prevention and treatment of AIDS.

We should also insist that governments attack cultural norms and practices that fuel the spread of AIDS. We all know of the macho culture that celebrates the number of women that a man can sexually conquer, the horrifying myth that AIDS can be cured by sleeping with a virgin or young girl, or the deadly expectation that a wife have unprotected sex with her husband even if he is HIV-positive. These dangerous, destructive practices are too costly to tolerate. We must not allow discomfort with the topic of sexual mores to stand in the way of loud and frank denunciations by governments.

> Governments and corporations should not seek to enjoy the rights of an international trade regime without also accepting the caveats inherent in the definition of those rights that permit compulsory licensing and parallel importing in the event of a health emergency.

Similarly, we must insist on government leadership in denouncing and ending discrimination that impedes the fight against AIDS. For example, how can we reduce mother-to-child transmission if HIV-positive women are afraid not to breastfeed their babies for fear of stigmatization? How can we reduce transmission among gay men, lesbians, bisexual and transgendered people if the discrimination they face precludes education regarding same-sex sexual practices? Again, the issue here is not resources, but political will.

Of course, we must understand that it is not solely ignorance or cowardice that leads governments to tolerate or entertain such dangerous and discriminatory practices. It is also despair, despair at knowing that the funds needed to sustain a vigorous prevention program, let alone to embark on widespread treatment, are way beyond their means. That is another reason why it is so important for the governments of the industrialized world to develop a comprehensive global plan for combatting AIDS. We need a global plan not because its absence excuses a lack of leadership by governments of the developing world, but because the solidarity and economic commitment of the industrialized world will help engender the hope needed to promote effective leadership.

In conclusion, human rights are not a panacea for the AIDS crisis. They will not magically produce the resources we need. They will not even tell us which resources should be devoted to fighting AIDS as opposed to addressing other important societal needs and interests. But they do require governments to address the crisis with the appropriate urgency and transparency. The duty to provide international assistance for securing economic and social rights requires governments of the industrialized world to devise and publicly adopt country-specific plans and timetables for meeting the extraordinary economic challenges of combatting AIDS. Governments of the developing world must proceed with similar transparency and resolve within their own countries. Such commitments permit the public scrutiny of economic priorities that is the best way we have of enforcing these human rights. If these steps are taken, we will have gone a long way toward containing this deadly disease.

– Kenneth Roth

Kenneth Roth is the Executive Director of Human Rights Watch, the largest US-based human rights organization, which monitors developments in more than 70 countries worldwide. During Mr Roth's seven years at the helm, the organization has more than doubled in size and has added special projects devoted to international justice, refugees, academic freedom, children's rights, and corporate responsibility. Prior to joining Human Rights Watch in 1987, Mr Roth served as a federal prosecutor in the US Attorney General's Office and for the Iran-Contra investigation. A graduate of Yale Law School and Brown University, Mr Roth has conducted numerous human rights investigations and missions around the world. He has testified frequently before the US Congress and international bodies and has written extensively on international justice, human rights abuses, and war crimes. Mr Roth can be reached through the offices of Human Rights Watch, 350 Fifth Avenue, 34th Floor, New York, NY 10118-3299 USA; email: hrwnyc@hrw.org.

Revising the Declaration of Helsinki: Ethics vs Economics or the Fallacy of Urgency

Constant vigilance is required to ensure that the rights of volunteers in clinical trials are protected, particularly in developing countries. In this presentation to the XIII International AIDS Conference (abstract ThOrE651), Dirceu B Greco, of the Federal University of Minas Gerais in Brazil, describes the debate that has raged over the proposed changes to the Declaration of Helsinki, particularly with respect to access to medical care for trial volunteers and to the use of placebos in the control arms of the trials. The presentation argues: (1) that all trial volunteers should have access to the best diagnostic, preventive, and therapeutic methods, regardless of the standard of care in the countries where the trials are taking place; (2) that large efficacy trials of vaccines and drugs should be done first in countries where the best diagnostic, preventive, and therapeutic methods are available; and (3) that the costs of providing care and prevention services should be considered an integral part of the cost of the trials. The presentation explains how a partnership between activists, scientists, ethicists, and medical associations was effective in resisting pressures to lower the ethical standards for clinic trials. The presentation concludes that the gains made by this partnership constitute an important step in the struggle to provide universal access to education and health.

Introduction

Everyone agrees that efficacious vaccines and more potent drugs are needed to curb the spread of HIV infection (and other infectious diseases). However, conducting clinical trials to evaluate these vaccines and drugs in the so-called developing world is full of challenges. The urgency of the situation is underscored by estimates from the Joint United Nations Programme on HIV/AIDS of 16,000 new cases of HIV infection daily and by the fact that 90 percent of these infections are occurring in the Third World. No one denies this urgency. However, what is worrisome is that this urgency is being used as a reason to lower the ethical standards for conducting clinical trials. In particular, there have been attempts to dilute the Declaration of Helsinki,[1] long the symbol of the ethical conduct of research, and the ethics guidelines of the Council for International Organizations of Medical Science.[2]

> Let us push for open discussion of our ethical standards, for improvements to these standards, for the attainment of the highest possible standards, and for these standards to be universally applied. Let us work toward better life conditions and access to health care for all.

TABLE 1. ACCESS TO MEDICAL CARE
Selected comparisons from different versions of the Declaration of Helsinki

1996 VERSION	1999 DRAFT	EARLY 2000 DRAFT	FINAL 2000 VERSION (EDINBURGH)
In any medical study, every patient – including those of a control group, if any – should be assured of the *best proven* diagnostic and treatment method (emphasis added).	In any biomedical research protocol every patient-subject, including those of a control group, if any, should be assured that he or she will not be denied access to the best proven diagnostic, prophylactic or therapeutic method *that would otherwise be available to him or her* (emphasis added).	In any medical study, every patient – including those of a control group, if any – should be assured of *proven effective* prophylactic, diagnostic, and therapeutic methods (emphasis added).	At the conclusion of the study, every patient entered into the study should be assured of access to the best proven prophylactic, diagnostic and therapeutic methods identified by the study.

TABLE 2. USE OF PLACEBOS
Selected comparisons from different versions of the Declaration of Helsinki

1996 VERSION	1999 DRAFT	EARLY 2000 DRAFT	FINAL 2000 VERSION (EDINBURGH)
This does not exclude the use of inert placebo in studies where no proven diagnostic or therapeutic method exists.	When the outcome measures are neither death nor disability, *placebo or other no-treatment controls may be justified on the basis of their efficiency* (emphasis added).	This does not exclude the use of inert placebo in studies where no proven diagnostic or therapeutic method exists.	The benefits, risks, burdens and effectiveness of a new method should be tested against those of the best current prophylactic, diagnostic, and therapeutic methods. This does not exclude the use of placebo, or no treatment, in studies where no proven prophylactic, diagnostic or therapeutic method exists.

The Declaration of Helsinki is a World Medical Association (WMA) document, but its values and principles are not “owned” by the WMA but rather are shared by the world community. In the last three years, there has been a concerted effort to modify the Declaration of Helsinki, especially in areas related to accessing medical care (see Table 1) and using placebos (see Table 2) during clinical trials.

Access to Medical Care

The 1996 version of the Declaration of Helsinki stated that each trial volunteer should be provided the “best proven diagnostic and treatment methods.” In 1999, a proposed revision to the Declaration would have altered this wording to the “best proven diagnostic, prophylactic or therapeutic method *that would otherwise be available to him or her*.” (Emphasis added.) This meant that if nothing was available, nothing would be provided. This proposed modification was based on the rationale that poor countries do not have access to the best proven therapeutic methods, and that the high costs that would be incurred to provide this level of care would scare off the pharmaceutical industry. Moreover, it was argued, scientists have no ethical obligation to provide more than what is available locally – even if drug company pricing is the primary cause of drug scarcity.

In the case of HIV vaccine trials in developing countries, the proposed modification would have meant that researchers would not have been obligated to treat any HIV infection that occurred during the course of the trial, lest that hamper their ability to evaluate important secondary endpoints such as the rate of disease progression. Of course, any trial in an industrialized country would ensure that such infections were treated. The claim that providing treatment during the trial would prevent proper analysis of the trial results is hypothetical and has not been quantitatively demonstrated. Indeed, recent studies show that it is possible to analyze the data even if antiretroviral treatment is provided to the volunteers who become infected.

The Use of Placebos

The absence of treatment, diagnostic methods, and counseling in many developing-country settings is also being used to justify the use of placebos in the control arms of trials, even when a known efficacious intervention already exists. The 1996 version of the Declaration of Helsinki stated that placebos could be used "where no proven diagnostic or therapeutic method exists." The 1999 proposed revision would have altered the wording as follows: "When the outcome measures are neither death nor disability, *placebo or other no-treatment controls may be justified on the basis of their efficiency*." (Emphasis added.) Thus, if the expectation was that the volunteer would survive the trial and not become disabled, the use of placebo would be justified! The rationale was that a placebo-controlled trial is more efficient. In this context, efficiency refers to economic considerations – ie, the trials would be less expensive and less time consuming, and fewer volunteers would be needed.

The use of placebos in vulnerable settings, even when a known effective therapy exists, is usually justified by the fallacious reasoning that the volunteers are poor to begin with and that their condition will not get any worse as a result of the trial. This is just a way of pretending that the problems of the trial volunteers are not the concern of the researchers. If the 1999 proposed changes had gone through, they would have justified unethical trials like a recent one in Thailand,[3] where a simpler method of avoiding vertical transmission of HIV was compared to a placebo instead of to the known regimen of AZT, which has been shown to be very efficacious (in the landmark clinical study ACTG 076[4]).

Costs of Treatment

The assertion is frequently advanced that providing treatment during a trial would result in inordinate costs, without any systematic attempt having been made to actually determine what these costs are. There is an indisputable obligation to protect volunteers in a trial. If costs are incurred in order to provide this protection, these costs should be considered as an intrinsic component of the trial and not as an excuse to lower the ethical standards of the trial.

Clinical Trials vs Access to a Developed Product

It is important to remember that although many countries are crying out for effective vaccines, drugs, preventive methods, and diagnostic tools, they are not all crying out for clinical trials. It may not make sense to conduct trials in the poorest countries. Often, the trials can be done in other countries (or regions, or communities) with similar incidences of infection, but where potential trial volunteers are not as destitute or as vulnerable.

The World Medical Association Position

The reaction in various international venues to the proposed changes to the Declaration of Helsinki forced the WMA to postpone the changes (which would otherwise have been enacted at the WMA Assembly in Tel Aviv in October 1999). Widespread international protest forced the WMA to discard the 1999 draft and to open up the process for further discussion. A new draft document was released in early 2000 and formed the basis for the discussions on the Declaration that took place at the 52nd WMA Assembly held in Edinburgh in October 2000.

With respect to the issue of access to medical care, the reference to "available care" that was in the 1999 draft was removed from the early 2000 draft. However, a much subtler change was inserted. Instead of requiring that volunteers have access to the "*best proven* diagnostic, prophylactic and diagnostic methods," the early 2000 draft required only that they be provided with "*proven effective* prophylactic, diagnostic and effective methods." (Emphasis added.) Could there be a clearer enunciation of the double standard? Best proven for the industrialized world, anything that is proven for the rest.

As for the use of placebos, fortunately the early 2000 draft reverted to the language used in the original 1996 version.

The 2000 Version of the Declaration of Helsinki[5]

After receiving suggestions from various national medical associations, NGOs, researchers, and ethicists from around the world, the WMA discussed and approved a final version of the Declaration of Helsinki in Edinburgh in October 2000. The final version is a definite improvement over the 1996 version; more important, none of the 1999 proposed modifications were included. The word "best" was reintroduced in the statement on access to medical care, and a new concept was added: an obligation to provide the best prophylactic, diagnostic, and therapeutic methods after the trial is finished. The actual wording is as follows: "At the conclusion of the study, every patient entered into the study should be assured of access to the best proven prophylactic, diagnostic and therapeutic methods identified by the study."

This wording represents significant progress, particularly in relation to trials conducted in developing countries. Unfortunately, there are also some problems with the wording:

1. There is no mention of access *during the trial* to the best prophylactic, diagnostic, and therapeutic methods.
2. There is room for misinterpretation. In the case of a vaccine trial, if treatment is indicated (for example, for a volunteer who became HIV infected during the course of the trial), the researchers or sponsors could argue that they do not have to provide treatment because this treatment was not "identified by the study."

The latter problem could have been resolved by substituting the words "relevant to the study" for "identified by the study." This change would have made it clear that there is an obligation to provide the best treatment even if this treatment had been established outside the context of any particular trial. This substitution was proposed by the Brazilian and South African delegations in Edinburgh, but was rejected by the Assembly.

Conclusion

The Declaration of Helsinki is of vital importance in ensuring adequate ethical standards for research on humans, whatever their race, origin, or economic power. Moreover, although the Declaration comes from the World Medical Association and was written by and for physicians, it is valued by all of society. As such, it deserves to be amply and thoroughly discussed and upgraded when required. In this case, it has been. Now it needs to be applied to each and every trial involving human subjects. We must also use the Declaration of Helsinki as a spearhead to help improve access to health care for all (and not only for people participating in a trial). This would provide all of society with the benefits of the research.

A Phase III trial of a potentially good vaccine concept or of a new drug should be done first in countries (industrialized or developing) where the best proven diagnostic, preventive, and therapeutic methods of care for volunteers are already in place or could be made available for the trial. This is the safest and most ethically sound way to proceed. If, at the end of the trial in these countries (with all ethical and scientific conditions fulfilled), the product has been shown to be effective, it must then be made available wherever it is needed.

During the critical discussions of the last few years on the proposed changes to the Declaration of Helsinki, activists, scientists, ethicists, and national medical associations were able to work together effectively to resist any lowering of the ethical standards for clinical trials, and to avoid widening the already enormous gaps separating the well-to-do in industrialized countries from destitute people all over the world.

The partnership among these various stakeholders was critical to our success. This partial victory is an important step in the much more difficult battle to provide universal access to education and health, and to demonstrate that the status quo of disparity is not an immutable fact.

The process followed in revamping the Declaration of Helsinki should also be applied to the guidelines of the Council for International Organizations of Medical Science. These guidelines are also in the process of being modified, a process that so far has proceeded in near secrecy.

Let us push for open discussion of our ethical standards, for improvements to these standards, for the attainment of the highest possible standards, and for these standards to be universally applied. Let us work toward better life conditions and access to health care for all. Let us fight for globalization of equality and solidarity!

– presented by Dirceu B Greco

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[1] World Medical Association Declaration of Helsinki, Somerset West, South Africa, 1996.

[2] International ethical guidelines for biomedical research involving human subjects. Geneva: Council for International Organizations of Medical Sciences (CIOMS), 1993.

[3] M Angell. The ethics of clinical research in the third world. *New England Journal of Medicine* 1997; 337: 847-849.

[4] CDC. Recommendations of the U.S. Public Health service task force on the use of Zidovudine to reduce perinatal transmission of HIV. *Morbidity and Mortality Weekly Report* 1994; 43 (no RR-11).

[5] World Medical Association Declaration of Helsinki, Edinburgh 2000 (www.wma.net).

Access to Treatment as a Right to Life and Health

In some countries in Latin America, in the absence of leadership from governments, activists have had to resort to the courts to obtain access to HIV/AIDS treatments for people with HIV/AIDS. In his presentation to the XIII International AIDS Conference (abstract TuOrE458), Edgar Carrasco, of Acción Ciudadana Contra el Sida (ACCSI), discusses the process that was followed in Venezuela. The presentation describes the very limited access people with HIV/AIDS had to antiretroviral therapies and treatments for opportunistic infections under Venezuela's health and social security systems. It provides details of lawsuits that were launched on behalf of several individuals living with HIV/AIDS, and that resulted in the courts ordering the government to provide treatments for these individuals and, eventually, for all people with HIV/AIDS in Venezuela. The presentation concludes that recourse to the courts is a useful tool for activists and that civil actions launched on behalf of people with HIV/AIDS can serve as an example for people with other chronic diseases.

As soon as antiretroviral cocktails were introduced in 1996, ACCSI set out to develop a strategy that would allow Venezuelans to access not only these new drugs, but also medical tests and treatments for opportunistic infections.

The Health System in Venezuela

As a first step, ACCSI identified which services were available to people with HIV/AIDS. In Venezuela, there is still no unified health system. There is a private (for cost) system that most people with HIV/AIDS cannot afford. Some health services are provided by the state, but these are scattered among several different departments and agencies. ACCSI researched the services being provided by the Social Security System in the Ministry of Labour, the Public Health System in the Ministry of Health, and the health services provided by the Ministry of Defence. The research revealed the following:

(a) Only 30 percent of the work force in Venezuela is covered by the Social Security System. Although the system does provide some medications for people with HIV/AIDS, specifically the reverse transcriptase inhibitors AZT and ddI, the services are extremely deficient and the medications are supplied in an irregular manner. Furthermore, the system does not provide protease inhibitors, medical tests, and treatments for opportunistic infections.

(b) The Public Health System provides some assistance programs (which are themselves deficient) and hospital services, but supplies no antiretroviral treatments, no pertinent medical tests, and no medicine for opportunistic infections (with the exception of tuberculosis).

(c) Within the health system of the Ministry of Defence, some reverse transcriptase inhibitors are being provided to professional soldiers, but those in the conscripted classes are receiving only routine medical attention.

ACCSI decided to focus its attention initially on the Social Security System as the area most likely to produce results.

Taking the Social Security System to Court

After some initial court actions that were not successful, ACCSI, together with a number of health professionals, lawyers, and AIDS activists, filed a suit in 1997 on behalf of 11 people with HIV/AIDS who were covered by the Social Security System. The lawsuit alleged that the claimants were not receiving proper medical attention. Specifically, it referred to the irregular supply of reverse transcriptase inhibitors and the failure to provide new protease inhibitors, medical tests, and medicines for opportunistic infections. The lawsuit was based on the rights of people with HIV/AIDS to non-discrimination, health, equality, access to science and technology, and access to social security, as guaranteed by the National

Constitution, the American Convention on Human Rights, the International Pact on Economic, Social and Cultural Rights, and other conventions signed and ratified by Venezuela. The lawsuit also made reference to the Universal Declaration of Human Rights.

In May 1997, the court upheld the lawsuit, thus recognizing the rights of the 11 claimants, and ordered the Social Security System to provide treatments (including protease inhibitors) at no cost on a regular basis. Five additional lawsuits were soon launched, resulting in another 300 people obtaining the right to treatment. By August 1998, as a result of these court decisions, the Social Security System had established a program of care and treatment for 2200 people with HIV/AIDS.

Legal Action against the Ministry of Defence

Because of the success of the court actions against the Social Security System, ACCSI filed a lawsuit against the Ministry of Defence on behalf of four soldiers with HIV/AIDS in the National Armed Forces. The lawsuit said that the soldiers had a right to antiretroviral therapies and adequate medical attention, at least during the period of obligatory service. This lawsuit was also based on the National Constitution of Venezuela and international treaties.

In January 1998, the court ruled in favour of the four claimants and ordered the Ministry of Defence to provide antiretroviral therapies and full medical services. As a result, the Armed Forces is providing appropriate medical care to soldiers living with HIV/AIDS during their obligatory service.

Actions against the Ministry of Health

Among people with HIV/AIDS, the court cases described above raised the level of consciousness of human rights and increased confidence in the judicial system. Consequently, in the years after 1997, more lawsuits were filed against the Ministry of Health. This resulted in an additional 1500 women, children, and men receiving antiretroviral treatments.

Up to this point, all the court rulings had applied only to the individual claimants named in the lawsuits. However, in July 1999 the Supreme Court ordered the Ministry of Health to provide antiretroviral medications, treatments for opportunistic infections and diagnostic testing – free of charge – to *all* Venezuelan residents living with HIV/AIDS. This was the first time the Court had ruled in the collective interest.

The Supreme Court said that the right to health and the right to life were closely linked in this case to the right to access the benefits from science and technology. It cited recent developments with antiretroviral therapies as examples of the achievements of science and technology; and it said that these developments allow people with HIV/AIDS to prolong their lives and to improve their quality of life. The Court also said that these treatments may lead to a cure in the long run.

Lessons Learned

ACCSI and its partners in this effort have learned the following lessons from this experience:

(a) The lack of political commitment from governments to respond to the needs of people with HIV/AIDS forces civil society to make use of the judicial system to obtain full adherence to the rights of people with HIV/AIDS.

(b) The courts are often very receptive to the claims of people with HIV/AIDS. This is particularly true of the Supreme Court.

(c) Legal actions need to involve not only lawyers, but also an empowered civil society and people with HIV/AIDS.

(d) Court actions launched on behalf of people with HIV/AIDS can serve as an example for people with other chronic and congenital diseases. ACCSI recently filed a suit on behalf of children with heart problems.

– presented by Edgar Carrasco

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A Human Rights Critique of the United Kingdom's HIV Response

The National AIDS Trust (NAT) is the United Kingdom's leading HIV policy and advocacy NGO. NAT is committed to promoting a human rights framework for HIV responses through work with communities, governments, professionals, and the private sector, both within the UK and internationally. In this presentation to the XIII International AIDS Conference (abstract WeOrE524), John Godwin and Saul Walker discuss current human rights issues related to HIV/AIDS in the UK, and NAT's perspective on the International Guidelines on HIV/AIDS and Human Rights as an advocacy tool.

In November 1999, NAT worked with the UK's All Party Parliamentary Group on AIDS to launch the *Handbook for Legislators on HIV/AIDS, Law and Human Rights*,[1] published by UNAIDS and the Inter-Parliamentary Union, a global union of lawmakers. The Handbook explains to legislators the relevance to their work of the UN's International Guidelines on HIV and Human Rights.[2] The launch linked politicians from the UK's parliaments and assemblies at Westminster, Cardiff, Edinburgh, and Belfast by live video link, simultaneously beamed to a number of African countries.

We fear, however, that despite the enthusiasm expressed at the time by all those who took part in the high-tech launch, the Guidelines and the human rights messages within it have had little actual impact on UK politicians and policy makers. As advocates, we confront the challenge of bringing the messages of the Guidelines to life within a UK context and conveying those messages to governments in a forceful way.

The UK and Human Rights

Historically, the UK has played a global leadership role in many human rights issues. UK authors co-wrote the original UN Declaration of Human Rights in 1948. Domestic laws addressing racial and sexual equality have been in place for 20 to 30 years. There was a lack of progress during the Thatcher years, but under Blair's New Labour government, which has been in power since 1997, progressive measures have been introduced.

Beginning in October 2000, the Human Rights Act 1998 incorporates the European Convention on Human Rights into UK domestic laws. A Disability Rights Commission has been established and began operations in April 2000. Social exclusion has become a national agenda item, with a special Social Exclusion Unit set up in1998 at Cabinet Office level that has already looked at some aspects of sexual health.[3] A new blueprint issued this year for the National Health Service declares the core principle that health care is a basic human right and commits the Service to reducing health inequalities.[4]

However, the relationship of the UK government to human rights is an ambiguous one. In June the UK played a role at a European summit in defeating an attempt to extend a binding Charter of Rights to all European states. In the lead-up to elections in 2001, the government is demonstrating reluctance to take a strong public stance on many issues affecting minorities and now avoids use of the language of human rights when dealing with such issues as law and order, drug law reform, and the position of asylum seekers.

The UK is now at a critical juncture in terms of the evolution of a human rights culture. There are threats and opportunities. And there are very real impacts on our HIV response.

The UK's Response to HIV

Compared with many other countries, the UK has had a successful response to HIV, with a cumulative total of 43,000 reported HIV diagnoses in a population of 60 million.[5]

On the face of it, our national HIV policy response has been an enlightened one. Punitive approaches have been avoided. The National Health Service provides access to HAART and high-quality clinical care. A diverse NGO sector has been resourced, including self-help and advocacy groups of people living with HIV. NGO AIDS groups have played a key role in championing human rights, for example through the publication in 1992 of a UK Declaration on the Rights of People Living with HIV and AIDS.[6] Delivery of targeted health promotion through a vibrant NGO sector has been credited with much of the success in keeping HIV incidence at comparatively low levels.

On the international stage, the UK plays a significant role in leading policy responses to HIV. At last year's Commonwealth Heads of Government Meeting, the UK government worked to ensure that a resolution committed all Commonwealth governments to stronger political leadership on HIV.[7] And an International Development Strategy is being developed that (at least in its draft form) commits the UK to supporting the human rights of people with HIV globally and achieving the progressive realization of rights to basic health services.[8]

Developing a Critique

These apparent successes risk breeding complacency. If we scratch the surface using the International Guidelines we soon see that all is not so rosy.

As elsewhere, within the UK the impact of the epidemic has been greatest on marginalized communities, particularly gay men, Africans, and injection drug users. As is now well recognized, this pattern of impact is no coincidence – laws and policies that contribute to the marginalization of these social groups aggravate HIV vulnerability. The Guidelines call on governments to collaborate with communities to promote a supportive and enabling legislative environment for vulnerable groups.[9] There are two current stark examples where UK government action has been inconsistent with this aspect of the Guidelines.

Laws That Erode HIV Responses – Two Examples

The first is an insidious law known as *section 2*8,[10] introduced by the Thatcher government in 1988. It prohibits local Authorities from promoting homosexuality. It has had the effect of limiting the extent to which schools conduct sex education that deals with homosexuality in an honest, supportive, and non-discriminatory way. It has also caused some Authorities to restrict funding for work outside of schools that supports gay men, including HIV prevention work. It has fueled a climate of homophobia not just within Authorities but in the broader community.

Governments have moved to repeal section 28 over the last year, but this has given rise to a particularly brutal and reactionary campaign in favour of its retention. Earlier this year in Scotland, a legal action based on section 28 sought to freeze funding to virtually every NGO working in HIV across western Scotland. Funds to HIV services were temporarily suspended. Fortunately the Scottish parliament succeeded in repealing the law as it applies in Scotland in June 2000, and the legal claim was discontinued. But before this was achieved, religious groups funded a massive media campaign and a private referendum of the entire Scottish electorate was conducted on the issue of the retention of section 28 as part of Scottish law. This was part of a political strategy to whip up community support to retain section 28, based on the premise that to do otherwise would threaten family values.

The result was a rising climate of hostility toward gay men, with bigoted views receiving widespread media coverage. Local support services reported that incidents of violent attacks on gay men rose during the height of the campaign to retain the section. There has been a very direct detrimental impact on the morale of people working in the NGO HIV sector in Scotland. More significantly, communities have experienced heightened stigma, discrimination, and violence toward gay men, aggravating social exclusion and making the job of reaching these men with HIV health promotion messages all the more difficult.

The fight to repeal this law goes on in the rest of the UK, but it is a bitter one, and the UK government has failed to provide adequate leadership on the issue. There is no prospect of repeal of the section in England and Wales for at least another year. And the existence of the section has influenced the government in introducing new sex education Guidance, which now warns against the *promotion of sexual orientation* and requires teaching the significance of marriage as a *key building block of society*[11] – which many argue serves to further marginalize gay relationships.

The second current focus for our advocacy is asylum law. The UK introduced a new Immigration and Asylum Act last year and the asylum seekers support scheme was overhauled. Under the new system, known as *dispersal,* asylum seekers are only offered housing away from London in regional areas and must rely on vouchers for income support.

Many of these asylum seekers are Africans with HIV. As African migrant communities historically have largely settled within London, HIV treatment and support services for Africans are almost exclusively London based. So there is a direct impact for HIV-positive Africans on access to services, particularly specialist services such as pediatric care, but also access to community and peer support. Stigma and dual discrimination based on race and HIV status are faced as asylum seekers are settled in predominantly white communities unaccustomed to addressing HIV as it affects heterosexual Africans. NAT has fought hard for an exception to this scheme for people with HIV, but government continues to deny that the rights of people with HIV are jeopardized by the scheme.

These are two current examples of policy responses that are symptomatic of the UK's failure at government level to address the impact of its laws and policies on the human rights of communities vulnerable to HIV. They are easy to identify as issues because they have been politically controversial; however, they are but two of many areas where UK policy responses fall far short of the ideal. The challenge is to position issues such as these within a holistic perspective that assesses what needs to be done across the whole of government, and within the context of a global epidemic. This is where the International Guidelines become particularly valuable.

International Guidelines: A UK Progress Report

The Guidelines are not legally binding. There are 12 guidelines, divided into three areas: institutional responses, law reform, and enabling environment. They effectively provide a best-practice checklist. The Legislators Handbook sets out detailed checklists for each of the Guidelines. To apply the checklist within a national context is not difficult. NAT has developed a table that is a running progress report on compliance, and we use this to plan our advocacy efforts (see Table). Strengths indicate achievements, weaknesses the gaps where action is required.

The beauty of using this mechanism to provide an overview of compliance is that we can begin to have a sense of the full range of actions required in order to achieve a comprehensive human rights response to the epidemic.

What is immediately apparent from our Progress Report is that there are many actions required, some of them fundamental. There is no UK-wide HIV strategy: in fact, no comprehensive HIV strategy addressing prevention, care, and treatment yet exists in any UK country, although there are some in the pipeline.[12] There is no intersectoral ministerial committee with oversight regarding HIV strategy, as there is no strategy to oversee.

While there are discrimination protections for some communities, gay men – the community most affected by the epidemic in the UK – do not enjoy legal protection against sexuality discrimination.

In prisons there are restrictions on access to condoms (you need a doctor's letter for each one!), access to cleansing materials is difficult or impossible, and, although combination therapies are in theory available to prisoners, access to HIV expertise in clinical services is often difficult and treatment support services are limited.

Despite the UK's role early in the epidemic of global leadership in establishing needle exchange schemes, lack of broader drug law reform means that the criminal status of drug use stands in the way of funding work to address public health needs through partnerships with injection drug users. And there is still no formal needle exchange scheme in Northern Ireland.[13]

The Guidelines direct us not to limit our gaze internally, but also to scrutinize our government's international role. The UK Department for International Development plays a significant global role in funding HIV-related development work. The Department professes a commitment to human rights and has over the last year elevated investment in HIV programs to top-priority status. We are keen to see the specifics of how the human rights aspects of HIV will be supported within new programs, for example advocacy activities in southern countries by and for vulnerable communities, promotion of the role of civil society in HIV responses, and support for organizations of HIV-positive people.

NAT and Human Rights Advocacy

As a national policy NGO, NAT is committed to actively holding UK governments to account for their human rights record in HIV policy. We are involved in a range of initiatives to raise the profile of human rights issues in UK responses.

In July 2000, NAT convened for the first time a UK HIV Policy Forum. With the phased introduction of devolved political power in the countries that make up the UK, this initiative has become essential – without such a Forum there is no one place where discussions on UK-wide HIV policy can take place. The

Forum brings together NGOs, clinicians, commissioners, and researchers to focus on those areas of policy that are common across the UK. Human rights issues are to be pursued through subgroups of the Forum, with an initial focus on employment, asylum, and treatment access issues.

In December, in partnership with the human rights agency Justice, we are conducting training for NGOs on the implications of the implementation of the Human Rights Act, and we are conducting training for employers on HIV and obligations under the Disability Discrimination Act.

We are working with the Department of Health in its development of a Sexual Health and HIV Strategy for England, through facilitating meetings of people with HIV on strategy development and through pressing for a strategy that encompasses a cross-departmental approach, so that strategy addresses not just medical treatment and STI prevention but also education, housing, social security, and immigration issues. We are supporting the development of a better-resourced voice for positive people through a year-long series of conferences and events and by advocating the need for government to support the involvement of positive people in planning and policy.

To highlight the need for the UK's international development work to improve its engagement with civil society and to consider the human rights implications of new programs, we are giving evidence to the International Development Committee's Inquiry on HIV in the House of Commons[14] and making representations to the Department for International Development on their HIV strategy. We are also arguing for our government responses to HIV at the domestic and international levels to be explicitly linked: it makes no sense for the two to be developed in isolation in the context of a global epidemic.

We are continuing our partnership work with the All Party Parliamentary Group on AIDS to reach legislators on all of these key issues.

Lessons from Abroad

NAT recommends the Human Rights Guidelines as an authoritative audit and advocacy tool that focuses the mind on the full breadth of policy that requires being scrutinized against human rights benchmarks. As the Legislators Handbook suggests, when applying the Guidelines domestically it pays to look to best-practice models from other jurisdictions on how to lever human rights up domestic policy agendas. In Australia a *rights analysis instrument* has been developed by their National Council on AIDS, Hepatitis C and Related Diseases to measure government compliance with the International Guidelines through a *scoring* mechanism.[15] And in Canada, a detailed plan was developed by the Canadian HIV/AIDS Legal Network (with extensive cross-sectoral consultation) to inform the work in the Canadian HIV/AIDS Strategy's component on legal, ethical, and human rights issues.[16] The use of such systematic approaches to ensuring a comprehensive human rights framework for HIV responses has been sorely lacking in the UK. We have much to learn!

– John Godwin and Saul Walker

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[1] *Handbook for Legislators on HIV/AIDS, Law and Human Rights*. UNAIDS/IPU, Geneva,1999, available at www.unaids.org/publications/documents/human/index.html.

[2] *HIV/AIDS and Human Rights – International Guidelines*. UNAIDS, New York & Geneva, 1998; also available at www.unaids.org.

[3] *Teenage Pregnancy Report*. Social Exclusion Unit, HMSO, London, June 1999.

[4] *The NHS Plan: A Plan for Investment, a Plan for Reform*. NHS/HMSO London, July 2000, at 3.

[5] It is estimated that a third of HIV cases in the UK are undiagnosed. Total reported UK diagnoses as at September 2000 were 43,026. *Communicable Disease Report* 2000 Vol 10, No 44(3) November 2000, at 399.

[6] The text of the UK Declaration is available at www.nat.org.uk.

[7] Resolution 55 of the 1999 Durban Meeting Communique; see www.chogm99.org/chogm99/s5.htm.

[8] *Better Health for Poor People: Consultation Paper*. Department for International Development (DFID), November 1999; the Final Strategy is due for publication in November 2000. See also *Human Rights Plan – Realising Human Rights for Poor People*. DFID, October 2000.

[9] Supra, note 2, Guideline 8: Women, children and other vulnerable groups.

[10] Section 2A Local Government Act 1986, inserted by section 28 Local Government Act 1988.

[11] *Sex and Relationships Education Guidance*. Department for Education and Employment, London, July 2000.

[12] A Draft Sexual Health and HIV Strategy for England is due for publication by the Department of Health in January 2001; an HIV Strategy for London is being developed by London Health Authorities and is due for publication in mid-2001.

[13] A pilot pharmacy-based exchange scheme commenced in Northern Ireland in late 2000.

[14] The IDC Inquiry Report is due for publication in January 2001.

[15] H Watchirs. International HIV/AIDS guidelines: does Australia comply? In: Australian Federation of AIDS Organisations *HIV/AIDS Legal Link* Vol 11 No 1 (March 2000) at 1.

[16] *Legal, Ethical and Human Rights Issues Raised by HIV & AIDS: Where Do We Go from Here? Planning for 1998-2003*. CHALN, 1999.

Table
International Guidelines on HIV/AIDS and Human Rights – UK Progress Report

UN Guidelines	UK Strengths	UK Weaknesses
Institutional response		
1 National framework	All Party Parliamentary Group on AIDS (Westminster-based Group debates UK and international issues)	No UK-wide government HIV strategy; slow progress on domestic sexual health strategies; UK HIV Prevention Strategy now outdated (1995); Delayed Sexual Health & HIV Strategy within England – now due 2001 HIV strategy development located within Health Department rather than managed as a cross-departmental responsibility Weak multi-sectoral UK advisory body with limited role [Expert Advisory Group on AIDS]
2 Community partnership	Resourced NGO sector	Partnership work inconsistent in key areas, eg, asylum NGO sector contracting due to treatment-cost pressures, etc
Law reform & legal services		
3 Public health protection	Avoidance of compulsion / punitive responses Open-access GUM services	Antenatal screening has given rise to cases of testing without specific informed consent
4 Criminal law and corrections	No HIV specific offences Transmission prosecutions rare	Prisons – limited access to condoms and cleansing agents Sex work – lack of occupational health legal framework Drug use – criminal status of possession inhibits harm reduction; criminal law agendas now override public health approach
5 Anti-discrimination Privacy, Employment	Data Protection Commissioner Disability Discrimination Act Confidential testing, anonymous coded notification	Limited coverage of asymptomatic HIV by Disability Discrimination Act; broad exceptions to DDA weaken its impact No specific sexuality discrimination protections (limited coverage by Sex Discrimination Act)
6 Goods, services, and information	Quality of condoms and testing technologies well regulated	Lack of clarity on use of explicit material for targeted and general prevention work; concerns around condom pricing Restricted access to free condoms, particularly within institutions Testing / counseling services of uneven quality
7 Legal support services	Free HIV legal advice service – Terrence Higgins Trust's London-based service offers welfare, housing, immigration, and general advice	Legal aid difficult to access for many civil rights claims Access to advice difficult for non–English speakers Difficult to find HIV legal expertise outside London
Supportive and enabling environment		
8 Women children and vulnerable groups	Social exclusion and health inequalities are national agenda items	Asylum law impacts adversely on African families – dispersal outside London and voucher scheme causes hardship Section 28 and unequal age of consent disadvantage gay men Social Exclusion Unit fails to address HIV & sexuality
9 Changing attitudes through education, training & media	Some NGO health promotion campaigns address stigma, homophobia eg CHAPS, THT Homophobia campaign, Healthy Gay Scotland	No national approach to addressing HIV stigma and discrimination eg for gay, African, and injection drug user communities and for people with HIV
10 Codes of professional practice	Draft BMA Foundation for AIDS Quality Standards for HIV Care address discrimination and cultural sensitivity BHIVA Clinical Guidelines set HAART treatment standards	Inconsistent quality of HIV health promotion interventions – more robust social research basis required No national quality standards for social care and support Health care professionals, especially GPs, require training on stigma, discrimination, cultural issues
11 National human rights institutions	Disability Rights Commission (established 2000); Sex and Race commissions exist	No Human Rights Commission (except Northern Ireland) Race and Sex commissions fail to address HIV No sexuality discrimination protection
12 International cooperation	DFID Human Rights Plan published 2000; HIV and human rights addessed in UK's International Development Strategy; Use of Commonwealth Heads, G8 and UN meetings to highlight HIV leadership issues	Need to develop a specific HIV Strategy for the UK's international development program, which supports HIV advocacy and human rights activities for people living with HIV and affected communities in the South

Durban 2000: Abstracts on Legal, Ethical, and Human Rights Issues

There were over 140 abstracts at the XIII International AIDS Conference touching on legal, ethical, and human rights issues, a significant increase from the approximately 80 abstracts on this topic at the Geneva Conference in 1998. The topics addressed in these abstracts ranged from the banning of the use of condoms among youngsters in the Democratic Republic of Congo, to violations of human rights in Uruguayan prisons, to the rights and responsibilities of people with HIV/AIDS, and to the social and economic impact of the deportation of Pakistanis working abroad. About one-third of the abstracts dealt with access to treatment issues, a major theme of the Conference. The balance of the abstracts were spread fairly evenly over a number of topics. Almost two-thirds of the abstracts were from developing countries.

Only a small number of these abstracts can be included in this special issue of the *Review*. The following abstracts have been chosen because, together with the other articles in this special issue, they provide a representative sample of many legal, ethical, and human rights topics addressed at the Conference. Four of the abstracts deal with access to treatment issues (in South Africa, Argentina, Thailand, and Panama). There is one abstract on each of the following topics: the link between human rights and public health policy; gender issues and children's rights; informed consent and confidentiality; prevention and care among sex workers; the problems of doing prevention in a country in civil crisis; stigma and discrimination; pre- and post-test counseling; the rights of migrants to health; ways to engage parliamentarians to support constructive legislation and policy; criminalization of HIV transmission; and direct-to-consumer advertising of prescription drugs. Of the 15 abstracts presented here, 12 relate to developing countries.

If you would like to see other abstracts from the Durban Conference, they are available online at the site of the National Library of Medicine (United States) at http://www.iac2000.org/.

Abstract E1208: The Human Rights Rationale for the Provision of AZT to Pregnant Women with HIV: The Case of South Africa

Issues: The paper examines the legal and human rights arguments related to the decision of the South African government not to provide access to health-care services that would allow a reduction in the rate of mother-to-child transmission of HIV. This issue is currently the subject of an investigation by the South African Human Rights Commission.

Description: The South African government does not offer antiretroviral agents for the prevention of mother-to-child transmission of HIV. This is despite the proven efficacy of short-course antiretrovirals and the evidence that it would be cost-effective to provide such prophylaxis. The paper explores the protection offered by the Bill of Rights in the Constitution of South Africa to pregnant women and children. The Bill of Rights protects the right of pregnant women to equality and the full enjoyment of all rights and freedoms. The paper argues that the state therefore has an obligation to take reasonable steps to ensure that pregnant women with HIV have an equal opportunity to bear healthy children. The paper argues further that the constitutionally entrenched right to reproductive autonomy cannot be realized by women who are denied the information and resources to make fundamental decisions concerning reproduction. It also argues that the constitutional rights of the child to basic health-care services oblige the state to provide the means of reducing mother-to-child transmission of HIV.

Conclusion: The paper postulates that the provisions of the Constitution are irreconcilable with the government's decision not to provide antiretroviral agents to pregnant women with HIV to prevent mother-to-child transmission of the virus.

Presented by A Kleinsmidt, AIDS Law Project, Centre for Applied Legal Studies, Private Bag 3, PO Wits, Johannesburg, 2050, South Africa. Email: KleinsmidtA@law.wits.ac.za.

Abstract E579: Human Rights and Access to HIV/AIDS Treatment in Argentina

Issues: Since 1990, legislation has promised access to care and treatment for Argentine citizens, but in practice such accessibility is not guaranteed. In 1996, eight NGOs submitted a legal action against the Ministry of Health because of its failure to supply medicines. The Court ordered the Ministry to comply with its obligations to provide care and treatment.

Description: A case study was carried out on the accessibility of people with HIV/AIDS to care and treatment in a human rights context. The research goals were: (1) to analyze the situation regarding access to HIV/AIDS care and treatment; (2) to analyze the roles of government and civil society; and (3) to disseminate lessons learned. The research was carried out through: (1) a review of national and international literature, national legal instruments, international declarations, conventions and agreements having constitutional status; and (2) semi-structured interviews with government authorities, officials in public hospitals, NGO representatives, people with HIV/AIDS, and other key actors.

Conclusions: In the Argentinean population, there is a lack of awareness about the right to health care. The human rights of people with HIV/AIDS are violated because they have problems accessing care and treatment. Support guaranteed by legislation is not fulfilled; the system for the purchase and supply of drugs is complex and bureaucratic. This misuse of public funds creates an ethical problem. The basic human right of people with HIV/AIDS to be informed about the right to care and treatment is ignored by public health services, social security providers, and private medical companies: they usually do not properly inform their beneficiaries about their services. Consequently, NGOs need to strengthen the awareness of people with HIV/AIDS of the need to defend their right to health care. NGOs and groups of people with HIV/AIDS need to provide information about legal options and need to engage in lobbying, educational and social assistance, demonstrations, and legal measures to safeguard the human rights of people with HIV/AIDS.

Presented by MI Re, MB Bianco; LACCA-SO, Paraná 135 Piso 3ro. Dpto. 13, (1017) Buenos Aires, Argentina. Email: laccaso@ciudad.com.ar.

Abstract E4837: Thai NGO Campaign to Improve Access to Antiretroviral Treatment

Issues: Few Thai people with HIV/AIDS access antiretroviral treatment. The United States Trade Representative repeatedly pressures Thailand to restrict its right to produce affordable medicines. The links between international trade and access to essential medicines are difficult to understand.

Description: In September 1998, under US pressure, the Thai Patent Act was again amended. Twenty-five activists rallied outside the US embassy. An important motivation for our action was the case of the drug didanosine (ddI), an example of extreme profiteering by the pharmaceutical industry. As a result of networking with AIDS activists at an international conference, Thailand's case was placed on the political agenda in the US. In August 1999, a UNAIDS/WHO fact-finding mission made an assessment of the patent situation of HIV drugs in Thailand and presented recommendations to the National AIDS Committee. People with HIV/AIDS and NGOs became better informed about possible options for the Thai government to improve access to antiretroviral drugs. In December 1999, more than 100 activists rallied outside the Thai Ministry of Public Health, asking the government to grant a compulsory licence for didanosine. Other representatives of civil society came to support us. A compulsory licence was not granted, but a generic pharmaceutical organization has marketed a different formulation of the drug.

Conclusion: Because governments of developing countries are under pressure not to exert their rights under international agreements, NGOs need to monitor unfair practices. The issue of access to treatment has become a focus in Thailand for increased solidarity between NGOs, people with HIV/AIDS, and civil society.

Presented by P Suwannawong,[1]
S Aongsomwang,[2] P Suwannawong,[3]
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Abstract E162: The Right to Live

Background: There are over 3014 cases of AIDS in Panama, whose population is 2.5 million. PROBID-SIDA, an NGO, was formed to seek access to antiretroviral medication for people with HIV/AIDS (PWAs) in Panama. Two years ago, at the XII World AIDS Conference in Geneva, Switzerland, we presented an abstract announcing some activities we would develop, but no specific results.

Description: PROBIDSIDA has empowered PWAs and helped to form coalitions with media communicators, doctors, teachers, workers' unions, the National Lawyers Coalition, and congressmen. During these two past years, AIDS became a weekly topic in the press and on the airwaves. PROBIDSIDA presented two affidavits to the Supreme Court demanding human rights and equal benefits for PWAs. Both were rejected. This rejection led us to adopt extreme activities such as chaining PWAs and their families to the Social Security building, and an historic street mobilization that resulted in closing one of the main streets for 12 consecutive hours (with full media coverage).

Results: As a result of these actions, the Social Security staff board approved a massive purchase of treatments for HIV/AIDS and created an HIV/AIDS commission, of which PROBIDSIDA is part. Finally, in October 1999, PWAs began to receive adequate antiretroviral therapy. Another important result was the adoption of an STD/HIV/AIDS law, in which PROBIDSIDA played an important role as the representative of PWAs. This law recognized STD/HIV/AIDS as a state problem.

Lessons Learned: PROBIDSIDA demonstrated that people, when facing a crisis, can organize themselves to take constructive action. Fear and discrimination among PWAs are now less common in Panama. PWAs are not longer a problem but a part of the solution. This effort took two years of hard work and advocacy. 1284 Panamanians, men, women, and children died waiting for their right to live, for their right to be treated as human beings.

Presented by O Quintero, PROBIDSIDA, Apartado Postal, Plaza Panama 0833-0078, Panama. Email: probidsida@hotmail.com.

Abstract E523: HIV/AIDS, Human Rights and the Public Health Policy in Zambia

Issues: Several years of addressing and responding to the HIV/AIDS epidemic have revealed that many well-meaning and seemingly successful intervention strategies in preventing the transmission of HIV/AIDS may be undermined if a human rights–based response is not included. To this extent, the need to fully understand and appreciate the importance of protecting human rights associated with HIV/AIDS on one hand, and of mitigating the impact of human rights violations on the other, is both crucial and urgent.

Description: This paper attempts to unveil the complex interface between HIV/AIDS and human rights, and to describe how these are affected by the public health policy of Zambia. It explains, and provides a broad outline of, the legal and human rights of people with HIV/AIDS; explains how these rights are restricted by the Public Health Act; and advocates for new legislation that would embrace and guarantee the rights of people with HIV/AIDS or otherwise affected by HIV/AIDS. Essentially, the paper argues that although the constitution of Zambia has provisions that spell out individual rights and fundamental freedoms, such provisions usually deny to some what they concede to others; and that many substantive laws currently in force, especially public health regulations, work to the disadvantage of people with HIV/AIDS, and violate the rights and freedoms of those trying to avoid HIV infection and those already living with it.

Conclusion: Since HIV/AIDS is both a health and a human rights issue, the protection and promotion of human rights in the context of HIV/AIDS are both necessary and crucial to the protection of the inherent dignity of people affected by HIV/AIDS and to the achievement of public health goals. A public health policy justification should not be a legitimate basis for restricting human rights in the context of HIV/AIDS. Rather, a good public health policy would be one that does not encroach upon the rights of the citizens, but which empowers individuals and communities to effectively respond to HIV/AIDS.

Presented by P Mulenga, UNZA, PO Box 32379, Lusaka, Zambia.

Abstract D508: Linking the Issues: HIV, Gender, Human Rights, and Child Protection

Issue: There is general awareness of the links between vulnerability to HIV, gender inequality, limitation of human rights, and the abuse of children. This awareness is particularly high among AIDS service organizations, although it is often only conceptual and not reflected in the activities of the organizations. On the other hand, organizations working for gender equality, human rights, or the protection of children may be aware of the impact of HIV on their work, but have few means to translate this awareness into action.

Description: One of the objectives of the Southern African AIDS Training (SAT) Programme is to strengthen advocacy groups working on issues related to HIV infection, gender equality, human rights, and child protection in nine countries of southern Africa. Starting in 1991, the SAT Programme built partnerships with more than 100 organizations in the region. By 1998, we found that despite awareness of the substantive links between advocacy issues, the activities of the groups we supported continued to be confined to a single dimension. Therefore, the SAT Programme sponsored four national and regional workshops, bringing together advocacy groups working in the area of HIV, human rights, gender violence, and child abuse in Zimbabwe, Tanzania, and Zambia. The meetings exposed advocacy groups to each other's agendas and stimulated the creation of functional advocacy networks.

Conclusion: The meetings allowed the different organizations to identify common advocacy issues, identify common barriers and obstacles to achieving their advocacy goals, and develop synergistic approaches and strategies to address issues of common concern. These included violence against women related to disclosure of HIV status, property-grabbing by the families of husbands who died of HIV-related causes, sexual abuse of children orphaned because of AIDS, and economic and social discrimination of people living with HIV.

Presented by F Chiganze, J Decosas, J Chikore; Southern African AIDS Training Programme, Box 390, Kopje, Harare, Zimbabwe. Email: chiganze@sat.org.zw.

Abstract E154:
When the Patient Is the Last to Know: Informed Consent and Confidentiality of HIV Serostatus in South India

Issues: Informed consent and confidentiality with regard to HIV serostatus are generally regarded as fundamental principles of HIV/AIDS testing, counseling, and care. However, the actual clinical application of these principles varies considerably across cultures. In India, the patient may be the last to know of his/her HIV serostatus, after spouse, family, community, or other health-care workers. Clinicians may justify these disclosures on ethical or practical grounds. There has been inadequate discussion about the cross-cultural application of informed consent and confidentiality as it relates to disclosure about HIV serostatus.

Description: In this paper, we will use case histories to: (1) describe differences in the practice of informed consent and confidentiality in HIV/AIDS testing, counseling, and care in south India as compared with Western countries; (2) highlight the role of gender inequity (within the family and in the wider community) and poverty in shaping these differences; and (3) discuss the implications for those affected by HIV/AIDS. The paper is based on the experiences and observations of Asha Kirana, a non-governmental organization providing HIV/AIDS testing and counseling services in Mysore, south India.

Conclusions: Informed consent and confidentiality are understood and practised differently in India than in Western nations. While it is important that these concepts be applied in ways that are relevant to Indian cultural contexts, individuals are nonetheless entitled to certain rights and privileges that we believe should supercede cultural prerogatives. In order to protect the rights of individuals affected by HIV/AIDS in India, culturally relevant guidelines regarding informed consent and confidentiality must be framed and implemented without delay.

Presented by: M Sarvade,[1] R Ravindranath,[1] Tanuja,[1] Gururaja,[1] S Krishnan,[2] M Ekstrand,[3] R Vedanthan,[2] J Mandel.[3]

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Abstract E4945:
Legal Assistance: An Entry Point for Mediating for the Sexual Health of Street-Based Sex Workers

Introduction: This study describes the lessons learned, data, and experience of the use of legal assistance as an entry point in public health mediation to promote sexual health among street-based sex workers in the south Indian State of Kerala.

Project: During past few years, the Center for Social Research and Development has developed a legal referral system as part of the sexual health intervention programme among street-based sex workers in Kerala. Thanks to the peer outreach workers, whenever the law enforcement officers detain sex workers, the legal assistance team is contacted and immediate bail is arranged. (Many of the sex workers had never

> HIV programs in Burma present a policy and programmatic dilemma: how to help people living in a despotic system without helping the despots?

had the opportunity of getting legal assistance, or even having a lawyer visit them in the lock-up.) This professional relationship of trust has been used to educate the sex workers on STDs, the need for health check-ups, and safe-sex practices.

Outcome: During 1998-99, over two hundred visits were made to the local police lock-up to offer legal assistance. While providing bail services and negotiating for an early release, the legal team counseled the sex workers and were often successful in bringing them to an STD specialist for check-up. So far, 122 street sex workers have undergone the STD check-up and diagnostic testing for sub-clinical syphilitic infections. A trained counselor also provided pre- and post-test counseling. Among the 122 sex workers who received check-ups, a total of 524 clinic consultations were carried out; only 41 sex workers were free of STDs; among the other sex workers, 108 cases of STDs were identified.

Conclusion: Facilitating access to sexual health services is critical to successful intervention among the street-based sex workers. Providing legal assistance could be an entry point for successful mediation for sexual health among street people.

Presented by T Thomas, Center for Social Research and Development (CSRD), 34/767, Iyyapady House, near Civil Station, Malaparamba P.O. Calicut 673 009, Kerala State, India. Email: titot@md3.vsnl.net.in.

Abstract E4909: HIV/AIDS and Human Rights in Burma: Prevention Approaches in a Civil Crisis

Issue: Burma (Myanmar) has the second highest prevalence of HIV in Asia. The country has been in civil crisis since the military junta refused to honour the results of Burma's 1990 general elections. Widespread human rights abuses (including ethnic, religious, and gender persecution), censorship, and a narcotics-based economy, have contributed to social risk and vulnerability to HIV infection. Preventive intervention programs are urgently needed that can address the social components of Burma's uncontrolled HIV epidemic in this rights context.

Description: HIV programs in Burma present a policy and programmatic dilemma: how to help people living in a despotic system without helping the despots? Some donor agencies have chosen to engage with the junta, despite documentation of widespread rights violations, mismanagement, and limitations on programmatic activity. Two other approaches have recently been used: (1) radio-based education and prevention programs have succeeded in evading military censors and in delivering thorough and clear HIV/AIDS programming; (2) cross-border interventions have been mounted in several ethnic minority areas and have delivered prevention messages and technologies directly to vulnerable populations. These approaches will be described and discussed as alternative methods to mount HIV prevention activities in settings where civil society is lacking or is under threat.

Conclusions: Burma currently presents complex challenges to HIV prevention and care efforts, and is facing a severe epidemic of HIV/AIDS. Two innovative and alternative approaches to prevention are currently underway: radio-based education and cross-border interventions. Until the current political crisis moves toward resolution, these approaches may be feasible ways to assist the Burmese people.

Presented by C Beyrer, Johns Hopkins University School of Public Health, 615 N. Wolfe Street, E7138, Baltimore, MD, 21205, United States. Email: cbeyrer@jhsph.edu.

Abstract E791: Social and Legal Context of AIDS-Related Stigma and Discrimination: Result of a Consultation with Stakeholders in Four Asian Countries

Background: This report presents the findings of a four-country (India, Indonesia, Philippines, and Thailand) consultation with 82 stakeholders – consisting of academics, people with HIV/AIDS, legal experts, AIDS program managers, government officials, and staff of AIDS service agencies – on the extent, nature and related aspects of AIDS-related stigma and discrimination. There is a need to create a supportive social environment to facilitate or to negotiate safer behaviour patterns and to maintain the quality of life of people with HIV. However, in most developing countries, there is a great lag in developing non-discriminatory policies and legal reforms to protect the rights of people who are vulnerable to HIV infection or who have HIV. Limited data on AIDS-related discriminatory practices and policies also present barriers to developing appropriate advocacy efforts.

Method: As part of an ongoing human rights initiative of the Asia Pacific Network of People Living with HIV/AIDS (APN+), UNAIDS contracted APN+ to prepare a research protocol on the extent and nature of AIDS-related discrimination in selected countries. During August-September 1999, the research team traveled to four countries to collect data and to carry out consensus-building consultations with key stakeholders. The sample was selected based on a purposive, snowballing technique. An 18-item interview guide was used for data collection. Transcribed interviews were analyzed.

Result: The consultation revealed: widespread discrimination and human rights violations against people infected or affected by HIV/AIDS; a lack of informed discourse on AIDS and human rights issues; a lack of understanding of the linkage between human rights and AIDS; a lack of indicators to monitor program efforts; a lack of overall program initiatives; almost no empirical data on the extent and nature of human rights violations; low funding priorities; limited or no adequate structures for recourse; and a lack of understanding of the legal obligations of the state to protect the rights of people with HIV/AIDS.

Presented by J Thomas,[1] B White,[2] S Paxton,[3] B Wong,[4] M Maluwa,[5] P Toh.[6]

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Abstract D3776: Training of Medical Professionals in Pre- and Post-HIV Test Counseling in the Russian Federation

Issues: The lack of pre- and post-HIV test counseling and informed patient consent within Russian medical establishments has resulted in repeated human rights violations and is not conducive to effective behaviour change.

***Description*:** Project activities aim to increase and ensure patient access to pre- and post-HIV test counseling by providing Russian health personnel with the necessary counseling and communication skills for raising patient awareness about HIV/AIDS/STD prevention methods and behaviour change. AIDS Infoshare has conducted detailed research in 12 Russian regions to ascertain the attitudes of Russian medical professionals towards pre- and post-HIV test counseling practices and the reasons preventing the regular provision of this legislated patient right. Based on the results of this research, a training and resource manual has been developed for medical professionals, along with supporting patient materials. A competition for the creation of the most effective training program was conducted among project participants. The participants whose proposals were selected were awarded sub-grants to implement training in their respective regions. As a result of these regional training programs, 300 Russian health-care workers have been trained in doctor–client communication techniques and effective skills for conducting pre- and post-HIV test counseling. In addition, 2500 posters and 150,000 patient brochures were produced and distributed to 498 Russian government organizations and 282 NGOs working in the field of HIV/AIDS and STD prevention in all 89 Russian regions.

***Conclusions*:** Results of AIDS Infoshare research indicate that in 80 percent of all cases, counseling was not conducted before or after the HIV testing process, despite the 1995 federal legislation ensuring the provision of this confidential counseling service. The primary reasons attributed to the failure to provide counseling were: the lack of counseling skills among medical professionals; strict time limitations placed on medical visits due to the number of patients waiting to be seen; and a lack of awareness among medical personnel concerning the 1995 legislation.

Presented by S Erastov, Bulatnikovskaya Street 4-1-28, Moscow 113 403, Russian Federation. Email: infoshare@glasnet.ru.

Abstract E2980: Migrants' Right to Health

Issue: A number of studies have documented the fact that human mobility is associated with an increased risk of HIV infection. However, being a migrant is not a risk factor in and of itself; it is the activities undertaken during the migration process that are the risk factors. UNAIDS and the International Organization on Migration commissioned a policy discussion paper on migrants' right to health.

***Description*:** The paper outlines key existing laws, policies, and best practices in relation to the rights of migrants to health and associated care, treatment, support, and prevention, particularly in relation to HIV/AIDS/STD and reproductive health matters. The paper uses this framework of existing laws and policies to address ethical and economic dimensions, and to consider the effects of globalization and the implications of policies for migrant health. It concludes with recommendations for the future development of policies to improve the health status of migrant populations.

Conclusions: This paper argues for a number of changes to ensure better practice in relation to migrants' rights to health at global, national, and local levels. These include acknowledgment of the right to health-care access for all; attention to, and compliance by, all countries with international treaties and agreements to which they are a party; health-care access programs for non-nationals that move beyond emergency care to address physical, mental, and social well-being, particularly in relation to HIV/AIDS/STD and reproductive health; and attention to the gender disparities often involved in migrant worker movements, both within countries and across borders, and to gender/power relationships that frequently govern women's access to information and health care. The paper notes that measures are needed to ensure major sending, transit, and receiving countries have joint or tripartite health-access programs in place to address all time and place points on the moving continuum for citizens and migrant workers, including pre-departure, the migration itself, the initial period of adaptation, successful adaptation, return migration, and reintegration into the original community.

Presented by M Duckett, 43 Sofala Avenue Lane Cove, Sydney NSW 2066, Australia. Email: margaretduckett@hotmail.com.

Abstract E2986: The UK All-Party Parliamentary Group on AIDS: A Model for Engaging Parliamentarians to Support Constructive Legislation and Policy

Issues: Political commitment is a key determinant of the ability of a country to act effectively to address HIV. Parliamentarians can play a unique role in maintaining political consensus, and in prompting and scrutinising government policy. Parliamentarians also need NGOs, patient groups, and service providers to inform their views, balanced within their mainstream role as legislators.

Description: Since 1986, the All-Party Parliamentary Group on AIDS in the United Kingdom (UK) Parliament has been a key player in the UK's response to HIV. With membership consisting of approximately 150 members of the House of Commons and House of Lords, the group has delivered a non-partisan political consensus on HIV; has initiated and supported government policy; and has maintained exceptionally good links with the HIV sector outside parliament, thus ensuring their views a hearing in parliament and government. Through regular meetings, parliamentary questions, parliamentary debates, and meetings with the executive, it has ensured that a small number of well-informed parliamentarians are able to speak authoritatively on HIV and keep the issue high on the political agenda. This paper, by the group's Policy Adviser, will track the group's historical role in influencing the UK response to HIV/AIDS, in particular the group's recent activity in encouraging, lobbying, and setting the agenda for a national HIV/AIDS strategy at a time when the political importance of HIV has been falling. The paper also looks at the group's recent role in expanding the UK's view of HIV from a domestic health and human rights issue to an international development responsibility.

Conclusions: This paper argues that the All-Party Parliamentary Group on AIDS demonstrates great opportunities, and some weaknesses, inherent in this model of backbench grouping. It concludes that it offers a constructive example for the engagement of parliamentarians, and the linking of NGOs and people with HIV with legislative representatives, an example that could be adapted to the parliaments of other countries.

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Abstract E2865: Criminalization of HIV Transmission

Issue: In Europe, recent convictions at the national level of people who have transmitted HIV to others have been upheld by regional human rights courts. Convictions have also been recorded in Australia, the United States, and Canada. A new law in New Zealand requires people with HIV to tell their sexual partners of their HIV status even if they have protected sex. The matter has a particular urgency since governments in a diverse range of countries, such as Zimbawe, South Africa, Jamaica, Italy, and the United Kingdom have begun to debate whether to introduce or review their laws concerning offences against the person – a situation that parallels the introduction of antiretroviral therapy.

Description: The research carried out by a criminologist and a human rights lawyer, both living with HIV, attempts to outline the positive person's perspective on the criminalization of HIV transmission, and to delineate the narrow range of cases where the use of existing criminal laws is rational. In doing so, issues are discussed such as the purpose of criminal law and punishment; government responsibility for the success or failure of their public health campaigns to stop the spread of HIV, versus individual responsibility for one's HIV status; the situations of rape and aggravated rape; and instances of people being untested, either due to a lack of testing facilities or an unwillingness to be tested. In addition, the economic (ir)rationality of such laws is discussed in the context of government claims that they do not have the money to maintain or improve existing standards of health care and social services, whereas they do have the money for criminal trials and imprisonment. Finally, practical implications for people with HIV of criminalization of HIV transmission are discussed, including the increased stigmatization of HIV-positive people and a positive person's "right" to a sex life and "right" to found a family.

Conclusion: HIV-specific criminal laws are a discriminatory and inappropriate means of dealing with those who transmit HIV to others. In the narrowly defined instances where prosecutions should take place for HIV transmission or other acts, existing criminal laws such as rape and assault provisions should be utilized. Legislation that facilitates the prosecution of those who transmit HIV may have a profound and damaging impact on attempts to limit the spread of infection. Such legislation has more to do with assuaging public opinion than with confronting the moral responsibilities of people with HIV/AIDS and society; in fact, it reinforces the fear of AIDS. It is a quick-fix "solution" that fails to confront the social compact required if the transmission of HIV is to be reduced significantly. Criminal law categories are reflections of the interests of particular groups, a moral majority that refuses to accept men who have sex with men; sex workers; drug users; etc. As such, criminal law is being used to target, punish, and demoralize a "problem" population – ie, the HIV community perceived by society to be potentially (or actually) threatening to the existing distribution of power and privilege.

Presented by: N. Policek,[1] A Doupe.[2]

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Abstract E643: Direct-to-Consumer Advertising (DTCA) of Prescription Medicines – The Canadian Treatment Advocates Council Develops Its Position – Community Advocacy in Action

Background: The Canadian Treatment Advocates Council (CTAC) is a national organization driven by people with HIV/AIDS and advocating for the research and development of HIV treatments, for a cure, and for fair and equitable access to HIV treatments. Our mandate is to advocate with government and pharmaceutical companies on HIV treatment issues and to share our advocacy knowledge and skills with people infected with and affected by HIV/AIDS.

Issue: For some time now, the pharmaceutical industry has been lobbying Canadian regulators for relaxation of regulations governing advertising of prescription medications. In Canada, such advertising is currently limited to name, price, and quantity; therefore, advertising of prescription medicines is generally restricted to doctors and other health-care providers. Advertising of non-prescription drugs is already permitted, subject to certain conditions.

Description: The United States and New Zealand are the only two countries where DTCA is permitted. CTAC undertook to examine the issue of DTCA and develop its position. CTAC received presentations from proponents of DTCA and also from opponents of DTCA. In 1999, CTAC participated in consultations hosted by Canadian regulators. CTAC continued to examine the research available on advertising of non-prescription drugs, advertising of prescription drugs, and current regulatory controls in Canada and other countries. As well, the role of HIV community education and advocacy, and the potential impact of DTCA on HIV treatments, were explored. Discussions of available information, held over a period of twelve months, confirmed that there are flaws in the current regulatory system in Canada. The Canadian system is a passive system that provides for only voluntary pre-clearance of advertisements for prescription medications. CTAC finalized its position and a formal paper was produced and circulated widely.

Conclusions: DTCA of prescription medicines has not been proven to improve health outcomes or consumer knowledge of medications. Currently, available research suggests that such advertisements negatively impact the prescribing patterns of doctors and the doctor–patient relationship. DTCA will increase the cost of medications and ultimately the cost of health care to consumers. The health outcomes of consumers and consumer knowledge of medications must be the yardsticks by which the effectiveness of DTCA is measured. Current regulations are clearly inadequate and do not protect consumers. More research is required to ascertain the risks, benefits, and costs of DTCA to consumers. In the meantime, tighter controls are required to ensure compliance with existing regulations. A mandatory, transparent, consumer-centered review and reporting process is required. Adequate penalties and sanctions for violations must be enacted and enforced. Education programs administered by a neutral third party are effective in educating consumers about prescription medications and should be expanded.

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