

CANADIAN

HIV/AIDS POLICY & LAW

R E V I E W

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HIV Vaccines: Current Challenges and Future Directions

Volume seven of the *Review* will mark the tenth anniversary of the Canadian HIV/AIDS Legal Network with a series of articles that describe past developments and future directions in several areas of policy and law related to HIV/AIDS. The following article is the first of these, discussing current challenges and future directions in the development of and access to HIV vaccines. It argues that governments are under public health, ethical, and legal obligations to develop and provide access to HIV vaccines. It further explains what is required for governments to fulfill their obligations: additional commitment and resources for HIV vaccine development in the context of increased global research and development regarding diseases of the poor; increased support and advocacy for partnerships to develop HIV vaccines; enhanced regulatory capacity in every country to review, approve, and monitor HIV vaccines; and assurance of global supply of, procurement of, delivery of, and access to vaccines in the context of efforts to increase global access to public health measures and technologies.

HIV vaccine development is needed because the global AIDS crisis is still beginning. The

human and economic cost of the existing AIDS epidemic is already enormous. However, it

cont'd on page 20

Drug Policy in Canada – The Way Forward

This article is one of a series commissioned to mark the tenth anniversary of the Canadian HIV/AIDS Legal Network, discussing past developments and future directions in areas of policy and law related to HIV/AIDS. It takes a critical look at Canada's drug policy. Despite calls for a balanced approach focused on reducing drug-related harm, Canada's method of dealing with problems of illicit drug use has remained prohibitionist in nature, and by far the greatest part of federal funding is devoted to supply-reduction initiatives. Considerable changes in policy and law are needed to significantly reduce the harms associated with injection drug use in Canada. These include developing a comprehensive and integrated strategy, exploring alternative legal frameworks, piloting innovative approaches to reducing injection-related harms, and investing in broad social policies that address the determinants of injection drug use.

Injection Drug Use in Canada

Injection drug use remains a major public health concern throughout Canada. Adverse

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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 every four months by the Canadian HIV/AIDS Legal Network.

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Canadian HIV/AIDS Legal Network

The Network is a charitable organization engaged in education, 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.

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.

Comments?

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EDITORIAL

This year is the tenth anniversary of the founding of the Canadian HIV/AIDS Legal Network – an occasion to look back and look forward. The *Review* will mark the anniversary in several ways. We begin with a guest editorial in which the Hon Justice Michael Kirby reflects on what we have learned – and what we have yet to learn – about the HIV epidemic and our response to it. Over the year we will also publish articles reviewing important areas of policy and law related to HIV/AIDS. Each article will summarize key developments in the past five years, identify future directions in policy and law, and suggest essential reading. In this issue we feature articles on HIV vaccines, global access to treatment, discrimination, and drug policy in Canada. Apart from these special features, this issue continues with the changes introduced in the last issue. Feedback on the ongoing sections, as well as the anniversary articles, is welcome and may be directed to Theodore de Bruyn (tdebruyn@cyberus.ca).

Anniversaries – But What Have We Learned?

Is it little more than 20 years since AIDS first entered our consciousness? It seems forever.

Do you remember when you first heard about this strange new crisis? I do. The gay newspaper in Sydney, Australia, began carrying reports of “GRID” – an exotic new condition that had suddenly sprung up among sexually active gay men in North America. At first scientists associated it with the use of amyl nitrate (“poppers”), the recreational inhalant used by some people during sex. Well, I’m safe, I thought to myself. Never liked poppers.

Then, as precious friends became sick – very sick – and the funerals increased in number and intensity, it seemed that no one was safe. Most of us who read this *Review* will have sat at bedsides of the sick. Most of us will have wept. But sitting and weeping were never the correct response to HIV and AIDS. Soon the epidemic reached far beyond the gay men of North America, Europe, and Australasia. It expanded quickly into every corner of the world. Responses came up against religion,

poverty, ignorance. It was measured in statistics. Sixty million individuals infected with the virus. More than 35 percent dead from AIDS-related conditions. More than 90 percent living with HIV in developing countries where over 95 percent of AIDS deaths have occurred. Worldwide, 75 percent of all infections are the result of heterosexual sex.¹

Yet those of us who really knew about HIV and AIDS were always aware that HIV and AIDS were not about figures and tables – but about living and dying human beings. So what have we learned in 20 years? What have been our successes and failures?

We have learned that, clever as human inventiveness is, science cannot be switched on and off to come up, to order, with an instant cure, even to such a life-threatening condition. Or with an immediate vaccine that would protect the next generation from infection. Before HIV/AIDS, most of us in developed countries thought how clever we were. Humans had at last conquered

disease. It was only a matter of time before the great promise of the human right to health, expressed in the Universal Declaration of Human Rights of 1948, would be translated into reality for the world's billions. Cancer would be conquered. Heart disease would be laid low. But then, in the midst of our hubris, we were suddenly confronted by a new and seemingly invincible enemy. As so often in the past, this viral enemy used the pathways of human pleasure, especially sexual intercourse, to spread its terrifying presence.

In more recent years, with antiretroviral therapy, we seemed again to be on the pathway to medications that would keep in check (at least in richer countries) the worst assaults of the viral condition of HIV. The cure that would forever rid the body of the virus seems as far away as ever. The attempts to find, test, and ultimately distribute a safe universal vaccine seem too long delayed. The huge profits that such discoveries would bring have not been enough to secure action in time to save the millions affected. In most countries of the world, the worst ravages continue because the drugs that we know can make such a difference to life, and to quality of life, remain unavailable, unaffordable.

So we have been humbled by our intellectual limitations. Yet we have also learned how much easier it is for the world to be mobilized to fight other affronts to humanity than to fight this virus. In the aftermath of September 11, an enormous upsurge of power, determination, and military might was assembled to confront the enemy called terrorism. How many of us have wondered what might have been if only the same determination had been mobilized against HIV? What if in 1981 President Reagan had marshalled the same reserves of energy and enterprise against it? Sadly, we know that, in the first term of his presidency, the great communicator could not bring those magic lips around that tiny acronym "AIDS." Hundreds of thousands of his fellow citizens, and millions elsewhere, became infected in the silence of his inattention.

On the other side of the world, in Australia, we had a miracle of good luck. The federal Health Minister, Dr Neal Blewett, was the exact opposite of Ronald Reagan. A political scientist, cerebral, with many gay friends, sensitive and acutely aware of the havoc that AIDS was causing, he struck out on a remarkable political odyssey. In a country that plays its politics hard, he called in the Opposition spokesman on health, Dr Peter Baume. By good chance, Peter Baume was an expert in public health.

Together they designed a proactive strategy. Remarkable things were done. A massive public education program. Nationwide promotion of condom use. Moves to decriminalize prostitution. The demolition of the last anti-sodomy laws. A big program of publicly funded health care for people infected. Education in schools. Even arrangements for needle exchange in suburban pharmacies.

When the Australian graph of infections went down and remained, by world levels, very low, and other nations saw the fearsome toll of infections rise, we learned something more. Politics does count. Leadership matters. Informed interventions change the infection and death rate. Brave moves can have mighty consequences.

How could we teach these lessons to other countries? How could we do so in lands where religious opponents forbade the very mention of condoms or anal sex? Where political imperatives forbade needle exchange? We have, these past 20 years, learned the difficulty of doing what is right and urgent. In the real world of politics, bold action is often hard. Hardest of all is to know what must be done but to be unable to get it done because of ignorance, hypocrisy, dogma.

We have learned how the global machinery of the United Nations can bring knowledge of this epidemic to a single international meeting room. We can examine the statistical models. We can learn of the devastation that HIV has caused in sub-Saharan Africa. In Latin America. And now in India, as the virus reaches into the huge population centres of the subcontinent. We can witness the global scope of the epidemic and yet see the indifference that many have to events in faraway African villages. "Solidarity of humanity" has a nice ring about it. It sounds fine when uttered at a world conference. Yet in practice, that is all it usually is. Words. Mobilizing ordinary citizens to feel close empathy with infected men, women, and children in faraway countries is a big task.

Yet such mobilization is essential if politicians are to be moved to provide funding for research, education, promotion, and drugs. The cost of pharmaceuticals that make such a difference to ordinary lives is still beyond the pocket of most people infected with HIV in Africa, Latin America, and Asia. It is an outrage that it should depend on the chance of one's place of birth to decide whether pharmaceuticals that can make such a difference are available or not. Yet that is the reality.

In 20 years we have learned of the strength and purposefulness of non-governmental organizations. They

have rallied to support the sick and the dying. They have organized meetings. They have banged on tables to capture attention for the plight of the infected, of their loved ones, of orphans, and of those at risk.

To some extent, the HIV epidemic has mobilized people who once were quiet. Quiet about injecting drug use. Quiet about commercial sex work. Quiet about homosexuality. Quite bluntly, we have learned that silence on these and other topics means death. Individuals alone can do relatively little. But in groups and associations, at conferences and in the media, they can bring their powerful messages to a worldwide audience. They can demonstrate about the human right to access to pharmaceuticals. They can insist on the right to housing of the ill. They can confront those who mouth pious doctrines and exhibit indifference to the plight of fellow human beings.

The measure of liberty is the strength of civil society. The HIV epidemic has brought out powerful organizations of citizens to speak up for those who are infected and those who are at risk. In my own case, it was the sight of so many friends falling to HIV and AIDS that finally propelled me into honesty about my own sexuality. What a trivial, insignificant fact; yet at the time a deep dark secret. And my partner of three decades, Johan, now works as a volunteer helping people with HIV to have a full life. He is one of countless thousands around the world – families and friends – who have rallied in such practical ways. In 20 years we have learned the power of human love. We have learned how love can sometimes rise to the occasion in times of crisis and make a difference.

Above all, we have learned from people living with HIV and AIDS and their related conditions. We have learned from their fear. From their anger. From their resilience and determination. From the ups and downs of their treatment. From their dignity and care for others, not just themselves. Seeing them, and witnessing their pain, mobilizes us, who are the witnesses, to continue the struggle beside them.

In the next 20 years, will we have conquered AIDS? Will it by then be just a footnote to the history of epidemics? Will it have passed like the Great Plague, the Black Death, syphilis, and other conditions that have wreaked havoc on humanity and then disappeared? Or will it be a story like diabetes? Controlled for those who can get the medication, deadly for those who cannot? Will the Human Genome Project come up with solutions to HIV and AIDS? In 20 years will we have the vaccine that Robert Gallo thought would have been here long since?

Will the whole human family see this epidemic as it is – a danger to us all? Will the moralizing and stone throwing have been abandoned and replaced by strong action motivated by love for fellow human beings? Will the wealthy countries view the infected in Africa as brothers or sisters?

These thoughts went through my mind in January 2002. With Edwin Cameron, a South African judge who lives with HIV, I was in India. Outside Bangalore we sat on the mud floor of a meagre facility provided for people living with HIV. About us were nearly 40 children. Many were orphans. All were themselves infected with HIV. In India the problem is not, as in Australia, one of newly rising infection levels among young people – a new generation that needs renewal of essential education. In India, they face the first wave of the epidemic. Sadly, it is accompanied by widespread political indifference, social rejection, media silence, professional ignorance, legal impediments, and, all too often, shame.

So we have learned much in 20 years. But our lessons must be constantly renewed. In some places they remain to be learned for the first time. Law and social policy will never be quite the same after the HIV epidemic. Australia and a few other countries have shown that the law can play an affirmative and beneficial role. Politicians can actually save lives. Lawyers can help them. Astonishing news, but true.

The full history of the epidemic will one day be written. When that happens this *Review*, and those who have worked on it, will be acknowledged. Jonathan Mann and Peter Piot have taught us the links between human rights law and a successful response to this particular virus. The *Review* has helped translate their paradoxical instruction into practical reality in explaining achievable law reforms. I hope that the *Review* will continue to do so. I pray that one day it will no longer be needed. That day has not yet come. It is not even on the horizon. We have many miles to travel before we rest. We know that, in the eye of history, 20 years is nothing. But for us who have journeyed with this epidemic and felt its burdens, it seems forever.

– *The Hon Justice Michael Kirby, AC CMG*

Justice Kirby is a Justice of the High Court of Australia. He has been a member of the World Health Organization Global Commission on AIDS and chairperson of the UNAIDS Expert Group on HIV Testing of United Nations Peacekeepers.

¹The statistics in this editorial are derived from the Joint United Nations Programme on HIV/AIDS/World Health Organization. AIDS Epidemic Update: December 2001. Geneva: Joint United Nations Programme on HIV/AIDS/World Health Organization, 2001 (available via www.unaids.org).

FEATURES

HIV-Related Stigma and Discrimination – The Epidemic Continues

This article is one of a series commissioned to mark the tenth anniversary of the Canadian HIV/AIDS Legal Network, discussing past developments and future directions in areas of policy and law related to HIV/AIDS. It looks at HIV-related stigma and discrimination. The article summarizes the present situation as described in reports from numerous countries throughout the world. It reviews the institutional, non-institutional, and structural dimensions of HIV-related discrimination. It also identifies some essential components of anti-discrimination efforts: legal protection; public, workplace, and health-care programs; community mobilization; and strategizing on the determinants of health.

Fifteen years ago, in an address to the United Nations General Assembly, Jonathan Mann identified three phases of the AIDS epidemic in a community – the silent and unnoticed epidemic of HIV infection, the epidemic of HIV-related diseases that emerge later, and the epidemic of stigma and discrimination that characterizes people's and society's response to HIV and AIDS.¹ That third epidemic is the theme of a two-year World AIDS Campaign in 2002-2003.² It is timely to review the present situation and consider how to move forward, so that the World AIDS Campaign becomes the impetus for concrete and specific action on the epidemic of HIV-related stigma and discrimination.

The Present Situation

There is a growing body of evidence of HIV-related stigma and discrimina-

tion in the world.³ In the past five years, studies have documented stigma and discrimination against people with HIV/AIDS or vulnerable to HIV in Australia,⁴ Burkina Faso,⁵ Cameroon,⁶ Canada,⁷ Côte d'Ivoire,⁸ Gabon,⁹ Ghana,¹⁰ India,¹¹ Russia,¹² Mauritania,¹³ the Netherlands,¹⁴ New Zealand,¹⁵ South Africa,¹⁶ Switzerland,¹⁷ Uganda,¹⁸ the Ukraine,¹⁹ the United Kingdom,²⁰ the United States,²¹ and Zambia²² – to name only reports that have come to the attention of the author. The news is not all bad. In some societies the prevalence of negative attitudes toward people with HIV/AIDS is relatively small,²³ support for coercive measures has declined,²⁴ and institutionalized discrimination toward people with HIV/AIDS is not widespread.²⁵ On the whole, however, there is much to be gravely concerned about.

First, in many societies there are blatant and aggressive forms of stigma and discrimination, including violence, against people with HIV/AIDS. Elsewhere, where the initial panic has subsided and information, policy, and legislation counteract stigma and discrimination, overt forms may be replaced with subtler ones.

Second, stigma and discrimination based on HIV status are only one aspect of a complex of associated forms of stigma and discrimination. Stigmatizing attitudes and discriminatory practices toward women, gay men, drug users, sex workers, aboriginal peoples, ethnic populations, and prisoners frequently contribute to and strengthen stigmatizing attitudes and discriminatory practices toward people with HIV/AIDS. These associated forms of stigma and discrimination are often deeply rooted in societies and enormously difficult to change.

Third, many societies have insufficient protections for people with HIV/AIDS from discrimination in health care, employment, housing, education, travel and migration, and other areas of social activity. Where such protections are in place, they may not be enforced or may be difficult to use. The types of actions to which people with HIV/AIDS or members of vulnerable populations

may be subjected include HIV testing without knowledge or consent, disclosure of HIV status, failure to provide care and treatment, and denial of housing, employment, insurance, or permission to travel.

Finally, there is considerable evidence demonstrating that stigma and discrimination toward people with HIV/AIDS and vulnerable populations creates the conditions for the epidemics of HIV infection and HIV-related diseases to continue or flourish.²⁶ Women, children, gay men, drug users, sex workers, prisoners, and other vulnerable populations are less able to protect themselves from HIV infection because of cultural norms, laws, policies, and practices that place them at a disadvantage. People vulnerable to HIV are reluctant to be tested for HIV because of stigma associated with HIV infection and fear of disclosure of HIV status. People with HIV/AIDS may be deterred from accessing care because of the negative associations of HIV or because they anticipate or experience prejudicial behaviour from health-care providers.

Human rights declarations

Freedom from discrimination is a fundamental human right founded on principles of natural justice and enshrined in international and regional human rights instruments.²⁷ These instruments prohibit discrimination based on race; colour; sex; language; religion; political or other opinion; national, ethnic, or social origin; property; disability; fortune; birth; or other status. The United Nations Commission on Human Rights has declared that “the term ‘or other status’ in non-discrimination provisions in international human rights texts should be interpreted to cover health status, including HIV/AIDS” (resolu-

tion 1999/49). It has stated that “discrimination on the basis of HIV/AIDS status, actual or presumed, is prohibited by existing human rights standards” (resolution 2001/51).

The Guidelines on HIV/AIDS and Human Rights, developed by the Second International Consultation on HIV/AIDS and Human Rights convened in 1996 by the United Nations High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS,²⁸ are designed to translate the rights enshrined in these instruments into practice. They offer concrete measures that states can take to protect and promote the health and human rights of people with HIV/AIDS and vulnerable populations. The United Nations Commission on Human Rights has repeatedly invited states, United Nations bodies, and other agencies to take all necessary steps to ensure the respect, protection, and fulfilment of HIV-related human rights as contained in the Guidelines, including taking all necessary measures to eliminate stigmatization and discrimination against those infected and affected by HIV/AIDS (resolutions 1999/49, 2001/51).

At the United Nations General Assembly Special Session on HIV/AIDS held in June 2001, all 189 member states adopted a Declaration of Commitment on HIV/AIDS.²⁹ The Declaration recognizes that “realization of human rights and fundamental freedoms for all is essential to reduce vulnerability to HIV/AIDS” and that “respect for the rights of people living with HIV/AIDS drives an effective response.”³⁰ States made a commitment to:

[b]y 2003, enact, strengthen or enforce, as appropriate, legislation, regulations and other meas-

ures to eliminate all forms of discrimination against and to ensure the full enjoyment of all human rights and fundamental freedoms by people living with HIV/AIDS and members of vulnerable groups, in particular to ensure their access to, inter alia, education, inheritance, employment, health care, social and health services, prevention, support and treatment, information and legal protection, while respecting their privacy and confidentiality; and develop strategies to combat stigma and social exclusion connected with the epidemic.³¹

In view of the disproportionate impact of the HIV epidemic on women and girls, states made additional specific commitments to protect and advance their human rights.³² It is a disappointment that the states did not make similar commitments for other populations disproportionately affected by the epidemic and by discrimination, such as men who have sex with men, or injection drug users. Nevertheless, the unanimous agreement to protect the human rights of people with HIV/AIDS and vulnerable populations, as well to empower women and girls to protect themselves from HIV infection, is a milestone.

Dimensions of stigma and discrimination

Stigma and discrimination are at work in several ways in society to compound or augment the impact of the HIV epidemic. *Institutional discrimination* operates in those spheres – health care, employment, housing, education, travel and migration – where legislation, regulations, policies, and procedures can include discriminatory or anti-discrimination

provisions and practices. *Non-institutional discrimination* operates in those spheres – relations between individuals, within families, and

Even if only a minority of the population acts on its prejudices, fear of discrimination has a profound effect on people with HIV/AIDS.

within communities – that are beyond the direct purview of legislation, regulation, policies, and procedures. Here stigmatizing behaviour and discriminatory acts must be addressed through other means, such as public education and community mobilization. *Structural discrimination* refers to inequalities in both the institutional and non-institutional spheres of society related to gender, ethnic identity, socioeconomic status, and the like. These inequalities, which reflect the distribution and exercise of power and resources within the political economy of a society, often compromise people's capacity to protect their health or to be cared for when ill.

Institutional discrimination

A review of legislation on HIV/AIDS from 121 countries found that only 17 percent of these countries have developed specific legislation to protect people with HIV/AIDS from discrimination in employment, education, sports, housing, public services, and other social activities.³³ The review does not take into account legislation that does not specifically refer to HIV/AIDS but

nevertheless has been interpreted to apply to people with HIV/AIDS (such as legislation that provides protections on grounds of disability³⁴), and it relies on voluntary reporting on legislation from member states of the World Health Organization (70 of the 191 members did not report).³⁵ Even so, the finding suggests that work on protecting people with HIV/AIDS against institutional discrimination has hardly begun for large portions of the world's population affected by the epidemic. Also telling is the number of countries that have legalized mandatory or coercive measures, such as mandatory HIV testing for vulnerable populations; obligatory participation in prevention programs; quarantine, isolation, or forced hospitalization of people with HIV/AIDS; or penal sanction for deliberately exposing others to the risk of HIV transmission.³⁶ Such measures increase and reinforce the stigmatization of people with HIV/AIDS, and do little to protect public health.³⁷

Anti-discrimination legislation can be a useful tool in identifying, correcting, and remedying occasional and systemic discrimination against people with HIV/AIDS.³⁸ But it is not without its limitations. For individual complainants, the duration, complexity, and cost of procedures can, in effect if not by design, deprive them of a remedy.³⁹ Restrictive interpretations of anti-discrimination provisions by the courts and other bodies can significantly limit the grounds for complaint.⁴⁰ And subtle forms of prejudice, such as stigmatizing remarks by co-workers or avoidance in health-care settings, are difficult to document and address through anti-discrimination laws and policies.⁴¹

Non-institutional discrimination

HIV-related stigma is manifested in such attitudes as anger and other negative feelings toward people with HIV/AIDS; the belief that they are responsible for their infection and deserve their illness; avoidance and ostracism; and support for coercive public policies such as quarantine, mandatory testing, or public disclosure.⁴² Such attitudes have been associated with mistaken beliefs that HIV can be transmitted through casual contact,⁴³ as well as negative attitudes toward populations affected by the epidemic (gay men, drug users, and others).⁴⁴ Even when populations become more accustomed to and knowledgeable about HIV, stigmatizing attitudes toward people with HIV/AIDS can persist in a significant minority of the population.⁴⁵

Even if only a minority of the population acts on its prejudices, fear of discrimination has a profound effect on people with HIV/AIDS. For example, women do not disclose that they have HIV to their male partners and extended family for fear of abuse and rejection.⁴⁶ Identifiable ethnic populations are reluctant to support public HIV education campaigns directed at their populations because of the adverse reaction they expect from others.⁴⁷ People are reluctant to be tested for HIV because they fear the stigmatization and discrimination that would ensue if their HIV status were known.⁴⁸

Structural discrimination

The HIV epidemic exposes structural inequalities within society, particularly those related to gender, socioeconomic status, or ethnocultural identity. For instance, women are disproportionately affected by the epidemic because of their subordina-

tion to men in the domestic, economic, and political spheres of most (if not all) societies. They are less able to protect themselves from HIV infection, are more likely to be reproached for being HIV-positive, bear most of the burden of caring for the ill and dying, and are more likely to be abused and abandoned.⁴⁹ Similarly, Aboriginal people in Canada are more vulnerable to HIV infection because poverty, cultural alienation, and political exclusion have contributed to behaviours that either directly (injection drug use, unsafe sex) or indirectly (domestic violence, substance abuse) increase the risk of HIV infection.⁵⁰

The Way Forward

The conditions that foster or permit HIV-related stigma and discrimination vary from society to society. Popular beliefs, cultural norms, professional standards, legislative frameworks – these are specific to societies and countries. Thus, there is no single recipe for addressing HIV-related stigma and discrimination. But there are some essential ingredients. While the mix may vary according to the prevailing circumstances in a society or country, each has an important role in countering stigma and discrimination.

Legal protection

Legal protection against discrimination is an essential component of any anti-discrimination strategy. Legal protection includes not only anti-discrimination laws and regulations, but also the capacity to invoke and enforce those laws and regulations through the courts, human rights tribunals, professional regulatory bodies, and the like. Notwithstanding the deficiencies of individual complaint

procedures (discussed above), anti-discrimination measures create protections against arbitrary action and grounds for recourse in the event of such action. In addition, anti-discrimination measures provide an incentive for employers, professional associations, and similar bodies to develop anti-discrimination policies and procedures. Perhaps most important, anti-discrimination measures create a framework of rights that support communities and populations in mobilizing against stigma and discrimination. This is evident from the gains that, for instance, gays and lesbians in Canada and elsewhere have achieved as their rights have been recognized in employment, housing, pensions and other benefits, adoption, and spousal status.

Organizations can take a number of steps to assess and improve legal protection against HIV-related discrimination. The UNAIDS Protocol for the Identification of Discrimination against People Living with HIV can be used to determine whether laws, regulations, procedures, or practices are at present discriminatory.⁵² It includes a template that can be used to identify 37 forms of discrimination against people with HIV/AIDS in 10 areas of social life. The areas covered are health care; employment; justice/legal processes; administration; social welfare; housing; education; reproduction and family life; insurance and other financial services; and access to other public accommodations or services. In these areas, the Protocol aims to identify discriminatory practices as well as discrimination in law, regulations, and procedures. To date, the Protocol has been used in Côte d'Ivoire,⁵³ Philippines,⁵⁴ and Switzerland,⁵⁵ and is being used in a

project involving China, India, Indonesia, Philippines, Thailand, and Vietnam.⁵⁶ The protocol is not without limitations.⁵⁷ It does not measure the quantity or intensity of discrimination in a given domain. It is not

“Efforts to tackle HIV/AIDS-related stigmatization, discrimination and denial seem doomed to fail in the absence of a supportive legal framework.”

– Peter Aggleton

particularly sensitive in situations where HIV-related discrimination is actively discouraged. And it concerns itself only with institutional discrimination. Nevertheless, it provides an important starting point for identifying discriminatory provisions.

A second step is to identify, advocate for, and implement positive protections against HIV-related discrimination. The follow-up to the United Nations Declaration of Commitment on HIV/AIDS may be useful in this regard. At least one day of the annual session of the United Nations General Assembly will be devoted to the Secretary-General's report on the progress that countries have made in realizing their commitments.⁵⁸ In their input to the Secretary-General's report for 2002, countries are asked to state whether they have “legislation, regulations, and/or other measures in place to eliminate all forms of discrimination against people living with HIV/AIDS.”⁵⁹ Where HIV/AIDS organizations or other bodies have the capacity and the freedom to act

in this regard, they might use this reporting mechanism as an occasion to assess the status of positive protections (or the absence thereof) in their

Community mobilization, in concert with a supportive legal framework, can be an effective force for change.

country, and press for changes if required. Parliamentary forums, such as those established in Africa, Latin America and the Caribbean, India, and the UK,⁶⁰ could also be instrumental in reviewing and revising legislation.

Public, workplace, and health-care programs

Public programs intended to foster a more supportive and accepting environment for people with HIV/AIDS will need to address all the aspects of HIV-related stigma. It is not sufficient only to communicate accurate information about how HIV is – *and is not* – transmitted, important though this is to counter misapprehensions about casual contact with people with HIV/AIDS. It is also necessary to counter blaming and ostracizing responses to people with HIV/AIDS and stigmatized populations, and to promote solidarity with them.

Attitudes that influence behaviour within communities also influence behaviour in workplaces, health care, and other sectors. People carry their prejudices with them wherever they go. Even after anti-discrimination policies have been established, there continue to be reports of problems with disclosure of HIV status, avoid-

ance, denial of service or employment, and related actions in employment and health care.⁶¹ As services for people with HIV/AIDS become more “mainstream,” problems that were overcome in earlier stages of the epidemic, when services were offered in more specialized contexts, can recur.

Such behaviour, and the views that inform it, can and should be addressed through employment and health-care policies, which in turn need to be accompanied by workplace and health-care education and training. This is an ongoing process, in part because of turnover of staff in workplaces and health care, in part because the populations affected by the epidemic may change,⁶² and in part because calls for unwarranted measures can emerge as the epidemic evolves.⁶³

Community mobilization

In their analysis of HIV-related stigma, Robert Parker and Peter Aggleton stress the role of stigma in strengthening and reproducing social inequalities: “stigma is deployed by concrete and identifiable social actors seeking to legitimize their own dominant status within existing structures of social inequality.”⁶⁴ They suggest that educational programs by themselves are not likely to alter this dynamic. The power of stigmatized populations must be engaged through community mobilization to resist stigmatization and discrimination.

This involves working with “resistance identities” generated by the stigmatized in reaction to the “legitimizing identities” employed by the stigmatizer, and developing new identities that break through this conflict to bring about social transformation.⁶⁵ In the process, stigmatized populations overcome not only

the power of stigmatizing attitudes by others, but also the power such attitudes have when internalized by the stigmatized.

Community mobilization, in concert with a supportive legal framework, can be an effective force for change. The success of the Vancouver Area Network of Drug Users and Pivot Legal Society in defeating an attempt to close a health centre for drug users in Vancouver (see the report in Canadian News in this issue) is illustrative in this regard. The organization of drug users into a community-based group, coupled with the court’s recognition of that group as representing drug users, was instrumental in resisting discriminatory action. Similarly, AIDS advocacy organizations in El Salvador have appealed to constitutional and international law in challenging legislation allowing employers to impose pre-employment HIV testing on job applicants (see the report in HIV/AIDS in the Courts – International in this issue).

Community mobilization also enables diverse populations to modulate efforts to bring about change in accordance with the norms, traditions, and dynamics of their culture. Since the populations affected by HIV-related stigma and discrimination are diverse, both within a given society and across the world, this ability of communities to direct and refine efforts to counter stigma and discrimination is essential.⁶⁶

Strategizing on the determinants of health

The role of structural inequalities in the political economy of a society – particularly their role in rendering populations vulnerable to HIV-related stigma and discrimination – means that efforts to address HIV-

related stigma and discrimination will be incomplete without a strategy to analyze and alter these inequalities. This is a difficult and complex undertaking. Many of the determinants of health are outside the purview of public health and health-care services.⁶⁷ Nevertheless, as people working in health promotion have argued now for decades,⁶⁸ not to work on these determinants in any strategy to address the HIV epidemic, including the third epidemic, would be enormously shortsighted. In this regard, the statements in the United Nations Declaration of Commitment on HIV/AIDS on reducing vulnerability are quite to the point.⁶⁹

Conclusion

It is not easy to overcome the cultural, institutional, and structural conditions that lead to stigmatizing attitudes and discriminatory actions toward people with HIV/AIDS and vulnerable populations. But there are concrete and specific things that communities and governments can do to prevent or mitigate discriminatory behaviour. States have committed themselves to enact, strengthen, or enforce legislation, regulations, and other measures to eliminate all forms of discrimination against people with HIV/AIDS and members of vulnerable populations by 2003. It is vital that they act on this commitment, and it is equally vital that

organizations working in HIV/AIDS, human rights, development, and health hold them to their commitment and work with them to achieve it.

— Theodore de Bruyn

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Further Reading

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Herek GM, ed. AIDS and stigma in the United States. *American Behavioral Scientist* 1999; 42(7): 1101-1243.

UNAIDS. Protocol for the Identification of Discrimination against People Living with HIV. Geneva: Joint United Nations Programme on HIV/AIDS, 2000 (www.unaids.org/publications/documents/human/law/JC295-Protocol-E.pdf).

Resources associated with the World AIDS Campaign against HIV-related stigma and discrimination are available via www.unaids.org/wac/2002/index.html. Related resources on human rights, ethics, and law are available via www.unaids.org/publications/documents/human/#ethics.

Reports and info sheets on HIV-related discrimination in Canada are available at www.aidslaw.ca/Maincontent/issues/discrimination.htm.

Reports on HIV-related discrimination in various countries are listed at notes 4 to 22 below.

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² See www.unaids.org/wac/2002/index.html.

³ For an overview, see A Malcolm et al. HIV-related stigmatization and discrimination: its forms and contexts. *Critical Public Health* 1998; 8(4): 347-370.

⁴ J Grierson et al. *HIV Futures 3: Positive Australians on Services, Health and Well-Being*. Melbourne: The Australian Research Centre in Sex, Health and Society, La Trobe University, 2002 (www.latrobe.edu.au/hiv-futures).

⁵ UNAIDS and Network of African People Living with HIV. *Situation Analysis of Discrimination and Stigmatization against People Living with HIV/AIDS in West and Central Africa*. Geneva: Joint United Nations Program on HIV/AIDS, 2002 (available via www.unaids.org/wac/2002/background.html). E Chase et al. *Stigma, HIV/AIDS and Prevention of Mother-to-Child Transmission: A Pilot Study in Zambia, India, Ukraine and Burkina Faso*. London: United Nations Children's Fund/Panos Institute, 2001 (www.panos.org.uk/aids/stigma_countries_study.htm).

⁶ UNAIDS and Network of African People Living with HIV, supra, note 5.

⁷ T de Bruyn. *HIV/AIDS and Discrimination: A Discussion Paper*. Montréal: Canadian HIV/AIDS Legal Network/Canadian AIDS Society, 1998; S Matiation. *Discrimination, HIV/AIDS and Aboriginal People: A Discussion Paper*. Montréal: Canadian HIV/AIDS Legal Network, 1998; Alliance for South Asian AIDS Prevention. *Discrimination and HIV/AIDS in South Asian Communities: Legal, Ethical and Human Rights Challenges. An Ethnocultural Perspective*. Toronto: Alliance for South Asian AIDS Prevention, 1999; C Olivier. HIV-related discrimination in New Brunswick increasing. *Canadian HIV/AIDS Policy & Law Newsletter* 2000; 5(2/3): 52.

⁸ UNAIDS and Network of African People Living with HIV, supra, note 5.

⁹ Id.

¹⁰ Id.

- ¹¹ P Aggleton. *HIV and AIDS-Related Stigmatization, Discrimination and Denial: Forms, Contexts and Determinants. Research Studies from Uganda and India*. Geneva: UNAIDS, 2000 (available via www.unaids.org/publications/documents/human/#ethics); Chase et al, supra, note 5.
- ¹² The Russian NAMES Fund. Discrimination and human rights abuse in Russia. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 5(1): 22-27.
- ¹³ UNAIDS and Network of African People Living with HIV, supra, note 5.
- ¹⁴ AER Bos et al. Public reactions to people with HIV/AIDS in the Netherlands. *AIDS Education and Prevention* 2001; 13(3): 219-228.
- ¹⁵ The report, by J Grierson et al, is forthcoming at www.latrobe.edu.au/hiv-futures; cf. Friends "culprits" in HIV/AIDS disclosure. *Christchurch Press*, 16 June 2002.
- ¹⁶ M Richter. Certain legal aspects of AIDS discrimination in South Africa. *AIDS Analysis Africa* 2002; 12(5): 12-14; M Richter. Aiding intolerance and fear: the nature and extent of AIDS discrimination in South Africa. *Law, Democracy and Development* 2001; 5(2): 195-211.
- ¹⁷ F Dubois-Arber et al. HIV/AIDS institutional discrimination in Switzerland. *Social Science and Medicine* 2001; 52: 1525-1535.
- ¹⁸ Aggleton, supra, note 11.
- ¹⁹ Chase et al, supra, note 5.
- ²⁰ Terrence Higgins Trust. *Prejudice, Discrimination and HIV: A Report*. London: Terrence Higgins Trust, 2001 (available via www.tht.org.uk/policy_discrim.htm).
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- ²² Chase et al, supra, note 5.
- ²³ Bos et al, supra, note 14.
- ²⁴ Herek et al, supra, note 21.
- ²⁵ Dubois-Arber et al, supra, note 17.
- ²⁶ See the reports listed above at notes 4-22. MA Chesney, AW Smith. Critical delays in HIV testing and care. In Herek, ed., supra, note 21 at 1162-1174.
- ²⁷ The Universal Declaration on Human Rights (article 2); the International Covenant on Civil and Political Rights; the International Covenant on Economic, Social, and Cultural Rights; the Convention on Elimination of All Forms of Discrimination Against Women; the Convention on the Rights of the Child; the African Charter on Human and Peoples' Rights; the American Convention on Human Rights; and the European Convention on Human Rights and Fundamental Freedoms.
- ²⁸ 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 (www.unaids.org/publications/documents/human/law/hright2e.pdf).
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- ³⁰ Ibid at para 58.
- ³¹ Ibid.
- ³² Ibid at paras 59-61.
- ³³ R D'Amelio et al. A global review of legislation on HIV/AIDS: the issue of HIV testing. *Journal of Acquired Immune Deficiency Syndromes* 2001; 28: 173-179.
- ³⁴ D Patterson. Other developments. *Canadian HIV/AIDS Policy & Law Review* 2002; 6(3): 49.
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- ³⁷ Parker and Aggleton, supra, note 1 at 22-23.
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- ⁴⁸ Chesney & Smith, supra, note 26 at 1163-1165.
- ⁴⁹ Malcolm, supra, note 3 at 357-358. For analysis of a specific case, see Richter (2001), supra, note 16.
- ⁵⁰ Royal Commission on Aboriginal Peoples. *Report of the Royal Commission on Aboriginal Peoples*. Vol 3: *Gathering Strength*. Ottawa: Minister of Supply and Services, 1996. See also the article by K Thomas in Canadian News in this issue regarding HIV incidence among female Aboriginal injection drug users.
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- ⁵² Geneva: Joint United Nations Programme on HIV/AIDS, 2000 (www.unaids.org/publications/documents/human/law/JC295-Protocol-E.pdf).
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- ⁵⁶ J Thomas et al. *A Situational Analysis of HIV/AIDS Related Stigma and Discrimination in the Asia Pacific*. Progress Report. School of Health Services, Deakin University, Australia, 2002.
- ⁵⁷ Dubois-Arber, supra, note 17 at 1533-1534.
- ⁵⁸ Declaration of Commitment on HIV/AIDS, supra, note 29 at para 100.
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- ⁶¹ See, eg, Grierson et al, supra, note 4 at 109-110; Richter, supra, note 16.
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- ⁶⁹ Supra, note 29 at paras 62-64.

HIV/AIDS in Prisons: More New Developments

The Correctional Service of Canada has finally expanded access to methadone maintenance treatment in federal correctional institutions – after being sued by a prisoner who was denied access four years ago. Just how important expanded access to methadone treatment is in prisons is confirmed by yet more studies showing how prevalent injection drug use in prisons is. Education on hepatitis C is also important, and new materials have been developed and are being widely distributed. Finally, both in Canada and Russia, HIV-positive prisoners have complained that their privacy rights have been breached. These and other developments are described in the collection of articles below, compiled by Ralf Jürgens, Executive Director of the Canadian HIV/AIDS Legal Network. Ralf can be reached at ralfj@aidslaw.ca.

Canada: Federal Prison System Expands Access to Methadone

On 30 April 2002, a federal court judge in Winnipeg heard the case of a prisoner who filed a lawsuit alleging the federal government broke the law and violated his Charter rights by not providing him with methadone maintenance treatment (MMT).¹ Two days later, on 2 May 2002, the Correctional Service of Canada (CSC) expanded access to MMT in federal prisons.

The case

The prisoner, Barry Strykiwsky, said he spent most of his life robbing people to pay for his heroin addiction. Four years ago he wanted to end his addiction, and begged prison officials to let him begin methadone treatment. His doctors supported him, but prison officials refused his request. Strykiwsky then filed a lawsuit alleging the federal government broke the law and violated his rights under the *Canadian Charter of Rights and Freedoms* by not providing him with a treatment

commonly available to other Canadians. Shortly after the lawsuit was filed, Strykiwsky was given methadone and prison officials asked him to drop his case. Strykiwsky refused, saying that without court backing, his methadone could be taken away from him at any time.

Background

Since the early 1990s, many have recommended the introduction or expansion of MMT in prisons as an AIDS-prevention strategy that provides people dependent on drugs with the additional option of getting away from needle use and sharing.² *The main aim of MMT is to help people get off injecting, not off drugs.* Methadone dose reduction – with the ultimate goal of helping the client to get off drugs – is a longer-term objective.

Community MMT programs have rapidly expanded. There are ample

data supporting their effectiveness in reducing high-risk injecting behaviour and in reducing the risk of contracting HIV. There is also evidence that MMT is the most effective treatment available for heroin-dependent injection drug users in terms of reducing mortality, heroin consumption, and criminality. Further, MMT attracts and retains more heroin injectors than any other form of treatment. Finally, there is evidence that people who are on MMT and who are forced to withdraw from methadone because they are incarcerated often “return to narcotic use, often within the prison system, and often via injection.” It has therefore been widely recommended that prisoners who were on MMT outside prison be allowed to continue it in prison.

Further, with the advent of HIV/AIDS, the arguments for offering MMT to those who were not following such a treatment outside are

compelling: prisoners who are injection drug users are likely to continue injecting in prison and are more likely to share injection equipment, creating a high risk of HIV transmis-

Since 2 May 2002, prisoners with opioid addictions in the federal system are eligible for methadone treatment even if they were not already on such treatment outside.

sion. As in the community, MMT, if made available to prisoners, has the potential of reducing injecting and syringe sharing in prisons.

In Canada, methadone was rarely prescribed to anyone in prison until the mid-1990s. However, this has changed – partly because of the recommendations urging prison systems to provide MMT, partly because of legal action.³

In September 1996, the British Columbia Corrections Branch adopted a policy of continuing methadone for incarcerated adults who were already on MMT in the community, becoming the first correctional system in Canada to make MMT available in a uniform way. On 1 December 1997, the federal prison system followed suit. Until 2 May 2002, in the federal prison system and in many – but not all – provincial systems, inmates *who were already on MMT outside* could *continue such treatment* in prison. Only in the British Columbia provincial system and under “exceptional circumstances” in the federal system could inmates access MMT even if they were not on such treatment on the outside.

The new policy

Since 2 May 2002, prisoners with opioid addictions in the federal system are eligible for MMT even if they were not already on such treatment outside (and not only in “exceptional circumstances”).

On 2 May, Commissioner’s Directive 800 – “Health Services” was updated and published (available at www.csc-scc.gc.ca/text/plcy/cdshtm/800-cde.shtml) and “Methadone Treatment Guidelines” for the delivery of the MMT program released (available at www.csc-scc.gc.ca/text/plcy/cdshtm/800-1-gl_e.shtml). A corresponding “Policy Bulletin 127” was also published (available at www.csc-scc.gc.ca/text/plcy/cdshtm/b127-800_e.shtml).

According to the Methadone Treatment Guidelines, the following criteria are to be used in assessing an inmate’s eligibility for the methadone treatment program:

1. Diagnosis of dependence to opiates as established in the DSM-IV or a well-documented history of opiate addiction indicating a high risk of relapse as confirmed by a certified institutional physician; and
2. A small likelihood of benefit from non-methadone treatment as evidenced by a past history of treatment failures; and
3. Agreement to terms and conditions of the Methadone Maintenance Treatment Program as evidenced by acceptance and willingness to sign the Methadone Treatment Agreement.

The Guidelines further state (in paragraph 4) that

methadone providers share a responsibility to ensure their MMT program is delivered in a safe and responsible manner. Methadone providers must be vig-

ilant in maintaining a patient load that does not exceed their ability to uphold their obligations to the patient.

According to paragraph 5,

in most communities, including CSC, demand for methadone programs currently surpasses providers’ ability to supply the service. For these reasons, priority for methadone initiation must be given to inmates who meet the criteria outlined above as well as the following:

- Federally sentenced women who are pregnant and currently opioid dependent or were previously opioid dependent and are a high risk of relapse.
- Inmates who are HIV positive and currently opioid dependent.
- Inmates who have been determined to require treatment for Hepatitis C. A period of abstinence from all drugs including alcohol is required prior to initiation of Hepatitis C treatment.
- Inmates who are currently opioid dependent with a recent history (within the past 3 months) of a life-threatening opioid overdose, endocarditis, septicemia, septic arthritis and/or suicidal behaviour directly related to their opiate dependence.
- Inmates who are opioid dependent and will be released within the next 6 months with successful release plans for a community methadone provider.

Comment

While CSC needs to be commended for – finally! – expanding access to MMT in federal correctional institutions, once again it only did so many years after this was recommended by experts,⁴ and only after a prisoner took legal action against the Service.

As stated in recommendation 1 of the 1996 *HIV/AIDS in Prisons: Final Report*,⁵ “in order to prevent the further spread of HIV and other infectious diseases in prisons, and to provide better care, support, and

treatment for inmates with such diseases, Canadian federal and provincial prison systems need to ... take a proactive rather than reactive approach to the issues raised by HIV/AIDS, hepatitis, tuberculosis,

and drug use in prisons.”⁶ Unfortunately, six years later, the reactive approach that has characterized prison systems’ response to HIV/AIDS in prisons continues.

Canada: Privacy Commissioner Finds “Egregious” Violation of Inmates’ Confidentiality

The Privacy Commissioner has ruled that Kingston Penitentiary violated the privacy rights of several of its HIV-positive inmates. George Radwanski issued his findings on 22 May 2002 in response to a complaint brought under the *Privacy Act* on behalf of four inmates at the penitentiary. The HIV & AIDS Legal Clinic (Ontario) represented the inmates in the complaint. Glenn Betteridge, a staff lawyer at the Clinic, prepared this article. He can be reached at betterg@lao.on.ca.

The inmates complained about the posting of a so-called “pick-up list” at Kingston Penitentiary, a federal prison, on 19 January 2001. The list identified the inmates by name, and also contained the name of the HIV specialist doctor whom the inmates were scheduled to see that day. Pick-up lists are posted not only in staff

areas but also in cellblocks where inmates live. The posting of the 19 January pick-up list effectively outed the inmates on the list as being HIV-positive, thereby breaching their right to confidentiality of personal information and putting their physical safety at risk.

Canada’s Privacy Commissioner, Mr Radwanski, found that the HIV specialist doctor’s name was listed as a result of an administrative error made by a staff person who did not know that the doctor’s name should not be shown on the list precisely because it might reveal medical information about the inmate. Nonetheless, he went on the find that the complaint was well founded. Mr Radwanski writes that “the January 19 pick-up list revealed personal information of a particularly sensitive nature about sev-

eral inmates to others with no need to know. I find this to be an egregious violation of inmates’ confidentiality and on that basis, I have concluded that [their] rights under the *Privacy Act* were compromised.”⁷

Significantly, Mr Radwanski also found that the current practice of the Correctional Service of Canada (CSC) of publicly posting pick-up lists in cellblock areas is an invasion of the personal privacy of the inmates whose names are listed, even if the health-care provider with whom the inmate has an appointment is not specifically named. He recommended that CSC cease this practice and implement a system to remind inmates of their appointments that is more sensitive to privacy issues.

Russia: Prisoners Sue Because of Publication of Medical Information

In May 2002, hearings began into the suit brought by 14 prisoners against media organizations that published details from their medical records. In January 2002, the prisoners escaped from the high-security Novo Ulyanovsk penal colony. They had

been living in a hut on the edge of the camp in which (at least some) inmates with HIV or tuberculosis are segregated. Many were serving lengthy sentences for serious crimes such as murder or robbery. Following their escape, Russian media ran reports

stating that the prisoners were all infected with HIV and therefore a danger to society. One defendant, who is positive for TB but not HIV, has had his case dismissed. Other cases are pending.⁸

Canada: Innovative Educational Tools on Hepatitis C and Prisons: The SHARP Approach

The SHARP (Surviving Hepatitis C And Risks in Prison) Project was conducted by the John Howard Society of Greater Moncton, an organization providing support and direct services to men in conflict with the law and to their families. It was funded by the Population and Public Health Branch, Health Canada. The overall goal of this project was the development of a practical set of educational tools to provide inmates and their families with the information needed to better understand, cope with, and prevent the transmission of hepatitis C. Due to the overlap in certain risk behaviours, the tools also provide some information on HIV/AIDS and other communicable diseases.

Three educational tools – a deck of playing cards, a poster, and a pocket book – were developed in close collaboration with inmates and family members affected by hepatitis C. Inmates played an integral role in developing the content of all materials, as well as in the production of the artwork. Other project partners included inmate committees, Hepatitis C Moncton, SIDA AIDS Moncton, the

Moncton Hospital's Viral Hepatitis Clinic, the Correctional Service of Canada (CSC), the New Brunswick Department of Public Safety, the New Brunswick Department of Health and Wellness, and the Queen Elizabeth II Health Sciences Centre Hepatology Clinic.

A formal process and outcome evaluation of the project will be conducted following the widespread dissemination of the educational tools. Focus-testing results provide strong support for the relevance of the materials to the project's intended populations. The strategy is multifaceted and specifically targeted to the needs of inmates and their family members. It addresses various learning styles and motivational levels, and is appropriate for low-literacy populations.

The initial intention was to distribute the educational tools to correctional and community-based settings within New Brunswick. Additional funding from the CSC and Schering Canada has resulted in a much broader scope and a national dissemination plan. In mid-2002, approximately 22,000 decks of cards, 10,000 pocket

books, and 5000 posters will be distributed to all federal prisons in Canada, branches of the John Howard/Elizabeth Fry societies, hepatitis C organizations, and addiction centres, in addition to various other organizations that provide services to persons at high risk for HCV and other communicable diseases.

As a follow-up to the SHARP Project, the John Howard Society of Greater Moncton has received funding (June 2002 – March 2004) from Health Canada to develop, implement, and evaluate an inmate hepatitis C peer education program in all five federal prisons in the Atlantic Region of CSC. All materials developed as part of the SHARP Project will be incorporated within a much more comprehensive peer education and support strategy.

For additional information about the SHARP Project and/or about obtaining copies of the educational materials, contact the John Howard Society of Greater Moncton (tel: 506 854-3499 or email: jhsmctn@nbnet.nb.ca). All materials are available in English and French.

Canada: Recent Studies Confirm Prevalence of Injection Drug Use in Prisons

A number of studies undertaken in the 1990s have provided evidence of the extent of injection and other drug use in Canadian prisons. For example, a survey undertaken by the Correctional Service of Canada in 1995 among over 4500 prisoners showed that more than one in ten prisoners had injected drugs in the federal correctional insti-

tution where they were at the time the survey was carried out.⁹

Recent studies, released at the 11th Annual Canadian Conference on HIV/AIDS Research and at the 2002 conference of the Canadian Association of Nurses in AIDS Care, confirm the prevalence of injection drug use in prisons, and explored the role

of prisons in HIV risk behaviours among injection drug users.

Forster, Bruneau, and Zunzunegui assessed the influence of imprisonment on needle and paraphernalia sharing among male injection drug users.¹⁰ Among 636 study participants selected from a cohort of Montréal injection drug users, ex-inmates

(defined as those having been in a provincial prison during the past six months) reported significantly more needle/paraphernalia sharing (72.6 percent versus 51.8 percent) compared with those who have not been in prison. The study concluded that:

Detention facilities and blood-borne infection risk behaviours remained consistently associated in our study. Prison can at least be considered as a place concentrating IDU [injection drug users] whose drug consumption style increases infection risks. In addition, incarceration might put IDU at higher risk of HIV infection since education on safe injection practices and conditions for safe injection are not currently possible behind bars.¹¹

A study by Ramuscak et al examined how incarceration affects drug-use patterns among male inmates in six provincial correctional centres in Ontario. The study concluded that, despite correctional policies, drug use continues to occur during incarceration. Consistent with other studies, it found that there was a significant decrease in both the reported use of drugs and the frequency of use. Four percent of the 433 prisoners participating had injected inside.¹²

A third study, by Small et al, reported that 83.3 percent of 523 VIDUS participants (VIDUS is an ongoing cohort study of injection drug users that began in 1996 in Vancouver) had been to a federal or provincial prison over the course of their lives; 27.9 percent reported having injected drugs at some point within a correctional facility, and 161 individuals had been in detention, prison, or jail within the previous six months. Of these, 8.1 percent had

injected drugs there. Small et al concluded that “injection drug use within corrections is an alarmingly common reality for Injection Drug Users in British Columbia.”¹³

Their study qualitatively examined the drug-related harms associated with injecting inside British Columbia prisons. They conducted a series of 30 in-depth interviews with “corrections experienced male IDUs” and reported the following results:

- Drug use inside jail and prison is a reality for some incarcerated men that can lead to a variety of health and social problems. The harms associated with drug addiction are exacerbated in prison and unique risks exist due to the distinct social environment that exists within prisons.
- Access to drugs and syringes is partially determined through possession of “commodities” which are used as currency in the black market economy of prison.
- Social standing within prison culture also determines access to drugs. Social ties often take the form of “cliques” that are composed of individuals that may collaborate to acquire and consume drugs. Persons who are in protective custody are severely stigmatized and ostracized by their fellow inmates as being informers.
- The scarcity of drugs and syringes, and the inflated value of both, has negative consequences upon addicted individuals who are incarcerated. This may push addicted inmates into peril as a system of “dope debts” exists, and opportunities to generate income are extremely limited.

- The particular social context of prison presents hazards to those using drugs due to syringe scarcity, the inflated price of drugs, finite resources, physical coercion and violence.¹⁴

Syringe scarcity, the inflated price of drugs, finite resources, physical coercion and violence presents hazards to those using drugs in prison.

Finally, a study released at the conference of the Canadian Association of Nurses in AIDS Care in Vancouver in April 2002 showed that 70 percent of 97 women prisoners surveyed at the British Columbia Correctional Centre for Women injected drugs before being incarcerated, and that 21 percent continued injecting inside; 82 percent of the women who admitted injecting in prison shared their needles with other prisoners. At the conference, Dr Ruth Martin, a physician at the Centre and one of the authors of the study, said that it is “time for Canadian prisons to give out needles to prisoners, because drug use in prisons is a fact.”¹⁵ Dr Perry Kendall, British Columbia’s Provincial Health Officer, reacted by calling for a pilot needle distribution project at the Centre, saying that he continues “to think we have an ethical imperative to work on this.”¹⁶ Martin confirmed that the Centre would be a “good place for a pilot program,” but said that although she discussed the study findings last year with both federal and provincial prison officials, “authorities haven’t yet acted.”¹⁷

¹ Heroin addicted prisoner says denial of methadone a charter violation. CBC news, 30 April 2002 (accessed at www.cbc.ca/stories/2002/04/30/methadone_020430).

² See R Jürgens. *HIV/AIDS in Prisons: Final Report*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1996, at 67-73, 108-109 (available at www.aidslaw.ca/Maincontent/issues/prisons.htm).

³ See: D Kloeze. Inmate sues the Correctional Service of Canada. In: *HIV/AIDS in prisons: new developments. Canadian HIV/AIDS Policy & Law Review* 2002; 6(3): 13-15; R Jürgens. Prisoner settles case for right to start methadone in prison. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 5(1): 34-35; R Jürgens. Judge orders methadone maintenance treatment in prison. *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 3(1): 16-20; C McLeod. Is there a right to methadone maintenance treatment in prison? *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 2(4): 22-23 (all articles available via www.aidslaw.ca/Maincontent/otherdocs/Newsletter/newsletter-toc.htm#p).

⁴ See, eg, *HIV/AIDS in Prisons: Final Report of the Expert Committee on AIDS and Prisons*. Ottawa: Minister of

Supply and Services Canada, 1994, at 79.

⁵ *Supra*, note 2 at 99.

⁶ *Ibid.*

⁷ Letter to HIV & AIDS Legal Clinic (Ontario) from George Radwanski, Privacy Commissioner of Canada, dated 22 May 2002.

⁸ *Prisoners vs journalists in Russia*. *BBC News*, 19 May 2002 (via <http://news.bbc.co.uk>).

⁹ For a summary of studies undertaken in Canada and elsewhere, see: High-Risk Behaviours behind Bars (info sheet 2 in the series of info sheets on HIV/AIDS in prisons). Montréal: Canadian HIV/AIDS Legal Network, 2nd edition 2001 (available at www.aidslaw.ca/Maincontent/issues/prisons.htm).

¹⁰ M Forster, J Bruneau, MV Zunzunegui. The role of prison in HIV risk behaviours among injecting drug users. Abstract 331P, presented at the 11th Annual Canadian Conference on HIV/AIDS Research, Winnipeg, 25-28 April 2002. Also published in the *Canadian Journal of Infectious Diseases* 2002; 13(Suppl A).

¹¹ *Ibid.*

¹² N Ramuscak et al. How does incarceration affect drug use patterns among male inmates? Abstract 330P, presented at the 11th Annual Canadian Conference on HIV/AIDS Research, Winnipeg, 25-28 April 2002. Also published in the *Canadian Journal of Infectious Diseases* 2002; 13(Suppl A).

¹³ W Small et al. Incarceration and addiction: criminal vulnerability, HIV risk and injection drug use in the corrections system. Abstract 433P, presented at the 11th Annual Canadian Conference on HIV/AIDS Research, Winnipeg, 25-28 April 2002. Also published in the *Canadian Journal of Infectious Diseases* 2002; 13(Suppl A).

¹⁴ *Ibid.*

¹⁵ G Bohn. Give prisoners free needles: health official. *Vancouver Sun*, 16 April 2002.

¹⁶ *Ibid.*

¹⁷ *Ibid.*

HIV Vaccines: Current Challenges and Future Directions

cont'd from page 1

will be vastly outweighed by the cost of the coming epidemic, especially if the world takes insufficient action. The impending loss from HIV and AIDS can be measured in loss of economic activity, loss of workers and leaders, or loss of human lives, but the sum of any such measurement points to the need for further action. By any scale, the current overall effort against AIDS, including research on new treatments, vaccines, and microbicides, is not yet sufficient.

A central goal of HIV vaccine development is *adding* a safe, effective, inexpensive, and widely accessible tool to global HIV prevention and treatment efforts. As such, the efforts for HIV vaccine research, development, and access are interwoven into broader agendas for public health, economic development, and human rights. As with all vaccines, HIV vaccines will only have a major impact

where there is public access to health information and health care. Many individuals and communities will only use and benefit from HIV vaccines when they have access to and trust in health officials who would administer those vaccines. The success of HIV vaccine development is thus tied to the success of current efforts to ensure global access to health, including efforts predicated on fundamental human rights set out in international and regional treaties and declarations.¹ Realization of human rights obligations for public health is a central part of the HIV vaccine advocacy agenda.

HIV Vaccine Development – An International Public Health, Ethical, and Legal Obligation

A rights framework places HIV vaccine development and access in the

context of international law that defines obligations of states and non-state actors to promote public health. Simply put, technological advances, including vaccines and treatments against major diseases such as HIV, are a global human right and obligation. Furthermore, the obligation to develop an HIV vaccine is comparable to other fundamental human rights related to research, including the right to individual freedom and security, and the right to individual informed consent to participation in biomedical research.

Public health obligations

Powerful public health obligations exist for HIV vaccine development, founded on global health need, public health potential, and emerging scientific feasibility. Effective HIV vaccines, if delivered in combination with basic health care and other HIV prevention and treatment, could assist millions of people to avoid HIV infection or AIDS. The feasibility of developing effective HIV vaccines is based on scientific data. Several experimen-

tal HIV vaccines have been shown to protect monkeys against HIV infection and to generate immune responses in people. To build on this scientific potential, leading HIV vaccine designs must now be evaluated in Phase III efficacy trials to see what immune responses they elicit and what protection they provide. The resulting information must then be used to construct new generations of improved HIV vaccines. Rigorous research efforts must also be maintained to learn more about basic immunology, virology, and the dynamics of potential immune protection against HIV, and to continue improving HIV vaccine designs.

Ethical obligations

HIV vaccine development is a matter of global benefit and justice. HIV vaccines could potentially help halt the global economic devastation of HIV and AIDS. Safe, effective, inexpensive, and widely accessible HIV vaccines could have the highest comparative benefits in countries and communities with the least resources and the highest HIV infection rates. In their potential to address the disproportionate burden of HIV around the world, HIV vaccines represent a possible tool for a fairer and more just distribution of response to the epidemic. As with low-cost HIV treatments, diagnostics, and potentially effective vaginal microbicides, it is unethical not to invest in development of, and wider access to, potential HIV vaccines.

Legal obligations

Legally, states have an obligation by force of treaty and joint declaration to support scientific research on AIDS and access to the products of research. The broad international legal basis for obligations to address economic,

social, and health problems is established in the 1945 Charter of the United Nations. In this treaty, member states of the United Nations adopted the obligation to “take joint and separate action” toward solutions for international health problems (Article 56).² States have further recognized obligations for providing access to public health technologies under the 1948 Universal Declaration of Human Rights, which declared in Article 27(1) a fundamental right to “share in scientific advancement and its benefits.”³ The 1975 Declaration on the Use of Scientific and Technological Progress in the Interests of Peace and for the Benefit of Mankind⁴ and the International Covenant on Economic, Social, and Cultural Rights⁵ further declare the intention and obligations of states to cooperate internationally to realize economic, social, and cultural rights, including the right to benefit from technological advances.

In June 2001, the 189 member states of the United Nations directly affirmed their recognition of the need for a stronger global response to the AIDS epidemic and, as part of this response, the need for HIV vaccine research, development, and access, by negotiating and signing a Declaration of Commitment on HIV/AIDS. In the Declaration, governments committed themselves to “[e]ncourage increased investment in HIV/AIDS-related research, nationally, regionally and internationally, in particular for the development of sustainable and affordable prevention technologies, such as vaccines and microbicides, and encourage the proactive preparation of financial and logistic plans to facilitate rapid access to vaccines when they become available” (para 89).⁶

These international public health, ethical, and legal obligations should compel states to act. These commit-

ments also set a clear mandate for agencies affiliated with the United Nations system, such as the World Health Organization (WHO), the World Bank, and the World Intel-

Technological advances, including vaccines and treatments, against major diseases such as HIV are a global human right and obligation.

lectual Property Organization to address HIV vaccine research, development, and access as an integral part of their ongoing work.

The Way Forward

Governments and international agencies, through their statements and actions, must work to fulfill these commitments related to HIV vaccine research, development, and access. They can do so in four ways.

Increased global research and development on diseases of the poor, including HIV vaccines

Global investment on health research and development related to HIV, tuberculosis, malaria, and other tropical diseases now amounts to less than five percent of all global health research and development, estimated at more than US\$70 billion annually. Many global leaders, including members of the international Commission on Macroeconomics and Health (CMH), have recognized the need to increase investment. As stated in the CMH December 2001 report,

There is also an urgent need for investments in new and improved technologies to fight the killer

diseases. Recent advances in genomics, for example, bring us much closer to the long-sought

Several international partnerships have been created among industry, government, and civil society for targeted HIV vaccine development.

vaccines for malaria and HIV/AIDS, and lifetime protection against [tuberculosis]. The evidence suggests high social returns to investments in research that are far beyond current levels.... The Commission therefore calls for a significant scaling up of financing for global [research and development] on the heavy disease burden of the poor.⁷

As a part of expansion of global research and development on HIV, tuberculosis, malaria, and other diseases endemic to poor countries, there must be a continued expansion of effort to develop HIV vaccines. Given the overlap in research agendas in areas such as immunology, virology, behavioural research, and clinical trial infrastructure and design, funding increases for HIV vaccine research can for the most part be gained in the context of overall increases in AIDS research and other research funding.

Increased support and advocacy for HIV vaccine development partnerships

HIV vaccine development requires partnerships. Today, relatively few companies are engaged in the inten-

sive process of designing and redesigning HIV vaccine constructs. No company wholly owns all its vaccine technologies, and the vaccine development field is largely reliant on a complex web of agreements, contracts, licences, and partnerships. Few companies or government agencies have the resources independently to take advantage of new knowledge emerging from basic science, validate these concepts in animal studies, and then produce clinical-grade vaccines for Phase I safety studies and larger Phase III efficacy studies in people. Even fewer entities are ready and able to leap from small-scale laboratory-based vaccine production into complicated and expensive large-scale production. Research and development of a typical vaccine, from laboratory research to process scale-up and building of manufacturing facilities, can take many years and can cost hundreds of millions of dollars. Much of the world's expertise in practical development and manufacture of new vaccines resides with only a few major private for-profit vaccine companies such as Aventis-Pasteur, Chiron, GlaxoSmithKline, Merck, and Wyeth. These large companies face serious opportunity costs and other economic disincentives in deciding to dedicate their resources, personnel, and facilities to HIV vaccine development.

In response to this challenge, several international partnerships have been created among industry, government, and civil society for targeted HIV vaccine development. From the private sector, approximately 20 pharmaceutical and biotechnology companies are now contributing expertise for the design and manufacture of experimental HIV vaccine products for ongoing or potential

Phase I safety studies. This private-sector effort is almost entirely funded through support from national research programs such as the US National Institutes of Health (NIH) and from the International AIDS Vaccine Initiative (IAVI), which is in turn largely funded by seven governments. From civil society, a range of community and advocacy leaders and not-for-profit agencies have now partnered with HIV vaccine development efforts.

Examples of new HIV vaccine development partnerships include:

- The completion of a Phase III trial of a VaxGen gp120 vaccine by the Thai government, in collaboration with the Bangkok Municipal Authority and Mahidol University, and with support from the WHO, UNAIDS, and US and European government research agencies. The Thai government, with international support, is now planning a new Phase III trial of a canary-pox vector/gp120 combination vaccine at eight district hospitals and 67 health centres in the southern Thai provinces of Rayong and Chon Buri to begin in late 2002.
- The development of a prime-boost DNA fowlpox vector HIV vaccine by the Australian HIV Vaccine Consortium, formed in 2000 as a collaboration of seven academic, community, governmental, and private-sector institutions, and funded by the US NIH.
- The development of a DNA-MVA combination vaccine by an IAVI-funded partnership of researchers at the University of Nairobi, University of Oxford, the Imperial College, two compa-

nies – IDT and Cobra Pharmaceuticals – and government and civil society partners in both Kenya and the UK.

- The development of a VEE vector HIV vaccine based on a South African subtype C virus by an IAVI-funded partnership linking the company AlphaVax with South Africa's University of Cape Town, National Institute of Virology, and Medical Research Council.

These partnerships are proving to be effective in moving new HIV vaccine candidates into clinical testing.

Two major policy factors are key to the successful creation and continuation of vaccine development partnerships:

(1) *Government commitment and funding.* As one example, the success of IAVI in sponsoring five partnerships has depended in large part on growing commitment by five governments (India, Kenya, South Africa, Uganda, and the United Kingdom) as direct partners in vaccine development, and by seven governments (Canada, Denmark, Ireland, Netherlands, Norway, the United Kingdom, and the United States) as funding partners. As a second example, the effort of the US NIH and its sponsored international vaccine development partnerships has benefited from broad US legislative support for biomedical research by both the White House and the US Congress, allowing the US NIH to boost overall AIDS research funding to a projected total of US\$2.8 billion in 2003, including \$422 million for HIV vaccine research and development.⁸

(2) *The contractual basis of vaccine development partnerships.* The involvement of government agencies,

private-industry partners, and, more important, civil society in vaccine development are largely defined by the contracts underlying each partnership. Partnership contracts define licensing arrangements and parameters for sharing of research data and inventions. Partnership contracts also clarify responsibilities for public communication and education about HIV vaccine development. Clear understanding and support of the HIV vaccine effort by each partner (including community leaders, public officials, and public health professionals) underlie a great deal of the potential for any government to support HIV vaccine development. Public understanding, support, and involvement are key to the timely approval, launch, and oversight of planned Phase I vaccine trials. Solid development of strong vaccine-development agreements before Phase I vaccine trials begin will help in ensuring that HIV vaccine research fits within the context of overall human rights priorities for HIV awareness, prevention, treatment, and public health service delivery.

Enhanced regulatory capacity in every country to review, approve, and monitor HIV vaccines

International and national obligations for HIV vaccine development set an imperative for improved regulatory capacity in all countries to evaluate HIV drugs, vaccines, microbicides, and other medical interventions more efficiently. Regulatory capacity is a manifestation of national efforts to meet both human rights to technological advances against disease, alongside human rights to individual freedom, protection from harm, and individual informed consent regarding participation in medical research.

Small HIV vaccine trials have already been conducted in eight middle-income and low-income countries: Brazil, China, Cuba, Haiti, Kenya, Thailand, Trinidad, and Uganda. These countries have recognized the obligation to develop new HIV vaccine technologies in the context of national and local health needs. In these countries, however, the challenge of reviewing, approving, and monitoring HIV vaccine clinical trials has been a strain on regulatory resources, coordination, and technical expertise. As HIV vaccine trials are planned for these and other countries, trials are threatened by delays of months or years simply because of inadequate systems for regulatory review and approval.

Regulatory capacity regarding HIV vaccine clinical trials can be supported through:

- Development of national plans, such as those prepared by Brazil, Thailand, and Uganda, to ensure funding, coordination, and technical training for regulatory review.
- Development of national ethics guidelines and ethics review structures to clarify processes for resolving potential ethical concerns and debates, thus strengthening capacity to plan and monitor clinical trials.
- Facilitation of external technical advice, as has been done by the WHO and UNAIDS, to support countries in ensuring informed national decision-making, streamlined and comprehensive regulatory review, and high standards for clinical research practices and infrastructure.

National plans and national ethics guidelines must still be developed in about half the 12 middle-income and

low-income countries where HIV vaccine trials are planned in the coming decade. Although most countries

The challenge of reviewing, approving, and monitoring HIV vaccine clinical trials has been a strain on regulatory resources, coordination, and technical expertise.

have national laws and structures to require regulatory review of clinical research, many governments could be compelled through law and advocacy to improve funding resources, coordination, and technical expertise for improved regulatory review. More countries or communities could adopt formal mechanisms whereby new clinical trials must be designed in the context of overall community public health and HIV prevention efforts. Finally, international harmonization of biomedical research standards could be supported, so that research methods, protections, and results are comparable and applicable across national borders.

Assurance of global supply of, procurement of, delivery of, and access to vaccines

Global efforts to ensure public health continue to face serious and obvious challenges. Control of HIV infection and AIDS remains elusive in most countries. National and international efforts to ensure global access to other vaccines are also struggling. Major potential success exists for the global elimination of polio and the control of many childhood diseases, but achieving universal access to

newer vaccines such as those against hepatitis B or *Haemophilus influenzae* type B (Hib) has been slow. Although 500 million doses of the extremely safe triple vaccine (introduced more than 25 years ago) for measles, mumps, and rubella (MMR) have now been administered around the world, hundreds of millions of people remain unprotected against these three diseases. In most countries, public awareness, education, and appreciation for vaccination against disease and for HIV prevention remains very low.

This global context of vaccine delivery and overall HIV awareness, prevention, and care is the basis of potential accessibility to future HIV vaccines. Unless systems are improved to support manufacture of, delivery of, and access to all vaccines, future HIV vaccines will have little effect on the epidemic. Legal and policy work on HIV vaccines necessarily embraces promotion of existing vaccines and other HIV prevention and treatment technologies.

IAVI and others have identified several policy directions to accelerate global access to vaccines, including the following:

- negotiation of intellectual property arrangements as part of vaccine development efforts, including mechanisms for sharing new inventions, technologies, and research data;
- support of vaccine purchase and delivery by international initiatives such as the Global Alliance for Vaccines and Immunization, national governments, and private retail markets;
- creation of sales-based tax credits and other national financial incentives to encourage vaccine manufacture and sale;
- elimination of national taxes, tariffs, storage fees, and other trade barriers to vaccines;
- support of global differential pricing for vaccines and essential medicines to maximize global access while preserving private-sector incentives;
- inclusion of HIV vaccines into existing childhood vaccine liability compensation funds and expanding these funds to include adolescent and adult vaccines; and
- development of new vaccine-delivery infrastructures to reach high-risk populations in the context of sound public health strategies.

The success and experience of AIDS treatment advocacy, particularly with regard to access, are relevant to HIV vaccines. HIV treatment advocacy has successfully influenced policy on issues such as public review of research, access to experimental products, and national and international regulatory review and licensure of new products. AIDS treatment advocates are now demonstrating success in using law to compel international and national use and expansion of mechanisms for delivery, demand, and access to essential medicines and health technologies. Current policy work, including legal analysis and advocacy, to make AIDS drugs and other treatments accessible to the world's poorest countries, while allowing companies to recoup their costs and satisfy their shareholders, will clearly pave the way for future pricing and distribution of vaccines and microbicides.

Conclusion

The process of researching, developing, testing, and ensuring access to

HIV vaccines will be a long one. Legal research and analysis have a crucial role to play in informing HIV vaccine advocacy. Advocacy now for HIV vaccine research, development, and access in the context of broader global health will speed the effort. Advocacy now for delivery and access to all vaccines in the context of global public health efforts can increase the likelihood that HIV vaccines, once developed, are accessible to those who need them.

– Sam Avrett and Chris Collins

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⁴ United Nations. Office of the High Commissioner for Human Rights. Declaration on the Use of Scientific and Technological Progress in the Interests of Peace and for the Benefit of Mankind (www.unhcrch/html/menu3/b/70.htm).

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Further Reading

For more complete discussion and documentation of the issues raised in this article, see Avrett S. *HIV Vaccines for Developing Countries: Advancing Research and Access – Background Paper*. Montréal: Canadian HIV/AIDS Legal Network, 2002 (www.aidslaw.ca/Maincontent/issues/vaccines.htm).

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HIV Vaccines in Canada: Legal and Ethical Issues – An Overview

In July 2002 the Legal Network released an overview paper on legal and ethical issues related to an HIV vaccine in Canada.¹ The paper, which is based on a more detailed report prepared in collaboration with the Centre for Bioethics of the Clinical Research Institute of Montréal,² calls for the establishment of a Canadian HIV Vaccine Plan.

Why an Overview on Vaccine-Related Legal and Ethical Issues?

Current prevention efforts – including education about safer sex and provision of condoms, making sterile injection equipment available to people who inject drugs, peer counselling, providing HIV treatments to reduce mother-to-child transmission, and making blood supplies safer – have slowed the spread of HIV but have not stopped it. The best long-term hope for controlling AIDS is the development and widespread distribution of a safe, effective, and affordable preventive vaccine.

Research aimed at developing a preventive HIV vaccine is accelerating. Over the coming decade, Canadians will likely be involved in vaccine clinical trials both here and abroad. In fact, HIV vaccine trials in Canada have already begun. The existing trials, the likelihood of further trials, and the potential impact of a preventive HIV vaccine on HIV prevention programs all raise a number of legal and ethical issues that need to be addressed.

About the Overview

The overview is designed to provide a summary of the major legal and ethical issues related to the development and delivery of an HIV vaccine in Canada. The main audience is people

working in community-based HIV/AIDS organizations. Secondary audiences are researchers working on HIV vaccines and government officials working in HIV/AIDS.

The overview deals with HIV vaccines in Canada, but many of the issues it raises also apply to other developed countries, and some of them will resonate with people working on vaccine issues in developing countries. It focuses primarily on HIV preventive vaccines; however, the issues with respect to therapeutic vaccines are very similar.

What Does the Overview Contain?

Section 1.0 – The **Introduction** provides explanatory information on vaccines and clinical trials, a brief summary of the current state of HIV vaccine research globally and in Canada, and a description of the AIDS VAX[®] trial now underway in Canada and other countries.

Section 2.0 – **Investing in HIV Vaccine Development and Delivery** discusses the need for Canada to invest more resources in HIV vaccines and to develop a Canadian HIV Vaccine Plan.

Section 3.0 – **HIV Vaccine Clinical Trials** examines legal and ethical issues that arise during the conduct of large-scale HIV vaccine efficacy trials on humans. The subsection on “Working with Target

Communities” describes how governments, trial organizers, and communities can work together to ensure that the trials are of the highest quality. The subsection on “Recruitment” discusses which communities should participate in HIV vaccine trials and what compensation should be offered to participants for taking part in the trial. The subsection on “The Informed-Consent Process” examines measures that can be used to ensure that consent is truly informed, and describes what information should be disclosed as part of the process of obtaining consent. The subsection on “Obligations to Participants during and after the Trial” examines four specific obligations – the provision of preventive counselling, the provision of care and treatment to participants who become HIV-positive during the trial, the provision of compensation to any participants who suffer a vaccine-induced injury, and the dissemination of information on the results of the trial.

Section 4.0 – **HIV Vaccine Delivery** examines legal and ethical issues related to the eventual delivery of an HIV vaccine, and discusses the need for a formal HIV vaccine delivery plan.

What Does the Overview Conclude?

The most significant conclusion of the overview is that Canada needs a formal HIV vaccine plan. The overview calls on Health Canada to coordinate, and provide funding for, a Canadian HIV Vaccine Plan by 1 October 2003. The Plan should address both the development of vaccines and the

delivery of an eventual vaccine. The Plan should be developed in consultation with the provinces and territories, HIV/AIDS community organizations, HIV researchers, and other stakeholders.

The overview also concludes:

- that Canada should substantially increase its investment in HIV vaccine research and development in Canada and internationally;
- that all populations with significant HIV infection rates should be involved in human testing of candidate HIV vaccines;
- that communities should be involved in the design and implementation of HIV vaccine trials being conducted in their midst;
- that consent obtained for participation in an HIV vaccine trial should be truly informed, meaning that all reasonable steps must

be taken to ensure that potential participants understand the nature, benefits, and risks of taking part in a trial;

- that trial organizers must provide high-quality preventive counselling to all participants in an HIV vaccine trial;
- that trial organizers must ensure that high-quality care and treatment is provided to participants who become HIV-infected during the course of the trial;
- that the federal government should establish a no-fault vaccine-related injury-insurance program covering all experimental and licensed vaccines (both HIV-related and other); and
- that trial organizers should work with insurance companies to minimize the risks of discrimination for participants in an HIV vaccine trial.

– David Garmaise

Copies of the overview, an accompanying series of info sheets, and the longer background paper can be retrieved on the website of the Canadian HIV/AIDS Legal Network at www.aidslaw.ca/Maincontent/issues/vaccines.htm. Additional resources are listed in the overview and info sheet #8.

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¹ D Garmaise. *HIV Vaccines in Canada: Legal and Ethical Issues. An Overview*. Montréal: Canadian HIV/AIDS Legal Network, 2002 (available at www.aidslaw.ca/Maincontent/issues/vaccines.htm).

² D Thompson. *HIV/AIDS and Vaccines: Legal and Ethical Issues: A Background Paper*. Montréal: Canadian HIV/AIDS Legal Network, 2002 (available at www.aidslaw.ca/Maincontent/issues/vaccines.htm).

Drug Policy in Canada – The Way Forward

cont'd from page 1

health and social consequences of injection drug use are severe and include bloodborne disease transmission, death from overdose, unemployment, incarceration, violence, and crime.¹ According to recent estimates, approximately 125,000 Canadians inject drugs, and 30 percent of these individuals reside in Toronto, Montréal, or Vancouver.² From a population-health perspective, there is a complex and disturbing picture of poor health among people who inject drugs. Dense drug-using networks, mental health issues, homelessness,

social marginalization, poverty, and unemployment all contribute to drug users' ability or inability to navigate care and support systems and reduce the behaviours that put them at risk.³ The health of people who inject drugs is further complicated by discrimination experienced in health-care settings, and by avoidance and erratic use of primary-care services – patterns that have been documented since the 1960s.⁴

As early as 1993, Canadian researchers warned that an explosive HIV epidemic among injection drug

users was looming.⁵ Despite calls for immediate and serious attention to this matter, policymakers and health authorities throughout Canada failed to take action to offset the impending harms associated with injection drug use.⁶ As a result, injection-related HIV and hepatitis C (HCV) outbreaks and overdose deaths have reached epidemic proportions in many municipalities over the last 10 years.⁷ In Canada, people who inject drugs recently accounted for 26 percent and 63 percent of reported HIV and HCV positive tests respectively.⁸ The current

harms and costs associated with injection drug use continue to pose enormous challenges for health and enforcement authorities as well as for policymakers.

As early as 1993, Canadian researchers warned that an explosive HIV epidemic among injection drug users was looming.

Drug Legislation and Policy in Canada: A Hundred Years of Prohibition

Canada's laws and policies pertaining to illicit drugs are rooted in a long history of prohibition. Legislation related to the control of drugs was first enacted in Canada almost a hundred years ago. In 1908 the *Opium Act* became Canada's first prohibitionist drug policy, and in 1929 the *Opium and Drug Act* was created to regulate and control a greater variety of drugs.⁹ This Act, and the *Narcotic Control Act* and the *Food and Drug Act* that followed it, served as Canada's primary drug policy instruments until 1997, when the *Controlled Drugs and Substances Act* was created.¹⁰ With each new legislative scheme, the list of banned or "illicit" substances increased, as did the powers afforded to federal enforcement authorities working to address the "drug problem." As Riley notes, "the Controlled Drugs and Substances Act...is soundly prohibitionist and rather than retreating from the drug war rhetoric of the past it expands the net of prohibition further still."¹¹ In keeping with the tradition, the majority of amendments to the

Controlled Drugs and Substances Act have focused on reducing supply rather than demand.

A problematic approach to addiction

Emanating from Canada's prohibitionist laws is a dominant and highly problematic approach to addiction. Implicit in this approach are the notions that any amount of illicit drug use is unacceptable and that abstinence is the only worthy treatment goal. At the level of practice, this leads to discrimination against people who continue to use inject drugs, coercion of those seeking care into abstinence-based treatments, and the denial of essential and basic health care to those who desperately need it. There is, however, an established body of literature demonstrating that addiction is a chronic and relapsing condition that is shaped by a multitude of behavioural and social-contextual characteristics.¹² There is also considerable evidence indicating that while abstinence is one worthwhile goal of drug treatment, for many it is unattainable for long periods of time or may only be sustained for short periods.¹³ For those unable to maintain abstinence, there are a number of alternative treatments that have been shown to promote health and allow individuals to function fully in society.¹⁴ In any case, a failure to participate in drug treatment does not justify discrimination and coercion, and should in no way preclude the provision of basic health care.

Canada's Drug Strategy

From 1987 to 1992, in response to the growing acknowledgment of the limitations of past enforcement- and education-based prevention approaches, the federal government

provided approximately \$210 million in funding to a newly created National Drug Strategy.¹⁵ This initiative was designed to promote a balanced approach to dealing with the demand and supply of illicit drugs. A substantial portion of the funding was devoted to education and prevention for school-aged youth. In 1992, the federal government merged the National Drug Strategy with the National Strategy to Reduce Impaired Driving. The new policy was named Canada's Drug Strategy. With \$270 million in funding over five years, the Strategy aimed to coordinate prevention, treatment, rehabilitation, research, enforcement,

There is considerable evidence indicating that while abstinence is one worthwhile goal of drug treatment, for many it is unattainable for long periods of time or may only be sustained for short periods.

and control efforts of various federal departments.¹⁶ With no measurable outcomes reported, the impact of Canada's drug policy during this period is unclear. However, despite an emphasis on school-based prevention programming, the Canadian Centre on Substance Abuse reported that illicit drug use among youth actually increased during this period.¹⁷

Canada's Drug Strategy was renewed in 1998 with a primary goal of reducing "the harm associated with alcohol and other drugs to families and communities."¹⁸ The policy

states that because “substance abuse is primarily a health issue rather than an enforcement issue, harm reduction is considered to be a realistic, pragmatic, and humane approach as opposed to attempting solely to reduce the use of drugs.”¹⁹ The overarching goal and supporting objectives of the Strategy are to be met through a range of coordinated and interdependent components, including research, prevention, treatment, legislation, enforcement, and international cooperation. The concept of prevention in the Strategy is considerably broader than anything articulated in previous policies. Embracing a population-health framework, the Strategy aims to address not only substance use itself, but also broad determinants of health and injection drug use such as marginalization, disparities in education, income, and social and economic status. As in the past, Health Canada provides leadership for and coordination of the Strategy and all other activities related to illicit drugs currently undertaken by 11 different federal departments.²⁰

Problems with Canada’s Approach

While countries such as Australia, the Netherlands, Germany, and Switzerland have made significant progress in reducing drug-related harms, all indications suggest that harm related to injection drug use has increased in Canada.²¹ For example, HIV and HCV infection among people who inject drugs has reached epidemic proportions in Canada in recent years, and although incidence rates have decreased slightly, rates remain unacceptably high by North American standards. Reviews of Canada’s drug laws and policies indi-

cate numerous problems with current approaches to reduction of demand.²² An overemphasis on prohibitionist laws and abstinence-based approaches to drug treatment, as well as an absence of adequate funding, leadership, and coordination, have left Canada behind other countries in the effort to reduce harms related to injection drug use.

Although Canada’s Drug Strategy was renewed in 1998 and given priority in the federal Liberal “Red Book” (the governing party’s electoral platform), reviews have suggested that the Strategy “was renewed in principle but not in funding.”²³ The primary role of the Office of Canada’s Drug Strategy is to assist with the organization and administration of various committees focused on illicit drug issues. However, the Office does not have any power to directly manage or reallocate the nearly \$500 million spent on illicit drug issues by federal departments, nor can it speak on behalf of the departments working to reduce supply of or demand for illicit drugs.²⁴ Even with adequate funding or administrative powers for the Office of Canada’s Drug Strategy, it is unclear how the Strategy would unfold, as it essentially remains a “strategy without a strategy” – a vague statement of intent that lacks a clear description of activities, targets, and performance outcomes. Given that many health and enforcement initiatives are administered by the provinces and territories, the Strategy also lacks much-needed provincial and territorial “buy-in” and a clear statement of related responsibilities.

Lack of national data

A further problem relates to the fact that there is a lack of national data and information related to illicit drug

use. In the absence of such data, federal departments have been unable to provide meaningful performance reports of any kind. Indeed, it

Reviews of Canada’s drug laws and policies indicate numerous problems with current approaches to reduction of demand.

remains unclear whether the nearly \$500 million spent annually by federal departments has been well used. At present, the federal government cannot possibly evaluate Canada’s progress toward reducing drug-related harms. Ironically, the *Controlled Drugs and Substances Act* was initially introduced as a mere “house-keeping bill” until a further review of Canada’s drug laws and policies could be undertaken. Five years later, these reviews have only recently begun with a federal Auditor General’s review, the formation of a House of Commons Committee on the use of Non-medical Drugs, and the creation of a Special Senate Committee on Illegal Drugs. Despite good intentions, these reviews will be considerably constrained by a lack of data and information pertaining to illicit drugs.

Overemphasis on prohibition

The 2001 Auditor General’s report stated that 95 percent of the federal government’s expenditures related to illicit drugs was used for supply-reduction initiatives.²⁵ The Correctional Service of Canada and the RCMP account for approximately 33 percent and 36 percent of expenditures respectively.²⁶ Most of the expenses incurred by the

Correctional Service of Canada can be attributed to incarceration. At present, approximately 17 percent of offenders in federal prisons are serving sentences for offences under the *Controlled Drugs and Substances Act*.²⁷

A recent study found police intervention to be a barrier to sterile-needle acquisition.

By far the greatest part of RCMP expenditures on illicit-drug issues are related to complex and resource-intensive operations aimed at reducing organized crime and the supply of illicit drugs.²⁸ The available evidence suggests that supply-reduction activities such as those undertaken by the RCMP have little if any impact on illicit drug supplies and community drug-use patterns. For example, one study from Australia found no evidence that heroin seizures affected the price, purity, or perceived availability of heroin.²⁹ Similarly, analyses conducted by the United Nations Office for Drug Control and Crime Prevention suggest that a maximum of five percent of the global illegal drug flow is seized by law enforcement.³⁰ For this reason, heroin purity has increased and prices have decreased since the late 1980s,³¹ despite massive expenditures on drug interdiction efforts.³²

Several experts have presented compelling arguments suggesting that the current emphasis on prohibitionist drug laws, and the related practices of enforcement and incarceration, have made the problem of injection drug use and HIV/AIDS worse.³³ It has been well established that a prohibitionist response produces a black market, which results

in increased crime, violence, corruption, and harm to individuals who use drugs and to the greater society. The impact of enforcement approaches and incarceration on HIV/AIDS treatment and prevention has been demonstrated empirically. For example, incarceration has been found to be an independent predictor of HIV infection and interruption of antiretroviral treatment.³⁴ In terms of prevention, a recent study found police intervention to be a barrier to sterile-needle acquisition – a disturbing finding, given that difficulty accessing needles has been found to be independently associated with syringe sharing.³⁵

Lack of clear direction on harm reduction and social determinants

A further problem relates to the scope and effectiveness of activities currently undertaken to address harms related to injection drug use. Current demand-reduction initiatives have had a limited impact on injection drug-related harms and the associated causes. In the absence of clearly stated best practices, those who accept injection drug use as a public health problem remain confused as to how to operationalize the Strategy's goal of reducing drug-related harm. The Strategy acknowledges that it is the role of federal authorities to pilot new prevention and treatment approaches and articulate best practices. However, while innovative approaches such as safe injection facilities, heroin maintenance, and low-threshold methadone have been successfully employed in Europe and Australia, such measures have not been evaluated in Canada.

According to the Strategy, one aim of Canada's drug policy is to address the broad determinants of illicit drug use and the associated

harms. However, it appears there has been little if any coordinated effort to address key determinants of injection drug use such as poverty, homelessness, childhood abuse, and cultural dislocation. Any meaningful change in drug policy will necessarily require simultaneous changes in social policy.³⁶ This in turn will require high levels of cooperation and coordination among federal departments. Until such action is taken, Canada's approach to illicit drug use will remain a "band-aid" approach.

While innovative approaches such as safe injection facilities, heroin maintenance, and low-threshold methadone have been successfully employed in Europe and Australia, such measures have not been evaluated in Canada.

The Way Forward

It is clear that considerable changes in Canadian policy and law are needed to significantly reduce the harms associated with injection drug use. There is currently a huge imbalance in federal efforts, with 95 percent of federal expenditures related to illicit drug use devoted to supply-control strategies. These approaches have repeatedly been found to be ineffective at best. Given the ongoing rates of HIV and HCV infection among injection drug users, the federal government must recognize that it is no longer acceptable to invest a majority of its resources in supply-control strategies. There is an obvious need

to explore a redistribution of resources and alternative legislative frameworks. This will require a fundamental and courageous shift away from a long and well-established tradition of control and punishment.

First and foremost, the federal government must acknowledge the limitations of the current prohibitionist approach, move legislatively to decriminalize drug use, and promote public health approaches to dealing with problems of illicit drug use. In taking this bold step, Canada would be following the lead of countries like Germany and Switzerland that have given greater priority to problems associated with illicit drug use and, as a result, experienced significant population-level reductions in drug-related illnesses and deaths, as well as in health, social, and enforcement costs.³⁷

Harm reduction and beyond

Greater attention to the public health dimensions of illicit drug use will require a parallel acknowledgment of the limitations of a purely abstinence-based approach to drug treatment and a willingness to expand the service continuum to explicitly include harm-reduction programming. This continuum should include a range of low-threshold services, which have been critical to the success of drug policies in Europe.³⁸ As well, in the face of ongoing epidemics of HIV, HCV, and overdoses among people who inject drugs, there is an urgent need for federally funded pilots of programs such as safe injection facilities, heroin maintenance, and prison-based needle exchanges in Canada. Beyond this, much investment and coordination are needed to address the complex needs of current injection drug users as well as the factors that lead to

injection drug use in the first place. In order to move beyond mere “band-aid” approaches, drug policy must necessarily encompass social policy in the broadest sense.

Clear direction, specific targets

Collectively, these changes will require increased funding, leadership, and coordination. A more effective national strategy will be needed, one that provides clear direction to all levels of government and other stakeholders, and incorporates specific performance targets. This strategy

will require institutional arrangements that promote the accomplishment of its targets, and direction for programming that is pragmatic and effective. It should also encourage innovation and fund research to inform future decisions and respond more effectively to emerging trends.

Conclusion

Injection drug use continues to be associated with an array of severe adverse health and social consequences in Canada. Rates of HIV and HCV infection and other

Further Reading

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injection-related harms remain unacceptably high. Very much related to these ongoing problems is Canada's national drug policy. Despite calls for a balanced approach focused on reducing drug-related harm, Canada's method of dealing with problems of illicit drug use has remained prohibitionist and abstinence-based in nature. Almost all federal funding is devoted to supply-reduction initiatives, while innovative demand-reduction and harm-reduction approaches remain unsupported or untested.

At the heart of these problems is a lack of funding, leadership, and coordination. Considerable changes in policy and law are needed to significantly reduce the harms associated with injection drug use in Canada. These include developing a comprehensive and integrated strategy, exploring alternative legal frameworks, piloting innovative approaches to reducing injection-related harms, and investing in broad social policies that address the determinants of injection drug use.

— Thomas Kerr and Warren O'Briain

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CANADIAN NEWS

This section provides brief reports of developments in legislation, policy, and advocacy related to HIV/AIDS in Canada. (Cases before the courts or human rights tribunals in Canada are covered in the section on HIV in the Courts – Canada.) The coverage is based on information provided by Canadian correspondents or supplied by scans of Canadian media. Regular correspondents are listed on page 2; information about occasional correspondents is provided with their contribution. Address correspondence to David Garmaise, the editor of Canadian News, at dgarmaise@rogers.com.

New Immigration Law Comes into Effect As Regulations Finalized

The new regulations make it easier for same-sex partners to immigrate to Canada. However, the government has rejected suggestions to change the way it determines whether potential immigrants living with HIV/AIDS or other health conditions would place excessive demands on Canada's health and social services.

Canada's new *Immigration and Refugee Protection Act* came into force on 28 June 2002, now that the regulations under the Act have been finalized.¹ The regulations set out the details of how the Act is to be implemented, and govern issues such as health-based exclusions and the treatment of same-sex couples. Community organizations participated in public consultations on the regulations with the House of Commons Standing Committee on Citizenship and Immigration in February and March 2002.²

For the purposes of determining whether a potential immigrant would place excessive demands on Canada's health and social systems, the regulations allow costs to be projected over five years for most conditions, but up to ten years for chronic illnesses. This provision is being maintained despite concerns voiced by community organizations (and backed by the Standing Committee) that medical costs projected beyond five years would likely be inaccurate, given the pace of medical advances. In addition, contrary to the recommendations of the Canadian HIV/AIDS Legal Network, only potential demands (and not potential contributions) will be taken into account when determining whether demand is excessive under the new regulations.

The government did adopt one of the recommendations of community organizations – ie, that cohabitation should be only one of the factors

considered when assessing the genuineness of common-law relationships (including same-sex relationships) for the purpose of determining whether potential immigrants are eligible to enter Canada in the family class category. The government has created a new category, "conjugal partners," in addition to the "common law partner" category already included in the Act. Applicants who have been in a bona fide conjugal relationship with a Canadian sponsor for at least one year need not cohabit in order to be included in the family class; and like common-law partners and other members of the family class, they are exempted from the "excessive demand" considerations.

– Alana Klein

Alana Klein is a recent graduate of the Faculty of Law of McGill University and the author of *HIV/AIDS and Immigration: Final Report* (Montréal: Canadian HIV/AIDS Legal Network, 2001).

¹ Both the Act and the Regulations are available on to the website of Citizenship and Immigration Canada (www.cic.gc.ca – under "Immigration and Refugee Protection Act")

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Government Delays Release of Medical Marijuana Supply

The federal government's initiative to make marijuana available for medical use continues to run into problems and delays. In a recent development, the first crop produced by the government's designated grower turned out to be too impure to use. The delays have led to the launch of a lawsuit against the federal government.

Despite promises made by former Health Minister Allan Rock in December 2001 that a safe, secure supply would be available quickly, the federal government is far from ready to provide marijuana for medical use. Health Minister Anne McLellan has announced that the first crop produced by the official grower is so impure that Health Canada will not distribute it.

People are legally permitted to possess marijuana for medical reasons, but have little or no ability to acquire it legally.

The initiative on the part of Health Canada to produce and distribute marijuana was undertaken as part of new regulations that took effect on 30 July 2001 (the Marijuana Medical Access Regulations). These regulations provide a framework for Canadians to apply for and receive authorization by the federal government to use marijuana for specified medical reasons. The regulations state that marijuana can be acquired by those individuals in one of three ways: by growing their own, by designating a grower, or by receiving it from the official grower designated by the federal government.

Health Canada had requested research-quality seeds from US drug-enforcement authorities but was refused, and as a result was forced to cultivate seeds confiscated by police, resulting in a poor initial crop. The government's designated grower, Prairie Plant Systems, has been testing the 2000 plants produced in late 2001 in an attempt to develop a standardized seed to be used in a second crop. The government says that the delay in providing a safe, secure supply of medical marijuana will likely last until at least August 2002. However, there have been reports that the crop will then have to undergo clinical trials to establish its therapeutic benefits, which may mean that it will take years before the marijuana is available to consumers.

Development of a secure supply of marijuana for medical reasons is vitally important because the majority of individuals who have been authorized to possess marijuana for medical use have either not applied for, or not been granted, permission to grow their own supply or to designate a grower. This has created an impossible situation for people who are legally permitted to possess marijuana, but who have little or no ability to acquire it legally.

A civil action has been launched against the federal government over its failure to attend to the needs of people who use marijuana for medical

reasons. The lawsuit has been brought by seven seriously ill Canadians, only some of whom have been able to obtain authorization to possess marijuana for medical reasons. In the lawsuit, the applicants argue that in July 2000 the Ontario Court of Appeal gave the federal government one year to construct a meaningful and effective regulatory regime providing access to medical marijuana, and that the government has failed to do this. The lawsuit identifies three key problems with the regulations:

- The regulations are an obstacle course that deters and prevents most people from obtaining authorization to possess medical marijuana.
- Doctors have been forced to play the role of gatekeeper for the application process, a role they have determined they do not want to play.¹
- The regulations do not adequately address the issue of supply and access.

The applicants are asking that the regulations be struck down as unconstitutional, and that the government be forced to provide access to the marijuana cultivated by Prairie Plant Systems.

In related developments:

- A poll commissioned by Health Canada in February 2002 found

that 85 percent of Canadians support the use of medical marijuana. The poll also found that most Canadians do not understand the regulations governing medical marijuana. Most of the people polled believed that individuals are allowed to possess marijuana for medical use without having to apply for permission to the federal government.²

- Buyers clubs are being established in several cities to help people obtain marijuana for medical use. For more information, visit the website of the Cannabis Buyers Club of Canada (www.cbc-canada.com).
- A comprehensive website has been set up by two individuals in British Columbia to provide

information about the process of applying for medical marijuana. The site includes a discussion board where people can exchange information on their experiences with medical marijuana and the application process (www.medicalmarihuana.ca).

- The Senate Special Committee on Illegal Drugs recently released a discussion paper that concluded that there is no evidence to support the notion that use of marijuana leads to the use of harder drugs.³ The paper also found that public policies, whether prohibitionist or liberal, have little impact on levels and patterns of use.⁴
- Keith Martin, a Canadian Alliance Member of Parliament,

introduced a private members bill to decriminalize the possession of small amounts of marijuana (Bill C-344),⁵ but the Liberal government used parliamentary procedures to block the bill from coming up for debate.

— Liz Scanlon

¹ D Garmaise. Physicians dislike new medical marijuana regulations. *Canadian HIV/AIDS Policy & Law Review* 2002; 6(3): 34.

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⁵ An Act to Amend the Contraventions Act and the Controlled Drugs and Substances Act (Marihuana) (available on the website of the Parliament of Canada at www.parl.gc.ca by clicking on "Bills," "House of Commons: Other Bills," and "Bill C-344").

Report Recommends that HIV Become Reportable in BC

The Provincial Health Officer has recommended that HIV be nominally reportable and that a well-funded partner notification system be established. However, he also recommended that people be allowed to choose non-nominal HIV testing.

HIV may soon be nominally reportable in British Columbia. Dr Perry Kendall, the Provincial Health Officer, has released a report recommending that HIV be added to the list of reportable conditions under law.¹ British Columbia is currently the only province in Canada that does not require some form of HIV reporting. Dr Kendall also recommended that:

- an evaluation be conducted on the impact of reportability;
- individuals be given the choice to be tested non-nominally; and
- a partner-notification system be

developed and adequately resourced in order to ensure that appropriate notification practices are followed.

The report recommends that HIV be taken off the list of reportable conditions if the evaluation demonstrates that the net impact of reportability is negative, and that the problems cannot be remedied. This recommendation appears to be in response to community concerns. The community fears that the impact of enforcing reportability will be detrimental to individuals testing positive for

HIV/AIDS, and to the public in general, because of potential breaches of confidentiality by health-care professionals concerning the identity of HIV-positive individuals; because of the stigmatization experienced by people living with HIV/AIDS; and because people may not come forward for testing if they are concerned about the potential repercussions.

Technically, people in British Columbia already have the option of being tested non-nominally, but frequently they are not informed of this choice. The report recommends that individuals be informed of the option

of non-nominal testing and counseled on the consequences of both nominal and non-nominal testing.

The greatest impact of the recommendations would be the introduction of a partner-notification system. Currently, no formal system of partner notification exists in British Columbia. The report says that significant staffing resources will be needed to do partner notification properly. Given the current environment of severe provincial government cutbacks to the health sector, there is a risk that a partner-notification system may be instituted without adequate resources.

Until recently, HIV was reportable in all provinces except British Columbia and Québec. HIV became reportable in Québec in April 2002. Although the name of the person testing positive will not be included on reports filed in Québec, the reports will contain information on the age, sex, place of residence, and ethnic origin of the individual.

— Tarel Quandt

¹ PRW Kendall. *Provincial Health Officer's Report on HIV Reportability*. British Columbia Ministry of Health Planning, February 2002. Available via the website of the Ministry of Health Planning at www.gov.bc.ca/health-planning by clicking on "Office of the Provincial Health Officer" and "Other Reports."

Female Injection Drug Users in Vancouver Face Higher Risks of HIV Infection

A new study presents some disturbing information about HIV infection among injection drug users in Vancouver's Downtown Eastside. Women, and especially Aboriginal women, are disproportionately affected.

The rate of HIV incidence is about 40 percent higher for female than for male injection drug users in the Downtown Eastside of Vancouver, according to a study headed by Patricia M Spittal that was published in April 2002 in the *Canadian Medical Association Journal*.¹ The study also revealed that over 40 percent of female injection drug users are Aboriginal. These findings are a clear indication that female injection drug users, particularly Aboriginal female users, are at much higher risk for HIV infection.

The researchers concluded that the much higher HIV incidence rate among female injection drug users is largely due to the unequal relationship between the sexes. Such power imbalances make women more vulnerable to infection. One manifestation of power imbalance is non-consensual sex. In the study, 69 percent of the women reported having non-consensual sex, compared with only 18 percent of the men. The researchers also concluded that the high number of Aboriginal women among the HIV-infected injection drug users is likely due to a convergence of vulnerabilities – ie, that being both a woman and an Aboriginal person reinforced their vulnerability to HIV infection.

The study provides additional

information that could be of vital importance in developing targeted prevention programs for injection drug users at risk for HIV infection. The study found that women who participated in the survey were found to be more likely to get HIV when they required assistance with injections or had unsafe sex with a regular partner. Among male participants, the study found that the likelihood of becoming infected with HIV increased when they borrowed needles. The fact that women have different risk factors than men led the authors to conclude (a) that sex-specific prevention initiatives need to be developed immediately, and (b) that more research is required into the processes and factors that cause drug-related harm among women.

Women who inject drugs are affected by a complex web of sociodemographic factors that place them at higher risk for HIV infection. Cultural and gender-specific needs must be taken into account when seeking solutions and developing programs to address the needs of female injection drug users.

— Kim Thomas

¹ PM Spittal et al. Risk factors for elevated HIV incidence rates among female injection drug users in Vancouver. *Canadian Medical Association Journal* 2002; 166(7): 894-899.

Business Group Drops Opposition to Drug Users' Health Centre

A legal intervention by the Vancouver Area Network of Drug Users has forced the Community Alliance to abandon a petition against a health contact centre in Vancouver's Downtown Eastside.

A street-level health contact centre for users of illegal drugs in Vancouver's Downtown Eastside is free to continue operations. A court challenge against the facility has been abandoned as a result of a legal intervention by drug users.

The centre opened in December 2001, following extensive public hearings. The Community Alliance, a coalition of merchant groups and property owners, launched a legal petition against the centre in October 2001, claiming that city bylaws were violated when a permit for the facility was granted. The case was heard by the BC Supreme Court. The Vancouver Area Network of Drug Users (VANDU) applied to the court for the right to defend the centre. Pivot Legal Society, a non-profit organization dedicated to legal advocacy on behalf of drug users and sex trade workers, represented VANDU at the hearing.

Before the bylaw issue could be addressed, however, the justice had to determine whether VANDU, the largest drug-user organization in Canada, had a right to participate in the proceeding. Justice Edwards found that VANDU was uniquely qualified to represent the drug users, and that the Community Alliance had violated the Supreme Court Rules when it failed to give notice of its petition to VANDU.

The Community Alliance had planned to argue that the zoning bylaws were violated when the health contact centre was approved in an area zoned for "retail or similar use." However, the Alliance was not prepared to engage in a debate about the need for the services provided by the centre, an issue they could not avoid once VANDU was accepted as a party to the proceeding. In April 2002, the Alliance announced that the lawsuit would be too costly to pursue, and that it was dropping its petition.

John Richardson, a lawyer with Pivot and counsel for VANDU, commented that the Community Alliance's legal argument attempted to use a narrow zoning provision to avoid addressing larger social issues. "The Alliance petition tried to use the courts to do an end run around a very extensive public consultation process that resulted in near-unanimous support for the health centre," he said. "The centre is desperately needed to address an ongoing public health emergency in the largest illegal street drug scene in North America. Attempting to close such a facility because it is not a 'retail use' is an example of how court processes can be abused when legal issues are taken out of their proper social context." Richardson's legal response focused on the consequences the

closing of the centre would have for residents of the area, and argued that the permit authorities had the power, under the Official Community Development Plan, to relax zoning requirements when strict adherence would result in undue hardship.

The health contact centre aims to facilitate access to health services for the approximately 5000 injection drug users and other marginalized residents of Vancouver's Downtown Eastside. Located near the corner of East Hastings and Main in the heart of Canada's largest illegal-drug scene and poorest neighbourhood, the centre offers basic health-care services tailored to drug users. It represents the first part of the Vancouver Agreement's five-part strategy to provide more effective health and community services for people living with addictions. The centre follows a low-threshold access model focused on reducing the harm associated with injection drug use, such as the spread of bloodborne diseases, overdose deaths, and secondary illnesses. Users of illegal drugs in the Downtown Eastside suffer the highest rates of HIV/AIDS and hepatitis C in Canada, a situation that prompted the Vancouver Coastal Health Authority to declare a public health emergency in 1998 – a state of emergency that has not yet been lifted.

– Cheryl Rossi and Katrina Pacey

Cheryl Rossi is a freelance journalist and can be reached at cherylrossi@rocketmail.com. Katrina Pacey is a law student at the University of British Columbia and can be reached at kpacey@bcifv.org.

Justice Reduced: Legal Aid Slashed in BC

Serious cuts to legal aid services in British Columbia will have a devastating impact on people with HIV/AIDS and the organizations that serve them.

The government of British Columbia is dismantling legal aid services by slashing funding and restricting eligible services. In January 2002, the government announced that the legal aid budget will be cut by almost 39 percent over the next three years. By September 2002, all 60 regional legal aid offices will be closed and the number of staff lawyers, paralegals, and assistants will be reduced by 74 percent. Poverty-law services will be eliminated; family law services will be cut by 65 percent. Limited coverage will be maintained for representation on some criminal law, mental health, and immigration matters.

Because the cuts are so far-reaching, the government has had to introduce amendments to the *Legal Services Act*. Traditionally, legal aid coverage was mandatory for persons facing a legal problem that threatened their physical or mental safety or health; their ability to feed, clothe, and shelter themselves; or their livelihood. The proposed amendments will provide legal aid coverage in these situations only if funding is available.

The cuts will be disastrous for those living on low incomes or in poverty, including many people with HIV/AIDS. Eliminating poverty-law services will remove an essential resource accessed by people with HIV/AIDS and the community groups that serve them. People with HIV/AIDS, especially those in rural

areas, have relied on legal aid lawyers and paralegals for representation before administrative tribunals for employment insurance benefits and for needs associated with welfare (such as income, shelter, and health care). Cases where long-term disability benefits have been denied have been routinely referred to legal aid lawyers because of the complexity and severity of the cases. Without staff lawyers, people with HIV/AIDS will be less able to protect their rights. As well, the resources of community groups will be further stretched as they are forced to advocate on issues traditionally addressed by legal aid experts.

Community groups, the Canadian Bar Association, and the Law Society of British Columbia have strongly opposed the government's cuts. These organizations have argued that the current legal aid system should be retained because it has promoted the protection of the rights of poor and disadvantaged British Columbians (who are disproportionately female). They also declared that the cuts could have been avoided if the government had fulfilled its commitment to apply the 7.5 percent tax on lawyers' services to legal aid funding. Instead, the government has diverted these funds to other programs.

At the end of May, the Law Society held a Special General Meeting to discuss the cuts. More

than two-thirds of the over 1000 lawyers present passed a motion expressing non-confidence in Geoff Plant, the Attorney General of British Columbia, and criticizing him for reducing access to justice for poor people.¹ Although the Law Society has no authority to remove the Attorney General from his position, the non-confidence vote nevertheless sends a strong message to the government.

— Tarel Quandt

¹ Available on the website of the Law Society of British Columbia (www.lsbcc.org).

Ontario Set to Introduce New Privacy Bill

The Ontario government's proposed new legislation is an improvement over previous attempts, but there are still problems.

The Ontario government is planning to introduce new privacy legislation. The *Privacy of Personal Information Act, 2002* (PPIA)¹ is the latest in a series of attempts by the government to create legislation that covers the use of personal information (including health information) by the private sector. The last effort (Bill 159, the *Personal Health Information Privacy Act*) was roundly criticized by interested parties.

The government will likely move fairly quickly to introduce the legislation. Federal legislation (*Personal Information Protection and Electronic Documents Act*) that came into effect in January 2001, and that currently applies only to federally regulated businesses and cross-border trade in personal information, will apply to all other commercial activities and to all commercial health-related transactions across Canada by January 2004 unless provincial governments enact "substantially similar" legislation before then. So far, Québec is the only province to have adopted legislation that is substantially similar to the federal legislation.

In the context of HIV/AIDS, the PPIA is significant because it will regulate how, when, and why organizations collect, use, and disclose personal information about Ontarians. "Personal information" is defined as information that identifies the individual, or that can be manipulated to identify the individual (including through linking and matching).

Personal information includes personal health information – information relating to an individual's physical or mental health, and information relating to the provision of health care to that individual.

The PPIA is an improvement over earlier bills in several respects:

- It incorporates the ten principles of the Canadian Standards Association's *Model Code for the Protection of Personal Information*² in the purposes section of the Act. These principles support the right of individuals to provide or withhold consent with respect to information about them; the right to access personal information and to ensure that it is accurate; and the right to limit the amount of information that is collected, used, or disclosed. The principles also require a fair, independent, and accessible body to oversee the administration and application of any privacy legislation. In the case of the PPIA, this would be provided by the Information and Privacy Commissioner of Ontario.
- It would create a remedy for individuals whose privacy has been breached. Under the Act, an individual could bring an action for damages for harm resulting from the breach.
- It would require the creation of research ethics boards to oversee research initiatives involving the use of personal information.

- It would create a data institute at arm's length from the Ministry of Health and Long-Term Care, whose role would be to remove personal identifiers from personal health information provided to the Ministry of Health for purposes of analysis and management of the health-care system. The Minister of Health would have access to personal information only if the Information and Privacy Commissioner agreed it was in the public interest for the Minister to receive such information.

However, there are still problems with the draft legislation. The sections dealing with the collection, use, and disclosure of information are awkward and confusing. The PPIA establishes various sets of rules; the application of which rules depends on the nature of the information and the role of the person handling the information. The rules for accessing one's personal information are also confusing. These problems have been drawn to the government's attention by the HIV/AIDS Legal Clinic of Ontario (HALCO), one of the organizations that responded to a request for public input made in early 2002.³

– Matthew Perry

¹ The text of the draft legislation is available on the website of the Ontario Ministry of Consumer and Business Services (www.cbs.gov.on.ca under "Privacy Protection").

² Available on the Canadian Standards Association's website (www.csa.ca under "Standards").

³ See *Submission to the Ministry of Consumer and Business Services: Consultation Draft of the Privacy and Personal Information Act, 2002*, available on HALCO's website (www.halco.org under "Position Statements").

In Brief

Inaccurate Results Lead to Removal of Rapid HIV Tests

Two rapid HIV test kits have been withdrawn from use because some of their results have turned out to be inaccurate. Health Canada issued an advisory about the test kits after the British Columbia Centre for Disease Control found that some people who tested HIV-negative were actually positive.¹

The tests in question are the Fast Check HIV-1/2 (serum) test and the Fast Check HIV-1/2 (whole blood) test, both manufactured by Biochem ImmunoSystems. The serum test was intended for use only in laboratories. The whole-blood test was intended for rapid point-of-care testing by health-care professionals; it is the only rapid HIV test approved for such settings. Neither test was licensed for home use or was used to test blood donations.

Rapid HIV tests use a finger-prick drop of blood and provide results within 15 to 20 minutes. Health Canada estimates that, as of the end of April 2002, about 8000 people across the country had used the rapid tests. The number of false negative results is believed to be very low. Nevertheless, Health Canada advises that anyone who has received a negative result on a rapid HIV test since March 2000 should contact the clinic or health-care professional for further testing. Health Canada issued a letter to health-care professionals who perform HIV testing informing them of its concerns.

– David Garmaise

Canada Establishes Global Health Research Initiative

Several HIV/AIDS issues top the list of priorities for a new partnership of Canadian government departments and agencies called the Global Health Research Initiative (GHRI). The purpose of this initiative, which was launched in November 2001, is to create a formal collaboration to pool knowledge, experience, and resources to address the problems of global health through research. The International Development Research Centre, the Canadian International Development Agency, Health Canada, and the Canadian Institutes of Health Research (CIHR) are involved in the partnership.

Specific GHRI priorities include conducting research on HIV vaccine trials taking place both in Canada and in developing countries, and adapting findings of HIV/AIDS interventions in Canada for use in the developing world. As well, the GHRI was involved in consultations during the planning of the G-8 conference hosted by Canada in June 2002, particularly regarding the importance of health research to improve health and economic development in Africa.

More information about the work of the GHRI can be found on the CIHR website (www.cihr-irsc.gc.ca/services/partnerships/international/ghri_2_e.shtml).

– Liz Scanlon

BC Introduces Changes to Disability Assistance

A new bill introduced by the government of British Columbia will likely result in radical changes to social assistance for disabled persons in the province. However, Bill 27, the *Employment and Assistance for Persons with Disabilities Act*,² provides few details about how social assistance will be provided in future. The details will not be known until the regulations are released around August 2002.

The legislation appears to modify disability assistance in three major ways:

- The criteria for eligibility for disability assistance have been modified. The new criteria may be more restrictive, depending on the definitions developed in the regulations.
- Disabled recipients will be required to enter into, and comply with, an employment plan to assist them in becoming employable and finding employment. Although the government will have the discretion to exempt individuals from this requirement, it is not clear what circumstances will enable this discretion to be invoked.
- A new appeal process will be implemented. The new process will eliminate the opportunity for an open hearing and a subsequent right to appeal to a higher administrative appeal body.

The British Columbia Persons with AIDS Society (BCPWA) and other community groups are planning to make representations to the govern-

ment while the regulations are being developed. BCPWA has prepared an analysis of the bill; for copies, contact Naomi Brunemeyer at naomib@parc.org

– Tarel Quandt

Ontario Commission Criticizes Insurance Industry Record on Human Rights

The Ontario Human Rights Commission (OHRC) has called for measures to protect human rights in the insurance industry. The measures are contained in a report released in February 2002³ on the results of a consultation begun in October 1999.

The HIV & AIDS Legal Clinic of Ontario (HALCO) was one of the groups that participated in the consultations. In its submission, HALCO focused on problems most frequently encountered by its clients with group disability insurance, including:

- breaches of confidentiality by employers who collect medical information from employees in order to process insurance claims;
- privacy breaches by insurance companies;
- the refusal of insurance companies to provide copies of the group insurance contract to employees;
- repeated and frequent requests for medical information from people on disability to the extent that it becomes a form of harassment;
- cutting people off drug benefits because they are “expensive” or because people are on long-term disability; and
- the fact that people who are

wrongly denied benefits or wrongly cut off must have the financial resources to sue in court.

The OHRC accepted many of the criticisms of the industry that groups such as HALCO had put forward. It recommended that the Financial Services Commission of Ontario offer inexpensive dispute resolution services to settle disputes involving group disability insurance, and that insurance companies be required to provide employees covered by group insurance contracts with copies of those contracts. The OHRC also committed to following up with industry representatives with respect to claims handling problems and confidentiality breaches.

– Ruth Carey

HIV/AIDS Organizations Make Representations to Romanow Commission

Canada must commit more strongly to the five pillars of the *Canada Health Act* – universality, portability, public administration, accessibility, and comprehensiveness – in order to decrease the vulnerability of Canadians to HIV/AIDS and to support those living with the disease, HIV/AIDS organizations have told the Commission on the Future of Health Care (also known as the Romanow Commission).

The Romanow Commission was created by the federal government to consult with individuals and organizations across Canada about their visions of the future of health care in Canada. The Commission will recommend ways to ensure the long-term sustainability of a universally accessible, publicly funded health system.

A number of HIV/AIDS organizations submitted briefs to the Commission. In its brief, the Canadian AIDS Society (CAS) focused on the participation and empowerment of health-care users as a means of making health care more efficient and effective.⁴ The brief from the Canadian Treatment Action Council (CTAC) stressed the principle that Canadians are entitled to access health care regardless of their ability to pay, and stated CTAC’s opposition to the introduction of user fees and medical savings accounts.⁵ Both briefs emphasized that the federal government must commit strongly to a truly universal and accessible public health-care system for all Canadians, and that Canada must not allow privatization of the system. These messages were echoed in submissions from other HIV/AIDS groups across the country, and from organizations such as the Canadian Public Health Association, the National Council of Women, the Assembly of First Nations, and the Canadian Labour Congress. The Commission is expected to release its recommendations in November 2002.

– Liz Scanlon

¹ Health Canada. Health Canada advises Canadians about potential false results with certain rapid HIV test kits. 29 April 2002 (www.hc-sc.gc.ca/english/protection/warnings/2002/2002_31e.htm).

² Available via the website of the BC Legislature at www.legis.gov.bc.ca under “Legislation” and “Bills.” Look for the 3rd session of the 37th Parliament.

³ Ontario Human Rights Commission. *Human Rights Issues in Insurance: Consultation Report*. October 2001. Available via the website of the OHRC at www.ohrc.on.ca under “Policies and Consultations.”

⁴ *Health is a Human Right: Lessons from the Community-based AIDS Movement*, available on the website of CAS (www.cdnaids.ca under “CAS Resources”).

⁵ P. Lundrigan. Presentation on the Future of Health Care in Canada, 15 April 2002, available on the website of CTAC (www.ctac.ca under “Health Care Reform”).

INTERNATIONAL NEWS

This section provides brief reports on developments in HIV/AIDS-related law and policy outside Canada. The coverage is selective, and court cases are covered in *HIV/AIDS in the Courts – International*.

Contributors to International News in this issue are Richard Elliott, Michaela Figueira, Lily Hyde, Kuambu Mwendela, Ann Strode, and Simon Wright. We welcome information about new developments for future issues of the Review. Address correspondence to David Patterson, the editor of International News, at dpatterson@aidslaw.ca.

Military Testing – Two Steps Forward, One Step Back

United Nations Expert Panel Rejects Peacekeeper HIV Testing

In November 2001, UNAIDS convened an Expert Panel on HIV Testing in UN Peacekeeping Operations in Bangkok, Thailand, to dis-

After full consideration, the Panel unanimously rejected mandatory testing of peacekeepers.

cuss whether the UN should introduce mandatory HIV testing for peacekeeping forces. After full consideration, the Panel unanimously

rejected mandatory testing and endorsed voluntary HIV counselling and testing (VCT) for UN peacekeeping operations. The Panel concluded that VCT is the most effective means of preventing the transmission of HIV, including among peacekeepers, host populations, and the spouses and partners of peacekeepers. The Panel stressed that VCT should be provided to peacekeeping personnel within a comprehensive and integrated package of HIV prevention and care services.

The Canadian HIV/AIDS Legal Network prepared the background paper on legal and human rights issues for the consultation, and the then President of the Legal Network, Lori Stoltz, participated in the expert consultation as a resource person. The report and the background papers are available via www.unaids.org/publications/documents by clicking on “Uniformed Services.”

Namibian Parliament Overrides SADC Panel, Labour Court on Military Testing

In May 2000, the Namibian Labour Court handed down a judgment in the first case to be heard in Namibia on the issue of exclusion from employment on the basis of HIV status.¹ Haindongo Nghidipohamba Nanditume was refused enlistment in the Namibian Defence Force (NDF) solely on the basis of his HIV status. He sought an order directing the NDF to discontinue discriminating against him on the ground that he is HIV-positive.

It was argued by the AIDS Law Unit of the Legal Assistance Centre that in excluding Haindongo from the NDF solely because he is HIV-positive, the NDF was acting contrary to the provisions of the Labour Act by unfairly discriminating against him.

In its judgment, the court found that an employer such as the NDF is not permitted to exclude people from employment on the basis of their HIV status, because being HIV-positive does not necessarily mean that one is not fit for employment. The court also found that an HIV test alone will not achieve the purpose of assessing fitness for employment and that pre-employment testing for HIV can thus only be undertaken as part of a broader assessment of physical fitness.

This judgment was an important step forward in the fight against discrimination on the basis of HIV/AIDS. The NDF originally applied for leave to appeal against the judgment but subsequently withdrew this application and stated that they would abide by the decision of the Labour Court.

In February 2001, the Namibian Ministry of Defence hosted a regional seminar to identify and define prevention, care, legal, and human rights elements of an HIV/AIDS Policy for the NDF. As other countries in the region face comparable policy ques-

tions, representatives of the defence ministries from seven other Southern African Development Community (SADC) countries were also invited to take part.

After lengthy discussions, participants reached consensus on the fact that since an HIV test alone is not an indication of physical or mental fitness, exclusion of recruits from defence forces on the basis of HIV status alone is irrational. The seminar adopted a set of recommendations, which represented a welcome step forward in adopting a rational and pragmatic approach to HIV/AIDS in the military that accommodates the specific needs of militaries without unfairly discriminating against people with HIV/AIDS.

However, less than three weeks after the adoption of these recommendations, the Namibian Minister of Defence tabled the Defence Amendment Bill, 2001, which contradicts the recommendations of the regional meeting on the issue.

Section 10(d) of the Bill provides that the NDF "shall not appoint any person who suffers from a disease or

ailment which is likely to deteriorate to the extent that it will impair his or her ability to undergo any form of training required to be undertaken or to perform his or her duties as a member of the Defence Force."

The Bill was approved by the National Assembly in March 2001, and by the National Council in May 2001 in its original form. The Defence Amendment Act, 2002, would now appear to require the NDF to exclude people solely on the basis of their HIV status. The advances gained by the judgment of the Labour Court in the matter of *Haindongo v Minister of Defence*, have thus been negated by the legislature in the context of the military. For further information, contact Michaela Figueira, AIDS Law Unit, Legal Assistance Centre, Namibia (mfigueira@lac.org.na).

¹ *Haindongo Nghidipohamba Nanditume v Minister of Defence*. 2001. Labor Court of Namibia. Case no. LC 24/98.

HIV Vaccines Meetings Address Legal, Ethical Issues

Expert Meeting on HIV Vaccine Research, Development, and Access

From 19-21 April 2002, the Canadian HIV/AIDS Legal Network hosted an international expert meeting in Montréal on global advocacy for increased funding for HIV vaccine research, development, and access.

Participants included experts from UNAIDS, the US National Institutes of Health, the International AIDS Vaccine Initiative, the International Council of AIDS Service Organizations, and the AIDS Vaccine Advocacy Coalition. Background materials for the meeting were prepared by Sam Avrett. The products of

the meeting include a comprehensive background paper that will be published on the Legal Network's website (at www.aidslaw.ca/Maincontent/issues/vaccines.htm). Other products to be published in English, French, and Spanish include the meeting report and background paper summary, an action plan, and a community advocacy kit.

An important outcome of the meeting was universal agreement that HIV vaccine development must be situated in the context of other prevention,

care, and treatment measures.

Conversely, prevention, care, and treatment strategies must include development of new technologies such as vaccines and microbicides.

The meeting was funded by the World Health Organization, UNAIDS, and Health Canada, with participation of six experts from developing countries and countries in transition (Kenya, Russian Federation, Thailand, Trinidad and Tobago, and South Africa) made possible by funding from the Canadian International Development Agency. For further information, contact David Patterson (dpatterson@aid-slaw.ca).

AAVP Holds Ethics, Law, and Human Rights Symposium in Durban

In April 2002, the Ethics, Law and Human Rights Working Group of the African AIDS Vaccine Programme (AAVP) held a two-day symposium and networking forum in Durban, South Africa, to build the capacity of persons living and working in Africa to respond to the ethical, legal, and human rights issues raised by HIV vaccine development, and to develop an African network in this area.

Funding was provided by the World Health Organization–UNAIDS HIV Vaccine Initiative. The Secretariat of the Working Group is supported by the South African AIDS Vaccine Initiative (SAAVI). For further information, contact Marsha Naidoo (naidoom@nu.ac.za), Coordinator of the Working Group.

Caribbean Countries Address Legal, Ethical, Human Rights Issues

Caribbean HIV/AIDS initiatives recognize the role of law, ethics, and human rights in preventing the HIV epidemic and mitigating its consequences.

Regional Strategic Framework on HIV/AIDS Adopted

The Caribbean Regional Strategic Framework on HIV/AIDS (formerly the Plan of Action) was adopted by the Caribbean Community (CARICOM) in 2000 to support national efforts to prevent and control the HIV epidemic and mitigate its consequences at national and regional levels. Priority Area 1 focuses on “advocacy, policy development and

The report and the subsequent consultative process can serve as a model for similar initiatives in the region.

legislation” and includes human rights, non-discrimination, international standards, best practices, vaccines, and health-sector reform. In 2001, the Canadian International Development Agency launched a regional pilot project called “Enhanced Support to HIV/AIDS in the Caribbean Region” that will, in part, support CARICOM to coordinate and operationalize Priority Area 1 of the Regional Strategic Framework on HIV/AIDS through March 2007. CARICOM has subcon-

tracted the Canadian HIV/AIDS Legal Network to provide technical assistance in the areas of law, ethics, and human rights. A regional workshop was held in Tobago in June. For further information contact Cynthia Eledu, Advisor to the Pan-Caribbean Partnership on HIV/AIDS, CARICOM (celedu@caricom.org). A further report will be published in the next issue of the *Review*.

World Bank HIV/AIDS Loans to Address Legal and Human Rights Issues

In April 2002 the World Bank approved a loan of up to US\$16.5 million for HIV/AIDS/STD prevention and control in Jamaica. The project appraisal document refers to the need for a suitable legal framework to protect people with HIV/AIDS, their families, and vulnerable populations from discrimination, as part of a comprehensive approach to care, treatment, and support.¹ The project will include workshops to sensitize lawyers and legal aides in HIV/AIDS issues. Similar project documents have been approved for Barbados and the Dominican Republic, with St Kitts and Grenada in the pipeline. The World Bank initiative reflects increasing recognition of the importance of law and ethics in promoting an enabling environment to reduce HIV transmission and the impact of HIV and AIDS.

Jamaica Publishes Report on Legal Issues and Law Reform

In 2001, the Jamaican Ministry of Health, with funding from USAIDS, commissioned McNeil & McFarlane, Legal Consultants, Kingston, to undertake a review of HIV/AIDS-related legal, ethical, and human rights issues in Jamaica. The comprehensive report, titled "HIV/AIDS Legal, Ethical and Human Rights Issues in Jamaica," covers international, regional, and national legal dimensions and developments. It addresses issues such as insurance, prisons, public health, immigration, employment, social welfare, and the criminal law. The report was discussed at a stakeholder meeting on 13 December 2001 that identified short- to medium-term action to achieve necessary reforms, including collaboration with other stakeholders. The report and the subsequent consultative process can serve as a model for similar initiatives in the region. The report is on the website of the National AIDS Committee (www.nac.jamaica.com).

¹ World Bank. Project Appraisal Document on a Proposed Loan in the Amount of US\$15 Million to Jamaica for an HIV/AIDS Prevention and Control Project (Second Phase of the Multi-Country HIV/AIDS Prevention & Control APL for the Caribbean). January 25, 2001. Report No. 23265-JM (available via www/wds-worldbank.org by clicking on "Browse by Country" and "Jamaica").

Africa: Networking, Capacity Building, and Training

This section reports on the development of HIV/AIDS coalitions among parliamentarians in southern Africa, capacity building in AIDS law networks in Kenya and Zambia, and HIV/AIDS training for South African magistrates.

SADC Parliamentarians Discuss HIV/AIDS, Legislation, and Human Rights

In February 2002, parliamentarians from 11 southern African countries met in Windhoek, Namibia, to develop their role in addressing HIV/AIDS and to discuss legislation and human rights. The Parliamentary Forum of the Southern African Development Community (SADC) resolved to hold this workshop last year when it established a standing committee on HIV/AIDS.

Among the contentious areas were Mauritius's mandatory testing of incoming workers and the criminalization of sexual acts of people with HIV who do not disclose their HIV status. South Africa reported experimenting with a law on compulsory partner notification that encountered huge resistance. Zimbabwean delegates reported that prostitution has been criminalized by the recent Sexual Offences Act; and that male homosexual acts remain illegal. Participants also reported that Angola would examine the rights of people with HIV, and that Tanzania would consider greater enforcement of laws against practices such as widow inheritance and the marriage of underage girls.

All South African MPs have signed a pledge to work against HIV/AIDS. However, since the South African All-Party Parliamentary Group on AIDS

(a sub-committee of the Health Portfolio Committee) was not successful, they are considering other models. The Tanzanian Parliament has formed a Coalition against HIV that nearly all MPs have joined and which is represented on the National Commission on AIDS. Botswana also has a parliamentary committee on HIV/AIDS. For further information, contact the SADC Executive Assistant Takawira Musavengana (tmusavengana@sadcpf.org) or consult the SADC Parliamentary Forum website (www.sadcpf.org).

CIDA Funds Kenya, Zambia AIDS Law Groups

In May 2002, the Canadian International Development Agency (CIDA) approved funding of \$272,000 for the Legal Network's project "Building Capacity to Address Legal, Ethical and Human Rights Issues in Kenya and Zambia." This project will provide funds for capacity building activities for the Kenyan Network on Ethics, Law and HIV (a project of the Kenya AIDS NGOs Consortium) and for the Zambian AIDS Law Research and Advocacy Network (through the International HIV/AIDS Alliance). Activities will include the undertaking of research, the publication of materials, and the holding of workshops and seminars on HIV/AIDS-related legal issues. The project will also support links between the Legal Network and legal

professional organizations in Kenya and Zambia, particularly through the provision of technical assistance by Legal Network members on issues identified by partners in Kenya and Zambia. For more information, contact David Patterson (dpatterson@aidslaw.ca).

Paralegal and advocacy training workshop held

In May 2002 the Zambian AIDS Law Research and Advocacy Network (ZARAN) held a national paralegal training and advocacy workshop. The objective of the workshop was to increase the capacity of organizations and individuals to advocate for rights-based interventions concerning HIV/AIDS. Among the participants were students from the University of Zambia and persons from other groups, including the Network of Zambian People Living with HIV/AIDS. Resource persons included senior lecturers of the University of Zambia: Dr Alfred Chanda, Dr M Munalula, and Judge K Chanda (retired), as well as Mwambo Mutale and Kaumbu Mwendela of ZARAN. An international perspective was provided by Michaela Figueira of the AIDS Law Unit, Legal Assistance Centre, Namibia. For further information, contact Kaumbu Mwendela (kaumbu@yahoo.com).

South Africa HIV/AIDS Training for Bench's "Ideological Virgins"

Judges do not enter public office as ideological virgins. They ascend the Bench with built-in and often strongly held sets of values, preconceptions, opinions and prejudices. These are invariably expressed in the decisions

they give, constituting "unarticulated premises" in the process of judicial reasoning.¹

Judges do not enter public office as ideological virgins.

The Law, Race and Gender Unit at the University of Cape Town in South Africa has spent six years developing training materials and programs to develop the capacity of judicial officers to recognize the "unarticulated premises" referred to above. Much of this work has focused on race and gender. However, in 2002 the Unit began developing materials and a training program on HIV/AIDS for the magistrates who act as Commissioners of Child Welfare.

These magistrates are responsible for applying the Child Care Act, which deals with, for example, the placement of children in need of care. The magistrates themselves and many other stakeholders had raised concerns that they were inadequately equipped to deal with the impact of HIV/AIDS on the children coming through their courts. The concerns included dealing with their own prejudices and misconceptions regarding HIV/AIDS, applying the "best interests of the child" principle (eg, the testing of children for HIV before placement), and understanding the law on HIV/AIDS.

From 6-8 March 2002, a pilot training program was held in Pretoria. It aimed at providing magistrates with an initial exposure to the importance of recognizing the social context we live within and how this may influence judgments. It also

looked in more detail at HIV/AIDS by:

- providing the participants with up-to-date and accurate information on HIV/AIDS;
- doing group work on identifying and dealing with discrimination and stigma based on HIV status or perceived HIV status;
- doing group work on welfare rights within the context of HIV/AIDS and, in particular, testing children for HIV; and
- providing an update on HIV/AIDS and the law.

For more information or for copies of the training materials, contact Paula Soggot (psoggot@law.uct.ac.za) of the Law, Race and Gender Unit or Ann Strode (Strodea@nu.ac.za), a consultant to the Unit on HIV/AIDS and the law.

Southern African Regional Meeting on HIV/AIDS, Human Rights, and Law

The AIDS Law Unit of the Legal Assistance Centre in Windhoek, Namibia, is planning to host a meeting of organizations in sub-Saharan Africa working on HIV/AIDS, human rights, and law, in August or September 2002. The aim is to provide a forum for sharing experiences and ideas and to establish a regional network of organizations working in this field. Organizations in the region interested in becoming involved in such an endeavour can contact Michaela Figueira (mfigueira@lac.org.na).

¹ Justice Edwin Cameron of South Africa, quoted in J Fedler, I Olckers, *Ideological Virgins and Other Myths: Six Principles for Legal Revisioning*. South Africa: Justice College, 2001.

Ukrainian Law Criminalizes Sex Work

The criminalization of prostitution in the Ukraine is cause for concern among organizations working with sex workers.

On 1 September 2001, prostitution was criminalized in the Ukraine with the adoption of the new Criminal Code. Formerly covered under the Administrative Code and incurring only a small fine, prostitution is now subject to greater penalties (fines, community service, and prison sentences).

The changes are said to be part of an effort to clamp down on those who “traffick” or recruit women into often unprofitable sex-work situations, usually abroad. However, there is concern among AIDS service organizations working with sex workers that their projects may be considered to be organized criminal entities promoting prostitution, especially if they organize networks of sex workers. There are also fears that the new legislation will drive sex workers further underground, making them harder to reach and impairing their access to health care and social services.

The legislation may also seriously hinder efforts to improve the attitudes of the police. A British Council police-training program held in March 2002 found that police officers believed that the new law was for the good of sex workers (as it would prevent them from infecting “innocent” clients). They claimed that if a woman is infected, she must stop working.

Both the Ministry of Health and the prosecutions department of the Interior Ministry have given assurances that HIV prevention among sex workers can continue as before, because the new laws apply to systematic prostitution (providing sexual

services regularly and over a period of time as an additional or only source of income), and not to the social or medical aspects addressed by HIV projects. Sex workers are named as a target group for interventions in the government strategy on AIDS.

The mechanisms for implementing the law have yet to be worked out. Around the Ukraine, projects report little or no change in the behaviour of sex workers or of the police thus far, although some women have said that clients are somewhat scarcer because of police harassment.

The new legislation in the Ukraine is perceived both as a threat and as an opportunity for moving beyond the narrow medical model of HIV preven-

tion. Addressing legal issues surrounding sex work can make HIV services more attractive to sex workers, and help tackle fatalism and indifference. In practice, this approach works better than workshops on condom use, as some funding agencies are slowly starting to find.

Current Projects with Sex Workers

In 2001, the International HIV/AIDS Alliance supported 20 projects carrying out participatory community assessments, including assessments among sex workers who inject drugs. The British Council and the International Renaissance Foundation also recently assessed eight service projects for sex workers. UNAIDS, the United Nations Development Programme, and the Counterpart Alliance for Partnership also work with this group. For further information, contact Lily Hyde (hyde@aidsalliance.kiev.ua).

Penalties for Prostitution and Related Activities

Criminal Code, Ukraine, article 303, provides the following penalties for prostitution and related activities:

1. Systematic prostitution (the provision of sexual services for profit): punishable by a fine of 50 to 500 times the non-taxable minimum wage, or up to 120 hours of community service.
2. Coercion into or involvement with prostitution by way of force or threat of force, destruction or damage to property, blackmail, or deception: punishable by a fine of 500 to 1000 times the non-taxable minimum wage, or six months' detention, or one to three years in prison.
3. Actions included in 1 and 2 relating to minors or to organized groups: three to five years in prison.
4. Pimping, as well as establishing, directing, or participating in an organized group that facilitates the provision of sexual services from men or women for profit: five to seven years in prison.

Other News

Ireland: Compensation Deal Regarding HIV-Tainted Blood Products

On 11 April 2002, the Irish government reached a deal with hemophiliacs who contracted HIV from tainted blood products in the 1980s (and the relatives of those who have died). A compensation package had been originally agreed in 1991, under which the government paid out 10 million euros in compensation in exchange for “no-fault” agreements. In 1999, however, the government had agreed the package was inadequate and promised further action. In March 2002, some hemophiliacs and their relatives had begun legal proceedings seeking additional compensation. The settlement allows those infected with HIV from tainted blood products to claim compensation from a tribunal originally established in 1995 to handle cases of hepatitis C infection only. So far that tribunal has heard some 1500 cases and awarded nearly _300 million in hepatitis C cases. The tribunal will decide compensation in the HIV cases on a case-by-case basis. The opposition parties indicated they would not oppose the deal.¹

¹ Irish Government Makes Blood Deal. *Associated Press*, 11 April 2002; K Birchard. Ireland agrees deal for infected haemophiliacs. *Lancet* 2002; 359: 1498; B Lavery. Ireland: Blood victims seek more compensation. *New York Times*, 15 March 2002.

HIV/AIDS IN THE COURTS – CANADA

This section presents a summary of Canadian court cases relating to HIV/AIDS or of significance to people with HIV/AIDS. It reports on criminal and civil cases. (Up to volume 6(1/2) of the Review, criminal cases were reported in a separate section.) The coverage aims to be as complete as possible, and is based on searches of Canadian electronic legal databases and on reports in Canadian media. Readers are invited to bring cases to the attention of Ralf Jürgens, editor of this section, at ralfj@aidslaw.ca.

Ontario Court Recognizes Constitutional Equality Rights of People “In Receipt of Social Assistance”

On 13 May 2002, the Ontario Court of Appeal released its unanimous decision in the *Falkiner* case, which declared the definition of “spouse” in Ontario’s social assistance legislation to be unconstitutional because it discriminates on the basis of sex, marital status, and receipt of social assistance.¹ The case is significant for people living with HIV/AIDS, given that a high proportion live on social assistance and thus face discrimination.

In 1995, the definition of “spouse” was changed in the regulations under Ontario’s *Family Benefits Act*.² Substantially the same definition was adopted in subsequent legislation,

including regulations under the *Ontario Works Act*³ and the *Ontario Disability Support Program Act*.⁴ Under the new definition, a person of the opposite sex sharing living quarters with a recipient or applicant is assumed to be a spouse as soon as they start living together, unless proven otherwise. Previously, the presumption took effect after three years. More recently, amendments have been made so that same-sex partners are also subject to this presumption.⁵

As a result of these changes, Sandra Falkiner lost her eligibility for social assistance benefits as a sole-support parent (along with many others). As long as she continued to live with a man, she would be assessed as

if the man were her spouse and his income was available for her support and that of her child.

Falkiner, together with three other women in the same circumstances, appealed to the Social Assistance Review Board, which allowed their appeal. The provincial government appealed this decision, but the Divisional Court dismissed the appeal.⁶

A further appeal by the government was also dismissed. The Ontario Court of Appeal found the definition of spouse breached s 15 of the *Canadian Charter of Rights and Freedoms*, the equality rights provision. That section prohibits discrimination by the state on any of the listed grounds and on grounds “analogous” to those listed. The court found that the definition of spouse in the province’s social assistance legislation violated s 15 for three reasons.

The court found discrimination on the basis of sex, an enumerated ground. Statistics show that almost

90 percent of those whose benefits were terminated as a result of the new definition of spouse were women, while only 54 percent of social assistance recipients were women. This clearly indicates a disproportionate impact on women.

This decision represents a potentially significant development in challenging discrimination based on poverty.

The court also found that the new definition discriminated on the basis of marital status. Married couples receive benefits in accordance with a benefit unit that reflects their actual economic position, while single parents in Falkiner's position are assessed according to benefit units that do not accurately reflect their economic situation. Marital status was accepted as an analogous ground under section 15 in a previous Supreme Court of Canada case.⁷

Third, and perhaps most significant, the court found the definition discriminated on the analogous ground of "receipt of social assistance." Receipt of social assistance has not previously been accepted in Canadian law as an analogous ground of discrimination under section 15. This decision therefore reflects a potentially significant development in challenging discrimination based on poverty.

The court went on to conclude that the breach of Falkiner's equality rights was not justified under section 1 of the Charter, which permits such "reasonable limits" as are "demon-

strably justified in a free and democratic society."

The government presented two objectives for its definition: treating married and unmarried couples alike, and allocating public funds to those most in need by ensuring that individuals use private resources before resorting to social assistance. The Court accepted that these are "pressing and substantial" objectives.

However, the government also had to show that the means chosen to achieve its objectives are proportional to the ends, by establishing that: (1) the definition of spouse is "rationally connected" to the government's two stated objectives; (2) the definition impairs Falkiner's equality rights as little as possible; and (3) the definition's positive effects outweigh its negative effects. The Court ruled the government failed on all three counts.

First, the Court said the definition of spouse was overly broad because it "treats as spouses persons who are not in marriage-like relationships because they do not have the necessary degree of financial interdependence." Because of its overbreadth, the definition was not rationally connected to the government's objective of treating married and unmarried spouses alike.

Second, the overly broad definition did not satisfy the minimal impairment requirement. The definition

does not reasonably capture the financial interdependence that characterizes spousal relationships. Instead, [it] seems designed to capture try-on relationships like those of the respondents, where the couple does [sic] share some expenses but has no mutual support obligations and no meaningful financial interdependence.

Because these relationships are not spousal, the definition therefore does not minimally impair the respondents' equality rights.⁸

Finally, the court ruled that the negative effects of the definition outweighed its positive effects because

the only possible positive effect of the definition is cost savings. The negative effects are considerable and include reinforcement of dependency, deprivation of financial independence and state interference with close personal relationships. I therefore conclude that the government has not met its onus of justifying the s. 15 Charter violation.⁹

The court dismissed the appeal, and upheld the judgment of the Divisional Court, which declared the definition of spouse to be unconstitutional and therefore of no force and effect. At the time of writing, it remains to be seen whether the government of Ontario will appeal the decision to the Supreme Court of Canada.

— John Nelson

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¹ *Falkiner v Ontario (Minister of Community and Social Services, Income Maintenance Branch)*, [2002] OJ No 1771 (CA) (QL).

² RSO 1990, c F2.

³ SO 1997, c 25, Schedule A.

⁴ SO 1997, c 25, Schedule B.

⁵ O Reg 33/00, effective 1 March 2002.

⁶ *Falkiner v Ontario (Minister of Community and Social Services, Income Maintenance Branch)* (2000), 188 DLR (4th) 52 (Ont Div Ct); [2000] OJ No 2433 (QL).

⁷ *Miron v Trudel*, [1995] 2 SCR 418.

⁸ *Supra*, note 1 at para 110.

⁹ *Ibid* at para 111.

Blood or Blood Products: Minister's Decision to Deny Application to Extraordinary Assistance Plan Upheld

In April 2002, the Federal Court of Canada decided the federal Minister of Health does not have the authority to award compensation under the Extraordinary Assistance Plan unless an independent medical review board finds that the applicant was infected with HIV as a result of the receipt of blood or blood products in Canada between 1978 and 1989.¹

The Extraordinary Assistance Program (EAP) was established in 1990 to provide financial assistance to anyone who was infected with HIV as a result of the receipt of blood or blood products between 1978 and 1989. It was established by an Order-in-Council that gave discretion to the Minister of Health to grant financial assistance where the applicant was found “on the basis of an independent medical review” to have received blood or blood products between 1978 and 1989 and to have become infected with HIV as a result.

Robert Thompson applied for assistance in July 1997, on the basis that he was infected during blood transfusions he received to treat his leukemia. He did not become aware he had been infected until 1993 and was unaware of the EAP until 1997. As a result, over ten years had elapsed since his leukemia went into remission in the mid-1980s.

An independent medical review concluded “there is no independent proof that Mr. Thompson received blood in 1978 ... or 1979 ... or ‘from early 1980, to mid-80’s’ [sic] ... and that he was infected as a result of blood transfusions.”² In June 1999 his application was denied by the Minister. He sought judicial review of

this decision in the Federal Court of Canada.

Thompson argued he was being unfairly penalized because the hospitals where he received the blood transfusions did not maintain records for more than seven years and, as a result, he could not provide these records as proof. He also submitted that insufficient weight had been given to his own evidence and that of family members.

In response, the Attorney General of Canada and the Minister of Health argued that, since the independent medical review board had concluded there was a lack of independent, reliable proof that Thompson had received blood or blood products in Canada during the relevant period, “there was no basis upon which the Minister [could] award compensation.”³

The judge accepted the respondents’ submissions and ruled that “in the absence of a positive recommendation from the independent medical review board ... the operation of the Minister’s discretion was not engaged.”⁴ In other words, the Minister has no authority to approve an application unless the review board concludes the person was infected through transfusion in the relevant

time frame. This suggests that the Minister’s hands are tied regardless of how the medical review board reaches its conclusion.

In any event, the court did not feel that the Minister’s exercise of discretion should be overturned. Citing previous cases,⁵ the court found that the proper standard of judicial review in such cases, where the decision lies within the Minister’s discretion, is “patent unreasonableness” – that is, a court will only interfere with the decision if it was patently unreasonable.

In the absence of a positive recommendation from the medical review board, the court found the Minister’s decision to deny Thompson’s applica-

The Court did not address Thompson’s main submission – that the medical evidence he needed was not available, through no fault of his own.

tion was not patently unreasonable. The Court described the medical review board’s report as “comprehensive” and as “a detailed review of the evidence and information submitted by the Applicant, and other information which was sought” by the board.⁶

The court stated that “the decision [by the medical review board] to recommend rejection of the Applicant’s application is, in my opinion, reasonable,”⁷ and therefore the Minister’s decision based on the board’s recommendation was not patently unreasonable.

However, the Court did not address Thompson’s main submission – that the medical evidence he needed was

not available, through no fault of his own, because the hospitals had not retained the records, and that it was unfair he should be denied compensation on this ground. It could be argued on an appeal, or in a similar case in future, that this makes the medical review board's negative recommendation itself defective, and that it is patently unreasonable for the Minister to deny an application based on such a recommendation.

— John Nelson

¹ *Thompson v Attorney General of Canada & Minister of Health*, 2002 FCT 450; [2002] FCJ No 615 (QL) (available at <http://decisions.fct-cf.gc.ca/fct/2002/2002fct450.html>).

² *Ibid* at para 28.

³ *Ibid* at paras 35-36.

⁴ *Ibid* at para 42.

⁵ *Baker v Canada (Minister of Citizenship and Immigration)*, [1999] 2 SCR 817; *BC Landscape and Nursery Association Ltd et al v Canada (Attorney General)* (2000), 186 FTR 62 (TD).

⁶ *Supra*, note 1 at paras 48 and 49.

⁷ *Ibid* at para 51.

Criminal Law and HIV Transmission/Exposure: One New Case

In a regular column, we have reviewed new developments in the area of criminal prosecutions for HIV transmission or exposure.¹ Since the last issue of the *Review*, one new Canadian case has come to our attention.

One-Year Sentence for Spitting

In May 2002, a prisoner with HIV was sentenced to an additional year in prison for spitting in the eyes of a correctional officer. At the end of February 2002 at the Bowden Institution in central Alberta, he

pleaded guilty to assaulting a peace officer. The sentencing decision has not been reported.²

¹ See, eg, R Elliott. Criminal law and HIV transmission/exposure: three new cases. *Canadian HIV/AIDS Policy & Law Review* 2002; 6(3): 64-66.

² HIV-positive prisoner sentenced for spitting. *Globe and Mail*, 10 May 2002: A7.

HIV/AIDS IN THE COURTS – INTERNATIONAL

This section presents a summary of important international cases relating to HIV/AIDS or of significance to people with HIV/AIDS. It reports on civil and criminal cases. (Until volume 6(1/2) of the *Review*, criminal cases were reported in a separate section.) While the coverage of Canadian cases aims to be as complete as possible, the coverage of international cases is selective. Only important cases or cases that set a precedent are included, insofar as they come to the attention of the *Review*. The coverage of US cases is very selective. Reports of US cases are available in *AIDS Policy & Law* and in *Lesbian/Gay Law Notes*. Readers are invited to bring cases to the attention of Ralf Jürgens, editor of this section, at ralfj@aidslaw.ca.

HIV-Positive Child Made Ward of Court after Father Refuses Treatment with Antiretroviral Drugs

In 1999, we reported a number of cases in Canada, the US, and the UK in which child-welfare authorities have disputed parents' decisions to refuse HIV testing or treatment for their children.¹ This article reports on new developments in one of those cases. On 10 May 2002, the English High Court heard submissions regarding the future of a three-year-old HIV-positive girl who was made a ward of the court after her father refused to allow her to be treated with antiretroviral drugs.²

In 1999 the girl was taken to Australia by her parents, who refused

to allow her to be tested for HIV, in spite of court orders. The mother had HIV but had refused to take antiretroviral drugs or to refrain from breastfeeding to reduce the likelihood of transmitting the disease to her child. After an initial High Court order to allow testing, the parents appealed but left the UK to avoid the jurisdiction of the court and did not appear at the hearing of their application. The Court of Appeal upheld the original order that the parents allow the child to be tested.³

The mother died of an AIDS-related illness in Australia in October 2001. Child-welfare officials there

began proceedings to obtain guardianship of the girl after the father refused antiretroviral treatment for her. The father fled with the child, but was apprehended by police. She was found to be HIV-positive. The doctor advised treatment with antiretroviral drugs but the father refused, saying that he was concerned about the toxicity of the drugs.

On 7 May 2002, the three-year-old girl returned to England with her father after an Australian court ruled that it would be in the child's best interest to return to the United Kingdom. While in Australia, the girl had been made a ward of the court, on

application by Camden council, the council for the north London area where she had previously lived with her parents. Court officials met the pair at the airport and took the girl into custody. She was taken to hospital, where her health status was assessed.

On 10 May 2002, the court allowed the girl to live with her father. However, she will remain a ward of the court, possibly until her 18th birthday. This means the court has the final say on all parental decisions.⁴

On initial assessment, it was found that the girl might not be as ill as was first feared. If the doctors do not recommend treatment with antiretroviral drugs, there may be no dispute about her treatment. If her

doctors advise that antiretroviral drug therapy is in her medical best interest and her father still disagrees, there will be a dispute. In disputes between parents and doctors over what medical treatment is best for a child, every attempt is made to reach a consensus. If this proves impossible, the court will be called upon to decide.⁵

Parents in Britain normally have the right to make medical decisions for their children, but a court can find that a child is “medically neglected” and order treatment. “A parent makes decisions for a child on the hypothesis that they are the best guardian for the child’s best interests, but if it’s demonstrated that this is not the case, then they have no role.”⁶

— John Nelson

John Nelson is an articling student at the HIV & AIDS Legal Clinic Ontario (HALCO). For more information, contact Richard Elliott at the Canadian HIV/AIDS Legal Network at relliott@aidslaw.ca

¹ R Elliott. HIV testing & treatment of children. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 5(1): 1, 3-9.

² C Dyer. Judge’s ruling sought over three-year-old HIV girl. *Guardian*, 11 May 2002.

³ *In re C (a Child) (HIV test)*, [1999] TNLR No 652 (QL); [2000] Fam 48; [2000] 2 WLR 270, aff’d *Re C (a Child)*, [1999] EWJ No 4861 (Eng CA Civ Div) (QL), reported in Elliott, supra, note 1.

⁴ C Dyer. HIV positive girl made ward of court after father refuses to allow her treatment. *British Medical Journal* 2002; 324(18 May): 1178.

⁵ *Ibid.*

⁶ John Harris, Professor of Bioethics, University of Manchester, quoted in *Kaiser Daily HIV/AIDS Report*, 8 May 2002.

English Court Upholds Ban on Newspaper Publishing Identity of HIV-Positive Health-Care Worker

In the last issue of the *Review*, we reported about an HIV-positive health-care worker in the UK who brought legal proceedings to prevent the National Health Service from notifying his previous patients that he is infected.¹ In February 2002, the Court of Appeal for England and Wales (Civil Division) upheld a ban on publishing his name and that of the health authority for which he worked.²

A health-care worker, “H”, was diagnosed with HIV while employed by the health authority, “N”. In order to carry out its policy of notifying patients in these circumstances, N requested that H supply particulars of his patients and their medical records.

H believed his patients were not at sufficient risk to warrant this action,

and did not want his HIV status revealed. He began proceedings against the health authority, seeking a declaration that the proposed patient notification was unlawful. Before starting his action, he obtained a court order prohibiting the health authority from disclosing his identity and the name of the health authority where he

had worked.

When H learned that a newspaper owned by Associated Newspapers Ltd (ANL) wanted to write a story about the case, he began proceedings against the newspaper. In November 2001, he obtained an injunction prohibiting the publication of information that could lead to his identification.

ANL applied to the High Court for a variation of both publication bans, arguing that they infringed the freedom of the press and seeking permission to name the health authority, to identify H's specialty, and to give the approximate date he was diagnosed with HIV. In December 2001, the judge replaced both previous orders with an order restraining ANL from publishing H's identity, whereabouts, or specialty, but allowing publication of the name of the health authority where he had worked.³

H appealed. The Court of Appeal set aside part of the lower court's order. It agreed that H's name and that of the health authority could not be revealed, but ruled that the newspaper could publish his specialty. The court considered the likelihood that H's identity could be deduced from the information published. The court felt that if the name of the health authority were revealed, many of its patients would call with concerns about their risk of exposure and, in the process, H's identity would become apparent. However, simply revealing H's specialty would not likely reveal his identity.

It remains for the court to rule on H's initial action and to decide whether the patient-notification exercise the health authority wishes to pursue is lawful.

— John Nelson

¹ See: UK: Court orders publication ban in case of HIV-positive health-care worker. *Canadian HIV/AIDS Policy & Law Review* 2002; 6(3): 74.

² *H (A Healthcare Worker) v Associated Newspapers Ltd* (2002) EWCA Civ 195; [2002] EWJ No 829 (QL).

³ *Supra*, note 1.

UK Court Rules Government Erred in Denying Housing Assistance to Woman with HIV

In March 2002, the English High Court of Justice ruled that municipalities have a duty to use their powers to provide assistance where refusal to do so would infringe an applicant's rights under the European Convention on Human Rights and Fundamental Freedoms.¹

"J" came to the United Kingdom from Ghana in February 1995. She overstayed her visa and had a child in February 2000. She was diagnosed with HIV while receiving prenatal care. Following the birth of her daughter (who was not infected), J was ill and hospitalized for three months. She had been living in the same house since shortly after she arrived, but was told in 2001 that she would have to move.

Having no place to go and very little income, she applied to the local authority for housing or financial assistance to pay the deposit and the first month's rent, and for assistance with rent thereafter. Her application was denied; she applied for judicial review.

She invoked the National Assistance Act 1948 (NAA), which directs local authorities to provide assistance with housing (s 21). She also invoked the Children's Act 1989, which imposes a general duty on local authorities to safeguard and promote children in need and to promote the upbringing of such children by their families, by providing a range and level of services appropriate to their needs (s 17). She also argued that failure to assist in obtaining accommodation breaches her right to respect for the home and family life under the European Convention on Human

Rights and Fundamental Freedoms (Article 8). Under the UK's Human Rights Act 1998, statutes must be read so as to give effect to the rights protected by the international Convention.

The local authority relied on section 21(1A) of the NAA and section 115 of the Immigration and Asylum Act 1999. The combined effect of these provisions is to exclude anyone with J's immigration status (ie, having overstayed her visa) from being provided with housing if the need arises solely due to being "destitute." This is defined as either not having adequate accommodation or the means to obtain it, or having adequate accommodation but not the means to meet other essential living needs.

The local authority decided that J was not sick enough to be in imminent need of care and attention. It decided her need for assistance had arisen solely because she was destitute and therefore no assistance could be provided.

At the time of her initial application, J had not submitted strong medical evidence regarding her illness. However, she later did submit very convincing medical reports but the authority insisted she still did not qualify for assistance. The judge stated that, given the new medical evidence, the authority was wrong to

conclude “that the risk to health was not imminent.” The judge found J’s need for assistance did not arise solely because she was destitute but also

This ruling is a significant contribution to the field of human rights law in that it requires a government to exercise its powers to provide financial and other assistance in a fashion that gives effect to legally binding rights originating in an international human rights treaty.

because of her medical condition. Therefore, the local authority had not properly exercised its power under the NAA. Its original decision was quashed and it was ordered to reconsider.

The court decided that the provisions of the Children’s Act 1989 did not give the local authority the power to provide financial assistance to J for her and her daughter to obtain housing. Rather, the only basis for providing a child with housing is to take the child into care, resulting in separation from his or her family.

In anticipation of possibly having to declare some sections of UK statutes incompatible with the European Convention on Human Rights, the court invited the government to make submissions. To avoid such a declaration, the government argued that powers given to a local authority under another statute, the Local Government Act 2000 (LGA), allowed the authority another means to give effect to J’s human rights to respect for home and family life. The LGA (s 2) bestows broad powers on local authorities to, among other things, “give financial assistance to any person.”

The court found that, regardless of whether J was eligible for assistance under the NAA, the LGA gave the

local authority the power to grant financial assistance. Furthermore, the local authority had a duty to do so in circumstances where a refusal would infringe J’s rights to respect for home and family life under Article 8 of the Convention. The local authority acknowledged that the failure to provide any assistance would infringe the Article 8 rights of J and her daughter.

This ruling may have a significant impact on many people with HIV/AIDS who have stayed in the UK after their visas have expired. Beyond that, it is a significant contribution to the field of human rights law in that it requires a government to exercise its powers to provide financial and other assistance in a fashion that gives effect to legally binding rights originating in an international human rights treaty.

It is open to the local authority to appeal this judgment.

— John Nelson

¹ *J v Enfield London Borough*, [2002] EWHC 432 (Admin); [2002] EWJ No 1164 (QL).

El Salvador: Activists Challenge Law Allowing Pre-employment HIV Testing

On 24 October 2001, El Salvador’s national legislature passed a law allowing employers to impose pre-employment HIV testing on job applicants, although it also prohibits employers from discriminating against those who test HIV-positive.

Article 16 of the Law on the Prevention and Control of the Infection caused by the Human Immunodeficiency Virus (Decree No 588) contains a general prohibition on

compulsory HIV testing, but allows testing in cases falling under article 31(10) of the Labour Code, which states that [translation] “upon request from an employer or administrative

authorities, a worker must undergo a medical exam whenever required in order to verify their health status.” The new law also states that compulsory HIV testing is permitted “whenever required” by a competent authority “for legal and penal purposes” (article 16).

The draft legislation submitted to the legislature by the Ministry of Health did not include this provision, which was added by deputies from the ruling ARENA party, which has a majority in the legislative assembly.

Mandatory pre-employment HIV testing directly contravenes the “Code

of Practice on HIV/AIDS and the World of Work” adopted by the International Labor Organization in 2001,¹ and contravenes as well the International Guidelines on HIV/AIDS and Human Rights.²

On 30 November 2001, activist Odir Miranda of the Atlacatl Association (an advocacy group for people with HIV/AIDS), with the support of the Fundación de Estudios para la Aplicación del Derecho (FESPAD – Foundation for Applied Legal Studies), initiated a proceeding before the Supreme Court of Justice (Constitutional Chamber) challenging the section of the law that allowed employers to impose pre-employment HIV testing.

The complainants argued that it violated the country’s Constitution, as well as the International Covenant on Civil and Political Rights and the American Convention on Human Rights. They pointed out that the law violates bodily integrity and privacy by allowing compulsory testing. Furthermore, the supposed prohibition on an employer discriminating against those who test HIV-positive offers little real protection and will be useless.

Judgment on this original challenge was pending at the time of writing. However, at the end of April 2002, Atlacatl and other groups belonging to the Alliance on the HIV Law (*Alianza de la Legislación en VIH/sida*) filed 30 complaints challenging the constitutionality of the provision on pre-employment HIV testing.³

A lawyer representing the activists indicated that additional challenges are planned.⁴

The stated objectives of the law are to prevent, control, and regulate the treatment of HIV infection, to

define the obligations of those with the virus, and to define a national policy on HIV/AIDS care, including the creation of a National Commission Against AIDS. There are several other noteworthy features of the legislation. Some are positive, but many amount to serious infringements of human rights. Key provisions include the following:⁵

- The law affirms that people living with HIV/AIDS, their family members, and acquaintances have a right to freedom from discrimination and stigmatization (article 4).
- The law does not establish universal access to HIV testing. However, it does recognize the right of every person living with HIV/AIDS to “health care, medical, surgical and psychological treatment,” as well as “counselling which is timely and with equal conditions” and “preventive measures to impede the progress of the infection” (article 5). The preamble affirms that it is the obligation of the state to provide free assistance to the sick who lack resources and to residents in general, whenever treatment is effective in preventing the spread of a transmissible disease. It remains to be seen whether the law will be useful in securing access to medicines (particularly antiretrovirals) and other key elements of health care for people living with HIV/AIDS in El Salvador.
- Similarly, the law asserts the right of every person living with HIV/AIDS to confidentiality; freedom from discrimination in employment and education; and to participate in lawful civic, social, cultural, religious, sportive, political, or other activities (article 5). It

makes specific reference to the rights of children and adolescents living with HIV/AIDS, and, in

The law violates bodily integrity and privacy by allowing compulsory testing. The supposed prohibition on an employer discriminating against those who test HIV-positive offers little real protection.

particular, to the obligation of the state to promote and support the creation of foster houses and assistance centres for them, and to ensure adequate feeding, medical attention, and psychological or other required assistance (article 8). The law makes no reference to other vulnerable groups.

- The law states that all persons, and especially those living with HIV/AIDS, “are obliged” to practise sex “in a responsible way,” using “adequate methods” with the purpose of “minimizing the risks of transmission” (article 9). Every person who learns they are HIV-positive is required by the law to disclose this to their past and present partner(s), permanent or casual (article 28).
- The law also prohibits a person with HIV/AIDS not only from donating organs, blood, or tissues, but also from breastfeeding, “except for research purposes.” Furthermore, any person who makes “undue, imprudent or negligent use” of fluids, thereby causing infection to another person,

may face punishment under the Penal Code (article 10). This raises the issue of whether HIV-positive women who breastfeed will face criminal charges, and whether the government will make sure they have alternatives.

- The law requires a person to disclose their HIV-positive status to health-care workers providing care, and requires their relatives or acquaintances to disclose this if the person is unable to do so (article 28). HIV-positive health-care workers who carry out risky procedures are required to not only use universal precautions, but also to inform their employer of their condition so as to be reassigned to

risk-free work (article 29).

- The law states that prisoners have the right to receive information regarding HIV prevention, but does not mention any right to condoms or other means of prevention. Prisoners also have the right to receive required medical and hospital care under conditions that respect personal dignity (article 26).

– Richard Elliott

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¹ Available on the website of the International Labor Organization's Programme on HIV/AIDS (www.ilo.org/public/english/protection/trav/aids/).

² Available via the website of UNAIDS (www.unaids.org).

³ El Salvador: Acciones de Inconstitucionalidad Contra el Art. 16 de la Ley del SIDA. *Boletines Informativos: Acceso Centroamérica*, 9 May 2002 (available via www.aguabuena.org).

⁴ A Giralt, A Soriano. Examen de SIDA será obligatorio. *El Diario de Hoy*, 25 October 2001 (www.elsalvador.com/noticias/2001/10/25/NACIONAL); M Sánchez. Consideran la Ley del Sida inconstitucional. *El Diario de Hoy*, 26 October 2001 (www.elsalvador.com/noticias/2001/10/26/NACIONAL); A López. Impugnan ley del SIDA. *El Diario de Hoy*, 1 December 2001 (www.elsalvador.com/2001/12/NACIONAL). See also: Ley salvadoreña sobre VIH/sida genera gran molestia. *Boletines Informativos: Acceso Centroamérica*, 10 November 2001 (www.aguabuena.org); F Robles. Salvador jobs law spawns new fears for those with HIV. *Miami Herald*, 18 December 2001; Salvadoran AIDS activists protest HIV testing in the workplace. *Kaiser Daily HIV/AIDS Report*, 22 February 2002 (available via www.kaisernetwork.org/daily_reports/hiv/); C Elton on "Morning Edition," [US] National Public Radio, 3 April 2002 (www.npr.org, accessed 10 April 2002).

⁵ Unofficial translation of Decree No 588, in communication from R Kiddell-Monroe, Regional Humanitarian Affairs Advisor (Latin America), Médecins Sans Frontières (Costa Rica), 7 March 2002.

Indian NGO Challenges Penal Code Prohibition of "Unnatural Offences"

On 7 December 2001, the Naz Foundation (India) Trust (NFIT), a non-governmental organization based in New Delhi, filed a petition in the Delhi High Court to repeal the "unnatural offences" section of the Indian Penal Code that criminalizes men who have sex with men.

NFIT, represented by the Lawyers Collective HIV/AIDS Unit, argued that section 377, which prohibits "carnal intercourse against the order of nature with any man, woman or animal," is unconstitutional on several grounds. Among these, the petition cites the social stigma and police abuse that impede HIV/AIDS outreach work with men who have sex with men and thus constitute a threat to the right to life. Section 377 is based on a British law from the mid-1800s that was long ago struck off the books in the United Kingdom.

Section 377 was among the topics raised by Aditya Bondyopadhyay, a lawyer and gay rights activist, at an NGO briefing of the United Nations Commission on Human Rights in April 2002. Bondyopadhyay noted that section 377 enables the police in India to blackmail, extort, rape, and physically abuse sexual minorities, but since formal charges under its provisions are rarely brought, the government can claim that the section is "benign." "Today the issue of section 377 ... is a question of corruption simply because it is one of the lucra-

tive and easy sources of supplemental income for a venal police," he told the gathering in Geneva.

A hearing before the Delhi High Court on 23 April 2002 set a six-week deadline for official statements on the petition to be made by the government respondents in the case, which include the National AIDS Control Organisation (NACO), the Delhi State AIDS Control Society, and the Police Commissioner of New Delhi. Another hearing is scheduled for August 2002. Whether NACO in particular endorses the repeal of section 377 will be a signal of the future direction of AIDS-related policy and law in India.

– Joanne Csete

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GLOBAL ACCESS TO TREATMENT

As mentioned in the previous issue, this section of the *Review* addresses issues related to improving access to adequate and affordable care, treatment, and support everywhere. It replaces the section previously called “Patents and Prices.” In this issue, we feature a review of achievements and challenges in recent years in opening global access to HIV/AIDS treatments. The article – one of a series commissioned to mark the tenth anniversary of the Canadian HIV/AIDS Legal Network, discussing past developments and future directions in areas of policy and law related to HIV/AIDS – describes the developments that recast the debate about access to treatment from one focused on patent entitlements to one focused on the right to health and treatment. It analyzes the role of national and international activism, strategically constructed alliances, and principled leadership in achieving this change. And it discusses continuing obstacles to equitable access to HIV/AIDS treatments for the world’s population.

Global Access to Treatment: Achievements and Challenges

Introduction

Just six years ago, AIDS was seen as effectively untreatable – a death sentence for all infected with HIV. Then a revolution occurred. In affluent countries, medications became available to most people with HIV/AIDS, sharply reducing AIDS-related sickness and deaths. But that hope has not reached the overwhelming majority of the world’s people with HIV/AIDS, for whom treatment remains inaccessible.

This article examines the impact of stringent patent regulation and global inequalities that have impeded access

to medication, and of significant changes in recent years that have mitigated their impact. These include increasing acceptance in international and domestic law of the right to health, and key events in the international arena. Activists have been largely responsible for these developments, as has the skilful creation of cross-sectoral alliances and principled leadership. These successes point the way to the further breakthroughs still needed for effective delivery of life-saving treatments to most of the world’s people with HIV/AIDS.

From Incurability to Treatment

AIDS was first observed in the United States during the Reagan presidency. The response was pronounced public prejudice and governmental denial.¹ There was no treatment and little public sympathy or understanding of the disease.² Well into the epidemic’s second decade, researchers discovered that administering the antiretroviral drug zidovudine (AZT) during pregnancy could reduce the rate of mother-to-child transmission by two-thirds.³ Barely two years later, it was dramatically announced in 1996

that careful use of antiretroviral drugs could effectively still the activity of HIV in the human body.⁴ A small group of clinical-trial patients

At an annual cost of approximately US\$10,000-15,000 per patient, the new drugs were exorbitantly priced.

had negated the equation between AIDS and death. For the first time, it seemed possible that AIDS could be viewed not as an invariably fatal disease but as a chronic, medically manageable condition.

In the intervening years, the epidemic's human form had changed profoundly. By the late 1980s, its demographic preponderance was no longer among Western gay men. It had become a largely heterosexually transmitted disease in Asia, Latin America, the Caribbean, and particularly Africa. The Joint United Nations Programme on HIV/AIDS (UNAIDS) estimates that since the start of the epidemic more than 60 million people have been infected. HIV/AIDS is now the leading cause of death in sub-Saharan Africa and the fourth-largest cause of death worldwide.⁵ It is "one of the most destructive microbial scourges in history,"⁶ "the worst worldwide pandemic in 600 years."⁷

Will treatment reach the vast numbers of those living with HIV/AIDS? Or will the outlook for them remain as bleak as it was for the gay men of the early 1980s whom HIV/AIDS first affected? For the great majority of those with HIV/AIDS, the new treatments have held little promise.⁸ The

exhilaration felt by doctors treating HIV/AIDS in the developed world⁹ contrasts starkly with the helplessness felt by those in developing countries. At an annual cost of approximately US\$10,000-15,000 per patient, the new drugs were exorbitantly priced. In countries where the average daily income was barely US\$1, they were unthinkably expensive.¹⁰

These prices were attributed largely to strict global patent protection under treaties such as the Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS),¹¹ which sets minimum standards of patent protection for World Trade Organization (WTO) member states.¹² Under TRIPS, patent protection lasts for 20 years, although compulsory licensing (production without the consent of the patent holder, with payment of adequate compensation) is contemplated as a safeguard, particularly – but not only – in cases of public health emergencies or unfair pricing practices.¹³

There is no doubt that "shared medical ignorance" about HIV continues to create a situation of near hopelessness about HIV/AIDS in resource-poor settings. But even where knowledge is available – and this includes significant areas of the resource-poor world – drug pricing inhibits improvement: "No longer was it the limits of medicine that defined the situation. Rather it was the inability to afford treatments because of resources."¹⁴

Treatment Activism and Access to Treatment

Progress in reducing inequities in access to treatment may be attributed in large part to a combination of critical interventions: acutely planned and directed national and internation-

al activism; strategically constructed alliances; and principled leadership, within organizations and at national and international levels.

The demand for affordable, accessible medical treatment for all people with HIV/AIDS has become one of the most dynamic movements in the history of global activism. Characterized by its energy and integrity, it has mobilized public opinion and support, and has had a dramatic impact on the international debate about drug pricing, corporate profits, and governmental responsibility. In the midst of current dogmas about "globalization," the movement has highlighted the gross inequalities between the globe's North and South, dramatically underscoring the latter's insistence on fair market policies.

The demand for affordable, accessible medical treatment for all people with HIV/AIDS has become one of the most dynamic movements in the history of global activism.

Philosophically, the question of access to treatment for people with HIV/AIDS raises compelling questions about the link between health and human rights (signal among which is the right to human dignity).¹⁵ The movement has brought about significant practical shifts in nearly every aspect of the debate about HIV/AIDS treatment, including the practical complexities of providing health services and large-scale entitlement to the best available treatment. And it challenges current

thinking with regard to discrimination, medico-legal ethics, and the rights of patients and vulnerable populations.

Health Rights and Access to Treatment – Perceptible Progress

The activists' struggle has brought perceptible gains, particularly since the XIII International AIDS Conference in Durban focused world attention on glaring inequities in access to treatment. Drug prices have come down, the international climate favouring access to treatment has greatly improved, and major developments within international organizations have enhanced prospects for access for greater numbers of people with HIV/AIDS.

Perhaps the most fundamental advance has been a perceptible shift in global debate and thinking. International instruments such as the Universal Declaration on Human Rights (UDHR)¹⁶ and the International Covenant on Economic, Social and Cultural Rights (ICESCR)¹⁷ have long enshrined the right to health. The larger question is their practical import. Health is fundamental, but also extremely vulnerable. The 2000 World Health Report of the World Health Organization (WHO) notes that health, although an “inalienable asset,” is “subject to large and unpredictable risks, which are mostly independent of one another.”

Key insights

In the 1980s, the HIV/AIDS epidemic prompted two key insights on the interconnections between health and human rights.¹⁸ First, the suggestion that rights protection for those with HIV/AIDS was inimical to the rights of the uninfected was shown to be unfounded, in logic and in practice.

Instead, the “AIDS paradox”¹⁹ gained recognition: security of rights and protection against discrimination for those with HIV/AIDS is the most effective way to enhance prevention and education programs, which in turn minimize transmission, thus protecting the uninfected.

Second, the correlation between human rights vulnerabilities and vulnerability to HIV/AIDS was documented and established.²⁰ In short, human rights violations facilitate the spread of HIV. Through these insights, the late Jonathan Mann and others prepared the doctrinal and ethical foundation for questioning patent regulation of life-saving treatments. Presciently, Mann and his associates noted in 1992:

A logical outcome of the successes of the AIDS activism in the industrialised world ... will be to connect issues and struggles in the developing and industrialised countries.... [A]ccess to AZT, other antiretroviral agents and drugs to treat opportunistic infections are all extremely limited or totally absent in the developing world.²¹

A third, more recent critical insight is that treatment and prevention are properly seen as conjoined, not counterpoised. Assertions that treatment of people with HIV/AIDS and prevention of new HIV infections represent two exclusive or conflicting options in responding to the pandemic, or that we must choose to direct funds and effort principally to either one or the other, are mistaken.²² Treatment assists prevention²³ in at least three ways.

Physiologically, treatment is a form of prevention. This is most evident in mother-to-child transmission: treatment with antiretroviral drugs can prevent an infant from acquiring

HIV from the mother. Some evidence also exists that an effective course of antiretroviral drugs may inhibit sexual transmission of HIV.²⁴

Treatment and prevention are properly seen as conjoined, not counterpoised.

Psychologically, treatment also enhances prevention because it affords those already infected with an incentive to come forward to be tested, to receive counselling, and to engage positively with the complexities of behaviour modification.

Socially, treatment also enhances prevention because it reduces the stigma of death and incurability that surrounds AIDS. Treatment offers hope. And hope dispels the notion that AIDS necessarily entails doom, that confronting it is fraught with failure and that, once infected, the subject faces only debilitation and death. Treatment has broken the equation between AIDS and death, permitting us to begin undoing the social stigmas and phobias that make frank and effective HIV prevention so difficult.²⁵

Popular action

Mann and others contributed to a growing consensus on the entitlement to health as a basic human right. In turn, the conceptual breakthrough has inspired popular action. Activists have mobilized public support – including through creative alliances between patients' rights groups, consumer protection groups, and the labour movement – to challenge protectionist arguments that deny medication to those in need. Treatment activists in several Latin

American countries did pioneering work. More recently, South Africa's Treatment Action Campaign²⁶ has been the country's most successful

What is striking is the way activists have invoked the right to health and to treatment.

civil society organization since the democratic transition of 1994.²⁷ From a skilfully constructed mass popular base within South Africa, it mobilized global support against drug-company practices. Subsequently, it invoked its local and international connections against the South African government's continuing refusal to implement a nationwide mother-to-child transmission program.²⁸ In the United States, ACT UP and other organizations challenged the presidential campaign of Vice-President Al Gore because of his support for policies protecting drug companies and patents.²⁹

What is striking is the way activists have invoked the right to health and to treatment.³⁰ These rights are also increasingly penetrating national jurisprudence³¹ and constitutions.³² Cases in Costa Rica,³³ El Salvador,³⁴ and Venezuela³⁵ have successfully asserted the rights enshrined in the Universal Declaration of Human Rights and international human rights covenants requiring governments to supply HIV treatments. This emerging trend indicates that governments' contention of limited resources is no longer accepted as conclusive. The new approach questions whether a matter of life and death for so many can be relegated to a non-reviewable ambit of

government policymaking on social and economic issues.

The International AIDS Conference in Durban in 2000 added considerable pace to these trends. Before the conference, a Treatment Action Campaign-organized global march for access to treatment set the tone for sessions that critically scrutinized international practices and corporate policies.³⁶ Thereafter, the court challenge that drug companies had mounted against South African legislation aimed at increasing access to medicines came to trial amid unprecedented international attention. The companies withdrew their suit; this was widely viewed as a victory for treatment activists.³⁷

International developments

Since then, civil society's push for access to treatment has contributed to three international developments.³⁸ The first is the Declaration of Commitment on HIV/AIDS issued by the United Nations General Assembly Special Session (UNGASS) on HIV/AIDS in June 2001.³⁹ The second was the establishment of a Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM). The third was the Declaration on the TRIPS Agreement and Public Health adopted at the Fourth WTO Ministerial Conference in Doha, Qatar, in November 2001.⁴⁰

The UNGASS was preceded by significant work in international forums. From late 1999, the World Bank emphasized AIDS as categorically important to world development.⁴¹ In April 2001, the UN Commission on Human Rights adopted a resolution on the protection of human rights in the context of HIV/AIDS, inviting states, UN bodies, and inter- and non-governmental organizations to "contribute to inter-

national cooperation in the context of HIV/AIDS-related human rights through, amongst others, working on advancing HIV/AIDS prevention and care programmes, including facilitating access to treatment and care in the context of HIV/AIDS, and through sharing knowledge, experiences and achievements concerning HIV-related issues."⁴²

Another Commission resolution stated that access to medications in the context of pandemics such as HIV/AIDS is "one fundamental element for achieving progressively the full realisation of the right of everyone of the enjoyment of the highest attainable standard of health."⁴³ It urged international, national, and regional organizations, governments, civil society, and business sectors to support strategies that "strengthen

Civil society's push for access to treatment has contributed to three key international developments.

health care systems and address factors affecting the provision of HIV-related drugs, including anti-retroviral drugs, *inter alia*, affordability and pricing, including differential pricing, and technical and health-care system capacity" and to "make every effort to provide progressively and in a sustainable manner, the highest attainable standard of treatment for HIV/AIDS." The UNGASS endorsement of this approach,⁴⁴ undoubtedly encouraged by the leadership of UN Secretary-General Kofi Annan,⁴⁵ was a significant breakthrough for access to treatment.

International public pressure ensured that the issue was high on the agenda of the WTO Ministerial Conference at Doha, Qatar, in November 2001. The outcome was a specific Declaration on the TRIPS Agreement and Public Health affirming that the Agreement “can and should be interpreted and implemented in a manner supportive of WTO Members’ right to protect public health and, in particular, to promote access to medicines for all,” and a main Ministerial Declaration stressing the importance of interpreting and implementing TRIPS “in a manner supportive of public health, by promoting both access to existing medicines and research and development into new medicines.”⁴⁶ This in itself was a signal achievement, and was rightly hailed as such. It not only affirmed countries’ right to use compulsory licences and parallel imports to meet public health objectives, but offered more flexible readings of international agreements.

These developments were reflected within the UN system. In March 2002, the WHO included antiretroviral drugs – including some generic versions – on its list of essential medicines.⁴⁷ (Generic drugs are those with chemical properties and biological effects equivalent to patented products, but produced and sold more cheaply by competitors of the patent holders.) In April 2002, the UN Commission on Human Rights again adopted a resolution on access to medication in the context of pandemics such as HIV/AIDS, incorporating elements of the WTO Doha Declaration.⁴⁸

Significantly, leaders in some (though regrettably not all)⁴⁹ developing nations have endorsed the activists’ demands. The Brazilian government, driven by such

demands, has been pre-eminent in its response, deciding in 1996 to “ensure access to [antiretroviral drugs] to 100% of identified HIV patients in the country.” Policy and legislation have ensured full and free access to antiretroviral drugs in the public sector.⁵⁰ Some African leaders have also joined the struggle for access to treatment for people with HIV/AIDS. President Festus Mogae of Botswana stated in December 2000 that the AIDS epidemic should be dealt with as an emergency “with measures that a crisis deserves,”⁵¹ including diversion of resources from military expenditure.⁵² Botswana later announced a commitment to providing people in the public sector who have HIV/AIDS with antiretroviral drugs.⁵³ In April 2002, Zambian President Levy Mwanawasa stated that his government would request US\$19 million from the Global Fund to purchase combination treatments for Zambians with AIDS.⁵⁴ In May 2002, the government of Zimbabwe declared its HIV epidemic a “national emergency.”⁵⁵

Meanwhile, drug prices have also fallen appreciably. It has been argued that this fall resulted from “credible threats of generic entry that have been made possible by the existence of a competitive market for [antiretroviral] drugs” that existed because Brazil and India in particular could produce antiretroviral drugs before WTO-regulated patent enforcement takes effect.⁵⁶ At present, a triple combination of antiretroviral drugs still costs approximately US\$10,000-\$15,000 per patient per year in the US and Western Europe. However, generic drug producers have stated they will sell the equivalent medicines for as low as US\$300 per patient per year.⁵⁷ Competition from generic producers, combined

with public pressure on drug companies, has pushed down the prices of even some brand-name drugs to around US\$700-\$1000 per year.

Drug prices have fallen appreciably, arguably because of competition from generic producers.

Médecins Sans Frontières (MSF) considers that, with expanded production, prices could fall to as low as US\$200 per patient per year. At these levels, antiretroviral drugs could be brought within reach of many more patients and, with international donor support, could be delivered to even more.⁵⁸

In sum, in the brief period since 2000, treatment activists have set the agenda. The debate about access to treatment has been transformed from legalistic assertions of patent entitlements to a growing insistence on the provision of adequate treatment at affordable prices for all the world’s people with HIV/AIDS. The conundrum of patent protection continues, however, to loom large in any contemplation of future developments.

Health Rights and Access to Treatment – The Conundrum of Patent Protection

The movement for access to treatment has struggled for regulatory flexibility for developing countries under the TRIPS Agreement⁵⁹ and for the power to depart from minimum standards of intellectual property protection in order to provide affordable HIV drugs. These measures include compulsory licensing

for countries with an existing infrastructure for generic manufacturing, and rights of parallel importation of

The debate about access to treatment has been transformed from legalistic assertions of patent entitlements to a growing insistence on the provision of adequate treatment at affordable prices for all the world's people with HIV/AIDS.

lower-priced patented drugs from other countries. The central question has been whether the public interest can prevail over corporate interests in compensation and reward and, if so, to what extent.

Arguments in favour of protecting intellectual property rights, including drug patents, are of different kinds. The first is the “cost” or “labour” argument: the innovator’s outlay of time, effort, and expense in developing a product should be compensated through a continuing charge on others who use the product. The second is the “reward” argument: the innovator is entitled to a just reward for inventive effort, as a matter of inherent desert. On this view, the idea or product in some sense “belongs” to the originator, and this should be recognized by a continuing impost on others who use it. The third, the “incentive” argument, is instrumental in nature: intellectual property protection is a method to garner assets that serve as a means for, and an incentive to, further research and development. The drug companies in

their public statements lay emphasis on this argument.⁶⁰

Intellectual property rights are not absolute

But none of these arguments, even at face value, establish a justification for absolute patent protection. The arguments from individual labour and reward in themselves by no means establish a case for undiminished patent protection.⁶¹ Nor do the arguments make a persuasive case for over-extensive regulation of ideas and their offspring, particularly in the face of an international public health crisis in which many millions may be saved through flexibility in patent regulation.

The debate of the past few years has underscored that legal protection for the commercial exploitation of ideas is not a natural or even self-evident right. It is a social construct – one engineered for the utility and interest of the public, and therefore only justifiable so long as, and to the extent that, it serves the utility and interest of the public. As Berger argues, public interest and not the profitability and mere compensation of the innovator are the principal values behind granting of patents.⁶²

In short, patent protection, being a product of social policy, must conform to human rights objectives if it is to continue. As Chapman states:

Ultimately a human rights approach requires that intellectual property protection serve the objective of human well-being, to which the international human rights instruments give legal expression. Human rights are inalienable and universal claims belonging to individuals, and in some situations to communities, but never to corporations. Human rights are understood to

exist independently of recognition or implementation while intellectual property rights are granted by the State according to criteria defined by national legislation. In contrast with human rights, which establish permanent and irrevocable entitlements, intellectual property rights are temporary; they exist for a limited period and can be revoked, licensed or assigned to someone else.⁶³

The case for patent protection undermined

This human-rights approach to intellectual property regulation, premised on pursuit of the public interest and on human well-being, may have seemed extreme or even eccentric some years ago. It no longer is. It is a matter of supreme – and to many, bitter – irony that the public-interest basis of patent protection (and, accordingly, its subordination to public necessity in a health emergency) was most dramatically asserted not where the HIV/AIDS

Patent protection, being a product of social policy, must conform to human rights objectives if it is to continue.

epidemic threatens to cripple poor nations, but in the United States. In the aftermath of the terrorist attacks on New York City and Washington DC in September 2001, when dissemination of anthrax spores appeared to threaten American lives, the US (and Canadian) governments proposed in short order to override the intellectual property rights in the drug required to treat it.⁶⁴ The bitter-

ness arises from the rigidly protectionist stance on patent protection the US government has otherwise taken (both before and since), and its threat to impose punitive sanctions on resource-poor countries that proposed to confront their own public health emergencies, particularly HIV/AIDS, by abridging patent protection.

Whatever aftertaste the North American anthrax scare may leave, it has incontestably established the public-interest premise underlying patent protection. It puts in appropriate perspective the clamant demand for access to treatment for those in the resource-poor world who are dying without such treatment.⁶⁵

Yet the struggle to realize that demand is still contested. Developing countries subjected to pressure by international drug companies, and by governments that support them, include India,⁶⁶ Brazil,⁶⁷ Thailand,⁶⁸ and, as noted above, South Africa. Pressure tactics have included trade sanctions, formal complaints at the WTO, and domestic litigation – this under an international trade regime that protects the already privileged while requiring developing nations to liberalize their markets and enforce patent protections.⁶⁹ Although some governments give intellectual property rights great weight under the international law regime – however selectively or even hypocritically – there is little recourse for their disregard of other rights: “There are no economic sanctions for those who persistently abuse or ignore the obligation, for example, to ensure the right to basic medical care for all.”⁷⁰

In any event, some of the arguments advanced about rewards and incentives for drug development have been particularly hollow in the context of HIV/AIDS. Many HIV/AIDS

treatments have been researched and developed not through the initiative or use of the profits of drug companies but through government-funded public institutions.⁷¹ Furthermore, enforcing patents in resource-poor countries has at best an indirect relation to the cost/reward/incentive arguments frequently advanced, because the commercial market for patented drugs lies overwhelmingly in North America, Europe, and Japan. More than three-quarters of the US\$406 billion global drug market projected for 2002 is in the world’s richest regions. Only a fraction of the exploitable market lies elsewhere (the whole of Africa accounts for just over one percent).⁷²

The inference is that patent protection in resource-poor countries can be justified only on the premise that porous borders may threaten resource-rich markets if drugs cheaply produced elsewhere are imported. In this light, policing non-viable markets to ensure commercial gain in other areas of the world is open to a charge of being bullying behaviour⁷³ – in particular because international instruments recognize a general right to the enjoyment of the benefits of scientific progress.⁷⁴ Where policing seems certain to entail the death of many millions because life-saving drugs will remain inaccessible, profound ethical questions inevitably arise.

WTO and TRIPS under scrutiny

Against this background, international organizations such as the WTO have come under increasing scrutiny. Proponents of the WTO claim its role is to encourage free and fair trade, setting efficient uniform standards and a rule-based mechanism for resolving disputes, with the ultimate goal of contributing to the well-

being of individual citizens in national economies.⁷⁵ But the interests of large corporations associated with wealthy nations have played an influ-

Some of the arguments advanced about rewards and incentives for drug development have been particularly hollow in the context of HIV/AIDS.

ential role in shaping not only WTO policies but also the interpretations of TRIPS.⁷⁶

Does TRIPS offer a sound and just framework for resolving the tensions between patent protection and the demand for access to treatment? From a purely intellectual property point of view, TRIPS proponents argue that it provides an adequate framework for the resolution of legal issues.⁷⁷ However, that does not address the larger question of whether international patent laws should be allowed to restrict nations from meeting minimum standards of human rights and services to which they have committed. Creating exceptions to TRIPS need not violate the overriding tenets of international agreements on trade. It would merely aim to secure the provision of basic socioeconomic rights to the world’s poorest communities.

Indeed, Berger has argued that TRIPS would fail in its stated aims if an interpretation compatible with recognition of the right to health were not adopted. In other words, regulatory flexibility is integral to the conception of TRIPS. A rational approach to intellectual-property protection would focus on whether a

country's comparative advantage lies in innovation rather than in imitation and adaptation of others' innovations. This focus would broaden the ambit

The Doha agreement, though rightly hailed as a breakthrough for equitable access to treatment, has limitations.

of regulatory concern beyond innovators, imitators, and adapters to include the interests of domestic consumers. International trade treaties should be capable of compliance with domestic constitutions; they should not be used to obstruct the constitutional duties of governments and states.⁷⁸

Patent Protection – A Continuing Obstacle to Equitable Access

The Doha Declaration was rightly hailed as a breakthrough for equitable access to treatment. But in its own terms the agreement has limitations, and it has not proved wholly effectual in correcting international practice to make it accord with the necessities of access to treatment.

One instance is Article 31(f) of TRIPS, which requires compulsory licences to be used “predominantly for the supply of the domestic market.” The Doha participants recognized the barrier this creates to using compulsory licences to export generic drugs. But they omitted to remove it immediately, instead instructing the WTO's subsidiary body, the Council for TRIPS, “to find an expeditious solution to this problem and to report to the General Council before the end of 2002.”⁷⁹ The outcome remains

unclear. The fact is that many countries – including those most direly affected by AIDS – entirely lack the industrial capacity to produce their own generic medicines. For them, TRIPS leaves little recourse. On the other hand, many existing antiretroviral drugs are not under patent in countries that manufacture generic medications; resort may be had to importation of generics either in the absence of a patent or under authority of a compulsory licence. However, as newer and better treatments become available, and as developing countries (such as Brazil and India) with generic production capacity are or become constrained under TRIPS, the limitations on exports will become an increasing problem.

A WTO meeting in March 2002 debated proposals by the United States, the European Community, and a large group of developing countries.⁸⁰ The US government was disinclined to approve parallel importation rights for generic drugs. Many developing countries and non-governmental organizations contend that the obvious solution is to lift TRIPS restrictions on the export of products essential to public health that are produced under compulsory licence.⁸¹

In any event, much still needs to be done to integrate the greater leeway promised under TRIPS into developing countries' domestic legislative regimes. Cambodia, for instance, has not yet utilized the extended transition period agreed to at Doha. Moreover, effective follow-up requires not only integration of the Declaration into technical assistance programs, but also compatibility between the policies and practices of pharmaceutical companies and the Declaration. Oxfam has observed that, “as if Doha had never hap-

pened,” the drug companies' lobby organization, Pharmaceutical Research and Manufacturers of America (PhRMA), recommended in February 2002 that the US government designate four new countries as “priority countries” for monitoring and for potential trade sanctions under US trade law, for their alleged “failure to protect patented pharmaceutical products.”⁸² With such resistant attitudes toward equitable use of intellectual property, access to treatment for people with HIV/AIDS remains elusive.

While the greater flexibility promised in Doha is proof of civil society's capacity to shape international policy, considerable follow-up advocacy regarding TRIPS is needed. Although a detailed discussion is not possible here, treatment-access advocates will also need to consider turning their attention to the General Agreement on Trade and Services (GATS), another pillar of the WTO system, and its anticipated impact on equitable access to health-care services and systems.⁸³

Access to Treatment – Continuing Challenges

In some significant respects, the scene has been set for realizing hugely increased access to treatment for millions of people with HIV/AIDS in the developing world who face avoidable death. The international debate has shaped itself to their calls. The international intellectual property regime is proving at least not wholly unresponsive to their demands. Drug prices have come down. And the establishment of the Global Fund is at least a light on the path to realizing health rights, including treatment for HIV/AIDS.

Yet enormous obstacles remain. First and most important, a massive

increase in public financing is required to strengthen health services and subsidize the purchase of medicines in developing countries.⁸⁴ Although the Global Fund is one of the most significant international developments for enhancing access to treatment, it is presently grossly underfunded and needs to grow rapidly to the point where it raises US\$10 billion a year.⁸⁵ Surprisingly to many, and regrettably, it is not yet clear whether the Fund will be used to pay for antiretroviral drugs.⁸⁶ In its statement of underlying principles, the Fund's transitional working group stated it would pursue "an integrated and balanced approach."⁸⁷ Balance and integration are important, as long as they are not coded language for postponing urgent funding for access to antiretroviral treatments.

Underlying the endowment of the Fund is the question of debt relief for heavily indebted nations, which include those that are bearing the greatest burden in the HIV/AIDS epidemic. It was estimated, before

A massive increase in public financing is required to strengthen health services and subsidize the purchase of medicines in developing countries.

the current focus on access to antiretroviral drugs, that Africa needs US\$3 billion a year for HIV/AIDS prevention and care. Yet many African countries spend 40 percent of their export earnings to service their foreign debt.⁸⁸ It is estimated that the 22 African countries that

have so far qualified to receive some relief under US legislation⁸⁹ are still burdened by almost US\$2 billion annually in debt repayments to creditor countries and institutions.⁹⁰ The Bush administration has budgeted only US\$998 million for 2002 for global HIV/AIDS, and plans to increase this amount to US\$1.1 billion in 2003.⁹¹ Given the predominance of the US in resources, trade, and wealth, this is inadequate.

Treatment advocates have never suggested that price is the only barrier to equitable access – barriers are numerous.⁹² On the social and infrastructural level, they include supply and storage problems, substandard drug quality, irrational selection of drugs, wasteful prescription and use, inadequate production, and insufficient and misdirected drug research and development.⁹³ On a personal level, compliance and monitoring must be assured. But studies have shown that antiretroviral medication can feasibly be supplied, accessed, administered, and monitored in resource-poor settings.⁹⁴ And breakthroughs in achieving affordable monitoring of virus levels and immune-system markers put this goal within closer reach.⁹⁵

The activists' success in securing drug-price reductions necessitates a broader focus on public-sector infrastructure and logistical problems of delivery and maintenance. The success that individual non-governmental organizations such as South Africa's Treatment Action Campaign have attained and, conversely, the continuing resistance on the part of the South African government to implement rational policies in drug provision, highlight the extent to which it would be imprudent to focus purely on the public sector in creating capacity for drug delivery.⁹⁶

Existing community organizations, both local and international,⁹⁷ churches and other faith-based organizations,⁹⁸ and trade unions will

Treatment advocates have never suggested that price is the only barrier to equitable access.

all have to be involved in the massive logistical and practical effort of delivering treatment to nearly 40 million people in resource-poor settings. If these broader paths are not followed, we risk limiting life-saving treatments to the relatively affluent, an unjust division on class lines. International policy documents such as the UNGASS Declaration of Commitment on HIV/AIDS recognize these imperatives.⁹⁹ Realizing them will require continued activism, the creation of more alliances, and political leadership of unprecedented proportions.

Experiences in Latin America and South Africa have shown that public-interest litigation can be a powerful and effective tool for gaining health rights. In South Africa, in particular, litigation strategies have been closely combined with the formation of inter-sectoral alliances, between treatment activist groups and churches and trade unions.¹⁰⁰ But the very success of these litigation strategies has derived from a broader acceptance of health as an enforceable right. Successful litigation in its turn can facilitate the development over time of the content and implications of a right through judicial and administrative interpretation in concrete cases, as well as through scholarly analyses.¹⁰¹

Conclusion

We should not underestimate the importance of what activism, alliance formation, and principled leadership have attained domestically and at the level of international institutions:

For many indigenous people in developed countries, and most ordinary patients in the Third World, notions of fundamental rights in the context of health-care may seem to be rhetoric rather than reality. Nonetheless, reporting obligations to the United Nations, the inquisitive investigations of international relief and human rights agencies, troublesome non-governmental organisations at home and the political process itself can help to turn serious deprivations of the fundamental right to health into the subjects of political action.¹⁰²

The treatment movement has succeeded in identifying a socioeconomic right, namely the right to health, and through insistence on progress toward its realization, brought the attainment of many other such rights into closer focus. It would not be an exaggeration to state that in this it has enhanced the possibilities of social justice in societies where it has been active and in the world itself. What remains is to build urgently on the foundations of what has been achieved. If we fail in that task, many tens of millions face avoidable death.

– Mr Justice Edwin Cameron,
with Alok Gupta

Mr Justice Cameron is a Judge of the Supreme Court of Appeal of South Africa. He can be reached at cameron2@mweb.co.za. Alok Gupta was research assistant to Justice Cameron in April-May 2002. He can be reached at galok@vsnl.com. The authors are grateful to Jonathan Berger of

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Africa, 16 October 2001, at www.cptech.org/ip/health/africa/dopatentsmatterinfrica.html, noting that important drugs such as Trizivir were omitted from the Attaran/Gillespie-White study, and that "lower prices for ARV drugs in Africa are due to credible threats of generic entry" made possible by production in absence of patent prohibitions.

¹² On 1 January 1995, the WTO (representing 144 countries as of 1 January 2002) replaced the General Agreement on Tariffs and Trade (GATT 1947) as the regulatory framework for multilateral trading (see www.wto.org/english/thewto_e/gattmem_e.htm).

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¹⁴ Bayer, *supra*, note 8.

¹⁵ See VA Leary. The right to health in international human rights law. *Health and Human Rights* 1994; 1(1) (www.hsph.harvard.edu/fbccenter/VINI1.htm).

¹⁶ Article 25: "Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family." See J Mann. Dignity and health: the UDHR's revolutionary first article. *Health and Human Rights* 1998; 3(2): 31-38. UDHR Article 1 reads: "All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood."

¹⁷ Article 12 recognizes "the right of everyone to the enjoyment of the highest available standard of mental and physical health." It requires governments, among other steps, to take necessary measures for the "prevention, treatment, and control of epidemic, endemic, occupational and other diseases," as well as to create "conditions which would assure to all medical service and medical attention in the event of sickness." Also see UN Committee on Economic, Social and Cultural Rights. General Comment 14 on "The right to the highest attainable standard of health" (Article 12 of the International Covenant on Economic, Social and Cultural Rights) UNESCO, 22nd Session, UN Doc. E/C.12/2000/4, CESCR General Comment No. 14 (2000), available via www.unhcrch/tbs/doc.nsf by clicking on "CESCR" and then on "General Comments."

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³⁹ United Nations General Assembly Special Session on HIV/AIDS. Declaration of Commitment on HIV/AIDS, supra, note 23.

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⁴⁶ Ministerial Declaration, Fourth Session of the WTO Ministerial Conference, Doha, 9-14 November 2001, WT/MIN(01)/DEC/W1, para 17 (available via www.wto.org).

⁴⁷ Joint press release by WHO/UNAIDS/UNICEF. Initiative to promote access to quality HIV medicines releases first batch of results today. Release WHO/19, 20 March 2002 (www.unaids.org/whatsnew/press/eng/pressarc02/HIVmedicines_200302.html). The list includes eleven antiretroviral drugs and five products for opportunistic infections. The antiretroviral drugs on the list allow for several triple therapy combinations. This is the beginning of a continuing process. More products and suppliers, when found to meet prescribed standards, will be added. The Access to Quality HIV/AIDS Drugs and Diagnostics project is part of a UN-wide strategy to improve access to HIV treatment. The strategy is meant to promote rational use of drugs; affordable prices for medicines and diagnostics; sustainable financing; and reliable health and supply systems. The Director-General of the WHO, Gro Harlem Brundtland, has stated that the WHO wants "to see an expansion in people's access to quality health care, particularly in relation to those diseases, like HIV/AIDS, that keep them poor and prevent the economic development of their communities."

⁴⁸ Resolution 2002/32, 22 April 2002 (available via www.unhcr.ch/hiv/documents.htm).

⁴⁹ On 17 April 2002, the South African government released a statement acknowledging for the first time that antiretroviral drugs "could help improve the conditions of PWAs if administered at certain stages of the progression of the condition, in accordance with international standards," and expressing a commitment "to work for the lowering of the cost of these drugs" (www.gov.za/speeches/cabinet/aid02.htm). At the time of writing it is unclear whether and how the South African government will carry this commitment to practical effect.

⁵⁰ According to the National AIDS Drug Policy of the Brazilian Ministry of Health (2001), "Congressional Bill 9113, of 13 November 1996, guarantees every patient access, free of direct costs, to all the medications required for his/her treatment, including protease

inhibitors."

⁵¹ AIDS: The Greatest Leadership Challenge. Address given at the Addis Ababa African Development Forum, 4 December 2000 (available via www.uneca.org/adf2000/daily_updates/index.htm).

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⁵⁶ Consumer Project on Technology, Essential Action, Oxfam, Treatment Access Campaign, and Health Gap, supra, note 11. Brazil enacted TRIPS-compliant legislation before it was required to do so by the TRIPS Agreement.

⁵⁷ New list of safe AIDS drugs, despite industry lobby. *New York Times*, 20 March 2002. For the Indian-based generic drug manufacturer Cipla, see: A very pushy drug dealer. *Times of India*, 29 April 2002 (available via www.cipla.com/whatsnew/ciplanews.htm#AIDS).

⁵⁸ See in general www.accessmed-msf.org/campaign/faq.shtm.

⁵⁹ TRIPS Article 8.1 states: "Members may, in formulating or amending their laws and regulations, adopt measures necessary to protect public health and nutrition, and to promote the public interest in sectors of vital importance to their socio-economic and technological development, provided that such measures are consistent with the provisions of this Agreement."

⁶⁰ Pharmaceutical Research and Manufacturers of America (PhRMA). Why do prescription drugs cost so much ... and other questions about your medicines (www.phrma.org/publications/publications/brochure/questions).

⁶¹ P Drahos. *A Philosophy of Intellectual Property*. Aldershot, England: Dartmouth Publishing Company Limited, 1996, at 52, quoted in JM Berger. Tripping over Patents: AIDS, Access to Medicines and the Manufacturing of Scarcity. LLM Thesis, University of Toronto School of Law, June 2001, at 22 (available via www.tac.org.za): "Concentrating on the labour of individuals might extinguish the possibility of private ownership of abstract objects altogether: Within an interdependent, differentiated society the labour of any one individual is made possible by the labour of others. If we define a direct contribution of labour in terms of a contribution that enables the production of an abstract object, this forces recognition of the fact that many ostensibly individually owned abstract objects are in reality collectively owned by virtue of joint labour."

⁶² Berger; supra, note 61 at 22-25 (section 1.1.1).

⁶³ AR Chapman. New projects focus on intellectual property and human rights. *Report on Science & Human Rights* 2002; 12(1) (<http://shraaas.org/report/xxii/ip.htm>).

⁶⁴ On the US and Canadian governments' approach to ciprofloxacin for the treatment of anthrax, see Editorial. Patent protection versus public health. *Lancet* 2001; 58: 1563.

⁶⁵ DM Berwick. We all have AIDS. *Washington Post*, 26 June 2001: A17: "Here is what the world needs: free anti-AIDS medicines. The devastated nations of the

world need AIDS medicines at no cost at all, or at a bare minimum, medicines available at exactly their marginal costs of manufacture, not loaded at all with indirect costs...".

⁶⁶ The Indian drug industry is an example of what happens when companies are given the authority to produce drugs for the local market without paying burdensome licensing fees. Currently, Lariam®, a malaria treatment, costs US\$37 in the US and US\$4 in India, while AZT cost US\$239 per month in the US and US\$48 in India. These lower prices may disappear if India is compelled to enforce domestically patented medicines. See www.iglhrc.org/issues/accesstotreatment/accesstodrugs.html.

⁶⁷ For an overview of Brazil's experience with providing HIV/AIDS treatment, see M Harrington: Brazil: What Went Right? The Global Challenge of Access to Treatment & the Issue of Compulsory Licensing, 10th National Meeting of People Living with HIV and AIDS, Rio de Janeiro, 3 November 2000 (<http://www.aidsinfonyc.org/tag/activism/brazil.html>).

⁶⁸ IGLHRC. Getting the law on your side: monopolies don't make a "free market" (www.iglhrc.org/issues/accesstotreatment/accesstodrugs.html).

⁶⁹ Oxfam. Rigged Rules and Double Standards: Trade, Globalization, and the Fight Against Poverty (available via www.maketradeafair.com).

⁷⁰ M Kirby, The right to health fifty years on – still sceptical? *Health and Human Rights* 1999; 4(1). Also available at www.lawfoundation.net.au/resources/kirby/papers/19981214_harv.html.

⁷¹ Consumer Project on Technology. Additional notes on government role in the development of HIV/AIDS drugs, 23 February 2000 (www.cptech.org/ip/health/aids/gov-role.html).

⁷² See www.accessmed.msf.org.

⁷³ One pharmaceutical company applied pressure to the Ghanaian government not to permit importation of a generic version of its drug, even though the drug was not patented in Ghana.

⁷⁴ ICESCR Article 15.1(b) recognizes the right of everyone "to enjoy the benefits of scientific progress and its applications" (www.unhcr.ch/html/menu3/b/1a_ceschr.htm).

⁷⁵ JM Lang, The WTO: Is it working? In: Are international institutions doing their job? Proceedings of the 90th Annual Meeting of the American Society of International Law (ASIL), 27-30 March 1996, Washington DC. Former Ambassador Lang stated that the US role in establishing the WTO "reflects a recognition that trade can serve as a useful catalyst to further the well-being of both national economies and individual citizens."

⁷⁶ SR Friedman. HIV-related politics in long-term perspective. *AIDS Care* 1998; 10(2): 93-103.

⁷⁷ A Otten, H Wager. Compliance with TRIPS: the emerging world view. *Vanderbilt Journal of Transnational Law* 1996; 29:391. The authors conclude that: "while it does not solve all the problems related to international intellectual property matters, the TRIPS agreement represents the most comprehensive international agreement on intellectual property protection to date and a basis for the future development of international rules."

⁷⁸ See Berger, supra, note 61 at 39-42 (sections 2.1 and 2.1.1).

⁷⁹ Declaration on the TRIPS Agreement and Public Health, Fourth WTO Ministerial Conference, Doha, 14 November 2001, para 6 (www.wto.org/english/thewto_e/minist_e/min01_e/mindecl_trips_e.htm).

⁸⁰ See documents at www.wto.org/english/tratop_e/trips_e/t_news_e.htm.

⁸¹ See Oxfam. TRIPS and Public Health. Oxfam Briefing Paper 15, April 2002 (www.cptech.org/files/Oxfam-Int-TRIPSPublicHealth.doc).

⁸² Ibid. The countries proposed to be targeted are Argentina, Colombia, India, and Turkey.

⁸³ The GATS text is at www.wto.org/english/tratop_e/serv_e/gatsintr_e.htm. For a discussion, see: DJ Lipson. The World Trade Organisation's health agenda. *British Medical Journal* 2001; 323: 1139-1140; A Pollock, D Price. Rewriting the regulations: how the World Trade Organisation could accelerate privatisation in health-care systems. *Lancet* 2000; 356: 1995-2000. See also: Liberalisation of Trade and Services and Human Rights. United Nations Sub-Commission on Human Rights, Resolution 2001/4, 15 August 2001 (available via www.unhcr.ch/hiv/documents.htm).

⁸⁴ Oxfam, supra, note 81 at 3.

⁸⁵ T France et al. The Global Fund: which countries owe how much? 21 April 2002 (www.hdnnet.org/UNGASS%20docs/GFATM/gf_article_april_21_2002.htm); M Lee. Africa shortchanged: the Global Fund and the G8 agenda. *Behind the Numbers* 2002; 4(4): 1-4 (available via the website of the Canadian Centre for Policy Alternatives at www.policyalternatives.ca); International Council of AIDS Service Organizations. *Global Fund Update: Information on the Global Fund to Fight HIV/AIDS, Tuberculosis and Malaria*. Toronto: The Council, 2002 (available via www.icaso.org by clicking on "Global Fund").

⁸⁶ Médecins Sans Frontières has expressed concern that "because donors and some in the international health community traditionally favour prevention at the expense of treatment, patients already infected will be written off as not sufficiently 'cost-effective' to treat"; see B Pecoul. Open letter to members of the transitional working group and technical support secretariat of the Global Fund to Fight AIDS, Tuberculosis and Malaria, 9 November 2001 (<http://lists.essential.org/pipermail/ip-health/2001-November/002386.html>).

⁸⁷ See www.globalfundatm.org/principles.html.

⁸⁸ D Toler. Analysts call for debt relief to address health needs. *AIDS Today* February 2000 (referring to an estimate of US\$3 billion a year from UNAIDS in 2000).

⁸⁹ United States Debt Relief Enhancement Act of 2002.

⁹⁰ See Africa Action's critique, 14 June 2002, of the Heavily Indebted Poor Countries (HIPC) debt initiative, posted on 18 June 2002 (available via the AF-AIDS Forum at <http://archives.healthdev.net/af-aids>).

⁹¹ SG Stolberg. Bush offers plan to help mothers avoid passing HIV to babies. *New York Times*, 20 June 2002.

⁹² See www.iglhrc.org/issues/accesstotreatment/accesstodrugs.html.

⁹³ M-H Bonin. Accessing essential medicines: Why we need a global campaign. September 2001 (www.aidslaw.ca/Maincontent/events/proceedings/e-agm2001/PDF.pdf). The author notes that of the health research funds of US\$60-70 billion available in 2001, 10 percent would go to health problems that affect 90 percent of the world's population, and points out that research and development of medicines is determined by market profitability – that is, "no market, no research." See also: K Prakash-Mani. Aid for the victims: the role of healthcare companies. *SustainAbility Radar*, February 2001: 19, also posted as "Drugs in the developing world" (available via www.sustainability.com); and Médecins Sans Frontières' recommendations to the 55th World Health Assembly, 13 May 2002 (www.lists.essential.org/pipermail/ip-health/

2002-May/002986.htm), which argue that instead of helping countries learn to live with an ever-shrinking pool of effective drugs for neglected diseases, the WHO should make research and development a part of its overall strategy to increase access to essential medicines.

⁹⁴ P Farmer et al. Community-based approaches to HIV treatment in resource-poor settings. *Lancet* 2001; 358: 404-409; P Msellati et al. Socio-economic and Behavioural Evaluation of the UNAIDS–Ministry of Health Initiative on Drug Access for HIV Infection in Côte d'Ivoire. Preliminary Report, May 2000 (supplied by Prof Didier Fassin of Université Paris-13 Nord); Consensus Statement, supra, note 7.

⁹⁵ A researcher at the University of the Witwatersrand has devised a greatly simplified, cheaper, and more accurate method of testing CD4 counts: DK Glencross et al. CD45-assisted PanLeucocating for accurate, cost-effective dual platform CD4+ T-cell enumeration. *Cytometry (Clinical Communications)* 2002; 50(2): 69-77.

⁹⁶ We are indebted here to our discussions with Dr Mandeep Dhaliwal of the International AIDS Alliance, London.

⁹⁷ Eg, AIDS Empowerment and Treatment International (www.aidseti.org) and Médecins Sans Frontières (www.msf.org).

⁹⁸ For steps in this direction, see *Summary Report: Ethical Dimensions of Issues of Access to Medicines and Care, April 7-9, 2002*. Notre Dame Center for Ethics and Religious Values in Business (available via www.nd.edu/~ethics by clicking on "International Conference on HIV/AIDS held at Notre Dame").

⁹⁹ Supra, note 23 at para 56: "By 2005, develop and make significant progress in implementing comprehensive care strategies to: strengthen family and community-based care, including that provided by the informal sector; and health-care systems to provide and monitor treatment to people living with HIV/AIDS, including infected children, and to support individuals, households, families and communities affected by HIV/AIDS; and to improve the capacity and working conditions of health-care personnel, and the effectiveness of supply systems, financing plans and referral mechanisms required to provide access to affordable medicines, including anti-retroviral drugs, diagnostics and related technologies, as well as quality medical, palliative and psychological care."

¹⁰⁰ See, eg, Heywood, supra, note 37.

¹⁰¹ Eg, VA Leary. The right to health in international human rights law. *Health and Human Rights* 1994; 1(1) (www.hsph.harvard.edu/fixcenter/VINI1.htm); BCA Toebes. *The Right to Health as a Human Right in International Law*. Antwerp: Intersentia-Hart, 1999; AR Chapman. Conceptualizing the right to health: a violations approach. *Tennessee Law Review* 1998; 65: 389. See also UN Committee on Economic, Social and Cultural Rights. General Comment 14, supra, note 17.

¹⁰² Kirby, supra, note 70.